Kentucky Public Health Data Resource Guide 2011

Kentucky Department for Public Health
Division of Epidemiology and Health Planning
chfs.ky.gov/dph

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Kentucky Department for Public Health
Data Users' Workgroup

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Table of Contents

Introduction

There are a variety of resources specific to Kentucky that provide public health data for program monitoring, assessment, and evaluation. Identifying and providing easy access to data resources are essential for effective public health decision making and research. The first Kentucky Public Health Data Resource Guide published in 2005 included twenty resources and the 2007 edition added four more. This document updates the 2007 guide and provides information on a new database — the Pregnancy Risk Assessment Monitoring System (PRAMS) Pilot.

A variety of health-related surveys that collect statewide data are described in this guide, as well as Kentucky-specific surveillance systems and registries. The types of data collected are included as well as strengths and limitations of each data source. Contact information is provided for every source and most contain web links for easy access to available data. New to the 2011 edition is information regarding each source's data release policy.

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

While many data sources are included, certain resources were not available for this year. For instance, the Children's Oral Health Surveillance System has been inactive for a number of years and the Environmental Public Health Tracking Network is still in its early development stage. Hopefully, these and other systems will be included in future editions.

This guide is a valuable resource for conducting public health research, monitoring public health goals or objectives, evaluating initiatives, or exploring Kentucky-related data sources. To recommend other useful and essential data sources for inclusion in future editions, please send a response to Sara Robeson, Division of Epidemiology and Health Planning, (502) 564-3418 extension 3567 or sara.robeson@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: http://chfs.ky.gov/dph/info/dpqi/hp/brfss.htm
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. The Kentucky BRFSS 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 and Control Branch. The surveillance is funded through a federal grant received from the CDC.

Description of the Data Collected

The Behavioral Risk Factor Surveillance System (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, Module, and State Added. Core questions are asked by all states. Module questions are groups of questions on particular topics developed by the CDC that states may decide 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. The BRFSS 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.

Specific Uses of Information

- Monitor *Healthy Kentuckians 2010/ Healthy People 2010/Healthy People 2020* goals
- Provide data to create and evaluate prevention and treatment initiatives of many public health programs including tobacco, diabetes, asthma, women's cancer screening, folic acid, and family planning
- Provide the groundwork for the Department for Public Health's obesity prevention initiative and publications, such as *The Kentucky Obesity Epidemic, 2008*
- Measure the risk of Human Papillomavirus (HPV) among young women between the ages of 18 and 26 with an intact uterus
- Monitor the prevalence of mental illness among Kentuckians 18 years of age and older
- Provide data for the Kentucky Arthritis Program work plan
- Prepare fact sheets and press releases on the importance of tobacco control
- Provide HIV testing data used to promote HIV Testing Day
- Develop portions of the epidemiologic profile included in the Kentucky HIV Prevention Plan
- Provide data for grant applications such as the Community Transformation Grant and the Coordinated Chronic Disease Prevention and Health Promotion Program
- Evaluate health disparities
- Monitor increases in breast and cervical cancer screening and map these data by area development districts
- Assess colorectal cancer screening rates by area development district and compare these data to colorectal cancer incidence and mortality rates

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: According to the 2006-2008 American Community Survey Three Year Estimate, 5.7% of Kentuckians were without landline telephones. This population is not reached, and could have socio-economic differences from the survey population.

The BRFSS only surveys adults in households. Individuals living in a group setting, such as a nursing home, college dormitory, the military, or prison are not surveyed.

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

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

Kentucky BRFSS 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 BRFSS web site. Contact the BRFSS coordinator if requesting Kentucky aggregated data or raw data sets. There are two data request forms *(see Appendices B and C)* available on the Kentucky BRFSS 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 BRFSS epidemiologist/coordinator via e-mail or fax. If the data user is producing a report, the BRFSS program needs to receive a copy of all printed and published materials using Kentucky BRFSS data. Please send copies to the address listed for the coordinator.

Average Yearly Sample Size	7,500
2010 CASRO* Response Rate	64.5%
Smallest Geographic Level Released	Area Development District (ADD)
Data Format	SAS, SPSS, comma delimited
Cost of Data Set	Free

*Council of American Survey Research Organizations

Data Release Policy

The program does not release data for small sample sizes (i.e. county level), since estimates produced from fewer than 50 unweighted 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 people 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.

Data Publications

The BRFSS program produces a yearly statewide summary including an analysis of over 25 risk factors and health behaviors by demographic variables and ADD. From 2000 to the present time, yearly data for almost every question on the survey can be found on the Kentucky BRFSS website, http://chfs.ky.gov/dph/info/dpqi/hp/brfss.htm.

Suggested Data Citation

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). *Behavioral Risk Factor Surveillance System Survey Data.* Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, [survey year].

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Central Nervous System Injury (CNSI) Surveillance Project

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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. Its purpose is to track cases of traumatic brain injury, spinal cord injury, and acquired brain injury as defined by the Centers for Disease Control and Prevention (CDC) and the Kentucky Revised Statues (KRS 211.470). Cases are taken from two sources. Inpatient hospitalizations as well as 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 (MCOD) 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 disposition at 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 MCOD and HDD files are population-based rather than relying on a sampling strategy. We have followed, to the extent possible, the CDC's *Central Nervous System Injury Data Submission Standards – 2002*. This is a widely accepted standard, meaning that Kentucky's results are comparable to those of many other states who conduct CNSI surveillance.

Specific Uses of Information

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

System Evaluation

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

Data Set Availability

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

Data Limitations

There are two main limitations to the CNSI data:

Incompleteness of residence data: Because the MCOD 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.

Timeliness: The MCOD file for a given year is typically not available until 18 months after the end of that year. For example, the 2007 state-specific files were released around August 2010. This is why the fiscal year 2010 Kentucky CNSI report was based on 2007 calendar year data.

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

KIPRC has published a report of the *Traumatic Brain Injury and Spinal Cord Injury Project* annually since 1998. The fiscal year 2011 report describes injuries that occurred in 2010 and will be available on the website (http://www.kiprc.uky.edu/projects/TBI/index.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.

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Childhood Lead Poisoning Prevention Program's (CLPPPs) Data Systems

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National Web Site:	http://www.cdc.gov/nceh/lead/

Sources of Information for the Database

Kentucky is currently working with the Centers for Disease Control and Prevention (CDC) Healthy Homes and Lead Poisoning Prevention Branch in attaining the Healthy Homes Lead Poisoning Surveillance System (HHLPSS). HHLPSS will enable the KY Child Lead Poisoning Prevention Program (CLPPP) to store and access all the data from one system. At present, the Case Management, Environmental Risk Assessment and the CLPPP lab data are housed in 3 different systems. The Case management database houses client/case information, as well as blood lead levels. The Environmental Risk Assessment database houses data from certified risk assessment reports, including lead hazards found, for those children with lead poisoning. The CLPPP lab data system holds all of the lab data.

Blood lead tests are routinely administered at local health departments, private physicians' offices and hospitals throughout the state as part of the Lead Poisoning Prevention Program, as well as other health and child related assistance programs. Blood lead samples are analyzed either by outside contracted laboratories or the in-house portable lead laboratory, Lead Care II. All laboratories, including those using the in-house portable machine, which receive and analyze blood lead levels are required to report these results to the Cabinet as mandated by KRS 211:902. These results should be reported to both the Cabinet for Health and Family Services (CHFS) and directly to the provider who sent the sample for analysis. Approximately 97.3% of all blood lead levels received by CLPPP are electronic. The current surveillance system, as well as the new system (HHLPSS), are considered part of KY CLPPP and are funded through the CDC Childhood Lead Poisoning Prevention grant. Ongoing technical support is provided and funded through the Maternal and Child Health (MCH) division.

Description of the Data Collected

The Case Management system collects data including, but not limited to, the following: 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 CLPPP, provider and insurance information, assigned case manager and health department, and other demographic and case specific information.

The Risk Assessment/Environmental system 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 Database also stores all the environmental measurements taken during the risk assessment. Some of these measurements include samples from paint, floors, dust, windows, soil, water, etc.

The CLPPP lab data system collects data including, but not limited to, the following: patient name, full address, date of birth, phone number, blood lead test results, blood lead test type (venous or capillary), sample date taken, provider and insurance information, testing lab, and other demographic information.

Strengths of the Data

Data is received in a timely manner and that allows for accurate reporting. With current electronic data submission nearing 100% there is very little manual data entry from outside labs. However, long-term Lead Care II users were recently identified resulting in an influx of lead reports that needed to be manually entered. The current system is population-based rather than relying on a sampling strategy.

Specific Uses of Information

- Case manager insures through various means of contact with the local health departments that follow-up care to elevated blood level cases is performed in a timely manner.
- Review history of a case
- Submit quarterly reports to the CDC
- Submit bi-yearly reports to the Adult Blood Lead Epidemiology Surveillance (ABLES) program
- Complete annual reports and performance evaluations
- Fulfill data requests
- Estimating the population of lead poisoned children in the state of Kentucky
- Estimating a populations' risk of lead poisoning based on their specific demographic and address information
- The CDC utilizes the data to assemble a national surveillance database.

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 are entered as is and can cause duplication within the system. b.) There is a lack of testing and reporting despite federal and state mandates. As a result, the reported screening numbers are subject to non-coverage bias.

No analysis capabilities: Data must be extracted out of all 3 data systems and placed into a capable program such as Access or SAS in order to perform any type of query. This causes the data analyzed to be a picture of the data on the specific download date and not on a real time basis.

System Evaluation

The data collected are based on CDC and NIOSH guidelines. The data are subject to computerized edit checks when entered.

Data Set Availability

The fully identified data sets are not available to the public. A data request can be submitted to the CLPPP data contact if specific data needs are identified. All data requests that are HIPPA compliant will be met. Data are generally given in aggregate form by county level. Tables and reports are available on the CLPPP website.

Data Release Policy

All data requests that are HIPPA compliant will be met. The 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 lead poisoned children is less than 5 for a county the exact count is not presented to help protect the identity of the client.

Data Publications

The CLPPP currently reports both adult and child blood lead data to the National Institute for Occupational Safety and Health (NIOSH) (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5326a2.htm) and the Centers for Disease Control and Prevention (CDC), respectively in the form of quarterly and bi-annual data submissions. The CDC website provides statistical information for the state of Kentucky based on the reports received from the KY CLPPP http://www2.cdc.gov/nceh/lead/census90/house11/house11.htm. Additional reports and data are available on Kentucky CLPPP's website http://chfs.ky.gov/dph/mch/poisoning.htm.

Suggested Data Citation

Kentucky Department for Public Health, *Childhood Lead Poisoning Prevention Program Data*, Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, [data year]

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Child Fatality Review
(CFR)

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State Web Site:	http://chfs.ky.gov/dph/mch/cfhi/childfatality.htm

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 in Kentucky. The system is designed to provide information on incidence, prevalence, and trends of causes of death to 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 and coroner report forms on all Kentucky resident children from birth to seventeen years of age who die of any cause of death. 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 monthly basis 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/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.

Specific Uses of Information

- Monitor *Healthy Kentuckians 2020 Goals*
- Monitor KIDS NOW Initiatives on Early Childhood Development
- Provide data for use in various projects
- Data are used to monitor select performance measures for the Title V Federal Maternal and Child Health Block Grant
- Evaluate health disparities

Data are used annually to 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.

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 out-of-state deaths to Kentucky residents. Not all cases are being captured in CFR and currently CFR does not have the capability to link death records electronically with coroner report forms.

System Evaluation

Data collection for CFR is monitored on a quarterly basis with review of the coroner report forms to ensure proper notification to reporting agencies (i.e. local health departments, law enforcement, and the Department for Community Based Services) 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 HIPAA compliant.

Data Publications

The CFR produces an annual report that contains trend data on causes of death to children from birth to age 17. 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: http://www.nhtsa.gov/Data/State+Data+Program+&+CODES

Sources of Information for the Database

The Crash Outcome Data Evaluation System (CODES) is funded by the National Highway Safety Administration (NHTSA) for the purpose of linking 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 2007, and with both inpatient and outpatient databases for years 2008 and 2009. The linkage is accomplished using a probabilistic methodology based upon research by Fellegi and Sunter (1969) and Jaro (1985, 1995), and implemented in software provided by NHTSA. 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.

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 ED's as a result of crashes on Kentucky's roadways. It thus 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.

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 predictive value positive (PVP) 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 PVP 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 Limitations

There are two main limitations to 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, so 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 it represents the population of persons who both crashed and were hospitalized in Kentucky, since these are the cases covered by our data sources. This question has been the focus of our 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.

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 the project's data owners and Board of Directors for case-by-case consideration.

Data Release Policy

Only aggregate data is released at this time.

Data Publications

Data publications can be found at http://www-nrd.nhtsa.dot.gov/Pubs/811181.pdf.

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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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. The EHMIS system was recently redesigned to be 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 twenty Environmental Health programs.

The Division of Public Health Protection 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, and swimming pools and beaches. All of these inspections are entered into in the EHMIS system. In addition to routine inspections, other services provided and documented in the EHMIS include public health complaints, rabies investigations, water sampling and public building inspections and plan review. Individuals with certifications that are regulated include septic system installers, tattoo artists, ear and body piercers, and food handlers and managers who are also managed within the EHMIS system.

Currently, the EHMIS system is supported through agency funds. These funds are procured through state environmental fees. Although this system is not mandated specifically, there are mandates that require the collection of onsite sewage, as well as accounts receivable information in an electronic database. Statutory requirements for data collection are included in KRS 211.350, KRS 212:240 along with 902 KAR 8:165.

Description of the Data Collected

The data are collected by local and state environmentalists and entered in the system locally. A third tier vendor, Custom Data Processing (CDP) stores the data. CDP is a data warehouse utilized for environmental data. These data are demographic data 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

Geocoding: The system has a comprehensive list of all regulated facilities along with demographic information such as seats, square feet, gallons, etc. In addition, the system details inspection and violation history, accounts receivable and owner/operator information. The system also has latitude and longitude coordinates for use in GIS and mapping analysis.

Timeliness: The data are entered on a daily basis and updated to the mainframe on weekly basis.

Specific Uses of Information

The data are 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 Custom Data Processing in real time and is backed up on servers at a different location nightly. This process ensures proper data retention and integrity.

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: The data system was rolled out on February 1, 2011. As a new system, bugs and glitches still may remain and are continually being processed and fixed. Because of this, data may be inaccurate and should be examined and analyzed as such.

Coding: Coding/definition disparities occur across the state along with different coding standards. Due to these inconsistencies, data cannot be uniformly compared across Kentucky or to other states.

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. 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 thus is 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. Open records requests must be acknowledged by the State within 3 days of receipt.

Suggested Data Citation

None suggested at this time.

Contributing Author

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Fatality Assessment and Control Evaluation (FACE)

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State Web Site: http://www2a.cdc.gov/NIOSH-FACE/state.asp?Category=0000&Category2=ALL&State=KY&Submit=Submit

National Web Site: http://www.cdc.gov/niosh/face/KYFACE.html

Sources of Information for the Database

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, Occupational Safety and Health Administration (OSHA) reports, the Collision Reporting Analysis for Safer Highways (CRASH) reports, coroner reports and 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 the 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.

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

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.

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.

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

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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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State Web Site:	http://chfs.ky.gov/dph/epi/hivaids.htm
National Web Site:	http://www.cdc.gov/hiv/dhap.htm

Sources of Information for the Database

There are several regulations which pertain to the reporting of HIV/AIDS related labs to the Cabinet for Health and Family Services, HIV/AIDS Branch, HIV/AIDS surveillance section. Below are listed some of the most wide reaching statutes and regulations.

KRS 211.180 Section (1)(b) states adoption of 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.

KRS 311.282 states physicians licensed shall not be civilly or criminally liable for disclosure of info to the Cabinet for reporting HIV results.

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.

According to state regulation 902 KAR 2:020, Section 7, 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 grant through the CDC to conduct surveillance and epidemiological activities.

Description of the Data Collected

HIV/AIDS data available to the public include demographic information including race/ethnicity, sex, age at diagnosis, county of residence/area development district (ADD), modes of exposure for 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 by race/ ethnicity, age groups, sex, mode of exposure, year of diagnosis, year of report, ADD, and county of residence. The availability of reported data is very timely. Published reports of the data are available semi-annually.

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 services and the creation of new services to address unmet needs
- Provides data for grant applications for HIV/AIDS prevention and services
- Used to identify target populations that are disproportionately affected by HIV/AIDS

System Evaluation

The data collection is routinely monitored utilizing quality control standards developed by the Centers for Disease Control and Prevention (CDC). Data reports are run on a monthly basis to evaluate these performance standards.

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 the most recent years are not used in trend analyses. HIV/AIDS data provided by the Kentucky Department for Public Health have not been adjusted for reporting delay. 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.

Data Set Availability

Kentucky HIV/AIDS raw data are not available for public use although data requests/reports can be filled at the public's request with restrictions for no cost. For HIV/AIDS semi-annual reports, please use the HIV/AIDS website: http://chfs.ky.gov/dph/epi/HIV-AIDS+Reporting+and+Statistics.htm. For all other requests, please contact Julie Nakayima at peace.nakayima@ky.gov or (502) 564-6539 ext. 3556.

Data Release Policy

An integral part of public health surveillance is the dissemination of health data to public health agencies, case providers, and the general public. Surveillance data are needed in order to analyze trends in occurrence and prevalence as well as to effectively plan and evaluate prevention and services 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 released compromise surveillance activities or affect the public perception of confidentiality of the surveillance system.
>
> HIV/AIDS data are released in aggregates to ensure the security and confidentiality of reported cases. Data release policies exist for data release of any nature. A strict data release policy is necessary because release of certain types of data, even without names, could be used to 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 those agreements.

Data Publications

The HIV/AIDS program produces a semi-annual data report by demographic variables and ADD. The HIV/AIDS website contains copies of HIV/AIDS statistical reports for the past several years as well as lists information on HIV prevention: http://chfs.ky.gov/dph/epi/hivaids.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].

Contributing Authors

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Hospital Inpatient Discharge and Outpatient Services Databases

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State Web Site:	http://chfs.ky.gov/ohp/healthdata/
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 with describes a single utilization of service received at an Ambulatory Facility (Ambulatory Surgery Center, Ambulatory Care Center, Specialized Medical Technology Services provider, or a Mobile Health Services provider) that performed at least one of a list of Current Procedural Terminology (CPT) procedure codes specified, or for dates of service on or after 2008, an Emergency Department visit. 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 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 (ICD9-Procedure 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 exploited 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 30 states covering inpatient events in over 90% of U.S. hospitals.

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 (H-CUP) 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.
- Hospitalization data and emergency department data are used in preparing grant requests and status reports for Kentucky Department for Public Health 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 2010.
- 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.

Data Limitations

The records comprising these data files are built from hospital-submitted or ambulatory facility-submitted claims to payors, commonly known as UB-92, 837 file format records, or HCFA-1500. The inpatient files contain all inpatient discharges from a given calendar year, these are claims data 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. State owned mental health facilities do not currently submit data.

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 (see Appendix G) before data files are transferred. Files containing the previous calendar year's data are available each July.

Average Yearly File Size:	Inpatient: 650,000 records. Outpatient: 700,000 records prior to 2008. After 2008, the average is 3,250,000.
Hospital Compliance Rate:	>99%
Smallest Geographic Level Released:	Inpatient: ZIP Outpatient: County
Data Format:	.txt files
Cost of Data Set:	$1,500 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 the annual Hospital Utilization Survey. Inpatient hospitalization data are used to produce inpatient hospitalization days by facility and payor, 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 payor 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) 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

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Influenza Sentinel Surveillance System (ISSS)

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State Web Site:	http://chfs.ky.gov/dph/epi/influenza.htm
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 health care 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 902-2:065) to report outbreaks of two or more ILI that occur within a one-week period of time to the LHD immediately. Nationally, the CDC requires notification of all pediatric deaths. 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 touch-tone system, or by fax or phone. 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.

Information on ILIs and absentees for a six week period in the fall are used to determine outbreak baseline numbers for LHD sentinel site participants. The baseline for HCPs and hospitals is three ILI. The nursing home outbreak baseline number is two. 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-Overall clinical activity remains low and there are no lab confirmed cases
- Sporadic-Isolated cases of lab confirmed influenza in the state and ILI activity is not increased, or lab confirmed outbreak in a single institution in the state and ILI activity is not increased
- Local outbreak-Increased ILI within a single region and recent (within the past three weeks) laboratory evidence of influenza in that region. ILI activity in other regions is not increased, or two or more institutional outbreaks (ILI or lab confirmed) within a single region AND recent lab confirmed influenza in that region. Other regions do not have increased ILI and virus activity is no greater than sporadic in those regions
- Regional-Increased ILI in greater than or equal to two but less than half of the regions AND recent lab confirmed influenza in the affected regions, or institutional outbreaks (ILI or lab confirmed) in greater than or equal to two and less than half of the regions AND recent lab confirmed influenza in the affected regions
- Widespread-Increased ILI and/or institutional outbreaks (ILI or lab confirmed) in at least half of the regions AND recent lab confirmed influenza in the state
    1. Lab confirmed case is a case confirmed by antigen detection, 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. Institution includes nursing home, hospital, prison, school, 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). In Kentucky, the 15 Area Development Districts are used. The identity of specific isolates from Kentucky and other nearby states, and information on the age of the person tested and date of collection of the isolate, are used to interpret whether outbreaks of influenza-like illness 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. The system complements that 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.

Specific Uses 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.

Data Limitations

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

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 general population. The data submission is not mandatory. Kentucky requests information on all pediatric deaths, influenza in pregnant women and individuals with risk factors. Sentential 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, [data year].

Contributing Author

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Kentucky All Schedule Prescription Electronic Reporting (KASPER)

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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 is 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 dispensers are required to report to CHFS every seven days the Schedule II – V controlled substances they have dispensed. Data on controlled substances administered directly to a patient, and data on a 48 hour or less supply of a controlled substance dispensed by a practitioner at a facility licensed by CHFS are exempt from the reporting requirement. KASPER funding is allocated by the Kentucky Legislature. CHFS has also been awarded funding to support KASPER enhancements under the federal Harold Rogers Prescription Drug Monitoring Program Grants administered by the U.S. Department of Justice, Bureau of Justice Assistance.

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 name, date of birth, and address
- prescription information including date filled, quantity, days supply, and prescription number
- prescriber name, address and identifier
- drug name, strength, National Drug Code (NDC) number
- dispenser name, address, and phone number

Strengths of the Data

KASPER supports improved public health and safety in Kentucky by providing data for use by 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 used to select representative stratified samples for the periodic KASPER User Satisfaction Surveys. Results of the surveys are used to identify user requested program improvements and system enhancements, along with desired user training.

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

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.

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 three full years plus the current year. Remaining data from inception of the KASPER program in 1999 are available from archival records for research purposes. Datasets provided for research purposes will not identify any individual prescriber, dispenser or patient.

Average Annual Controlled Substance Prescription Records Reported to KASPER 2006 – 2010	10,436,178
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, OIG reviews the request and obtains additional information as needed. 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, OIG may approve the request for data. 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 are publically available on the KASPER web site at www.chfs.ky.gov/kasper. The quarterly trend reports contain information regarding controlled substances reported to KASPER, KASPER usage statistics and prescribing and usage patterns by geographic area in Kentucky. The reports are available to download in PDF format. KASPER Trend 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].

Contributing Author

David R. Hopkins, Kentucky Office of Inspector General

Kentucky Birth Surveillance Registry (KBSR)

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State Web Site:	http://chfs.ky.gov/dph/mch/ecd/kbsr.htm
National Web Site:	http://www.nbdpn.org

Sources of Information for the Database

The Kentucky Birth Surveillance Registry (KBSR) is a state mandated surveillance system that is 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. The KBSR operates under the authority of 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, Early Childhood Development Branch. The surveillance system is funded with a mix of agency funds and a cooperative agreement from the CDC.

Description of the Data Collected

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

Strengths of the Data

The KBSR provides data on certain birth defects, genetic and disabling conditions, pregnancy outcomes and maternal risk factors that are not collected by other surveillance systems. The KBSR is a statewide mandated system; therefore, reporting entities are required by law to provide the data as described under KRS 211.651-670. Data are updated on a monthly basis. Data provided to KBSR occurs in a timely fashion with all birthing hospitals in the state currently submitting data through a vendor on a quarterly basis. Medical records abstraction is consistently conducted on a monthly schedule and data from 1998-2008 have been verified.

Specific Uses of Information

- Monitor *Healthy Kentuckians 2010 Goals*
- Monitor KIDS NOW Initiatives on Early Childhood Development
- Provide data for use in various projects by the Folic Acid Partnership of Kentucky, the March of Dimes Kentucky chapter, the Spina Bifida Association of Kentucky, and the National Birth Defects Prevention Network
- Data on specific abnormalities are currently being used for a National Birth Defects study.
- Data provided for the World Health Organization Craniofacial Study
- Data provided on specific birth defects for the Environmental Quality Commission report, “Children’s Health”
- Data are used annually for the preparation of the grant application “Cooperative Agreements for the Development and Improvement of Population-Based Birth Defects Surveillance Programs.”
- Data are used annually to monitor trends of birth defects among specific populations, geographical areas, and the state as a whole and to monitor any cluster outbreaks and to evaluate health disparities.

Data Limitations

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

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

System Evaluation

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

Data Set Availability

KBSR data from 1998 to 2008 are available to certain individuals provided an institutional review board (IRB) approval to access the data has been obtained. KBSR staff reserve the right to deny any data request they deem would violate state and or federal laws governing the data set. The data set is only available in aggregate form and NO identifying information will be released to any requestor under any circumstances. National data are available on the National Birth Defects Prevention Network web site. Data requests should be submitted to the coordinator listed above once Cabinet IRB approval is completed.

Data Release Policy

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

Data Publications

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

Suggested Data Citation

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

Contributing Author

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Kentucky Cancer Registry
(KCR)

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Data Contact:	Jaclyn K. Nee, MPH Kentucky Cancer Registry 2365 Harrodsburg Rd. Suite A230 Lexington, KY 40504-3381 (859) 219-0773 ex. 243 jnee@kcr.uky.edu
State Web Site:	http://www.kcr.uky.edu/

Sources 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 see 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 21,000 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. 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, and 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 - 2008) 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.

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

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. Hospitals 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.

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. 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 2008 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/

Example:

Kentucky Cancer Registry. (2011). *Cancer Incidence Rates in Kentucky*. Retrieved February 16, 2011 from http://www.kcr.uky.edu/

Contributing Author

Jaclyn Nee, MPH, Kentucky Cancer Registry

Kentucky Incentives for Prevention (KIP) Student Survey

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Data Contact:	Lisa Crabtree, M.A., KIP Survey Manager REACH of Louisville 501 Park Avenue, Louisville, KY 40208 (502) 585-1911 CrabtreeL@reachoflouisville.com
State Web Site:	http://www.reachoflouisville.com/kip.htm

Sources of Information for the Database

Biennially, 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, tobacco and other drug (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, with all student responses 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 is gathered and analyzed, a report outlining information specific to the district is sent to each participant. The entire administrative cost of the survey is borne by Kentucky's Division of Behavioral Health.

Description of the Data Collected

The KIP survey provides comprehensive information about student self-reported ATOD consumption patterns and consequences related to ATOD. In 2010, the survey involved 153 (out of 176) Kentucky school districts and over 120,000 students. Survey items assess such domains as demographics, ATOD use, ATOD related problems, ATOD accessibility, values (personal and parental), school safety, and gambling. REACH of Louisville is the evaluation contractor responsible for administration, scoring, and dissemination of results, and has held this responsibility for five survey administrations in 2003, 2004, 2006, 2008 and 2010.

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 Area Development District (region) and 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 each district that has 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, along with 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 responses and discrepancies and eliminates those surveys from the tallied results.

For more information about the KIP survey please visit: http://www.reachoflouisville.com/kip.htm

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.

Data Limitations

The primary limitation of the KIP survey is that the largest urban area in Kentucky does not participate in the survey, and is therefore 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 of Louisville, Inc. and are posted on their website. Significant efforts go into protecting the anonymity of responses (students know that a response cannot be traced back to them); subsequently, the anonymity of the responses greatly reduces the risk associated with telling the truth. However, some limitations associated with self-report data are inevitable.

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 of Louisville KIP website at http://www.reachoflouisville.com/kipreports.htm The *KIP Survey 2010: Statewide Trends Related to Substance Abuse, School Safety, & Gambling (2003-2010): Sourcebook* represents a total sample of 120,253 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 of Louisville (CrabtreeL@reachoflouisville.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 of Louisville (CrabtreeL@reachoflouisville.com, 502-585-1911).

Suggested Data Citation

REACH of Louisville, Inc. *KIP Survey 2010: Statewide Trends Related to Substance Abuse, School Safety, & Gambling (2003-2010): Sourcebook*. Louisville, KY: REACH of Louisville, Inc., [2010].

Contributing Authors

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Dr. Daniel Sanders, Jr., REACH of Louisville

Kentucky Occupational Safety and Health Surveillance (KOSHS)

Coordinator and Data Contact:

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State Web Site: http://www.kiprc.uky.edu/projects/KOSHS/index.html

Sources of Information for the Database

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 the 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 analyses on data variables are 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 initiatives are promoted through effective dissemination of occupational injury and illness data, results, and materials to occupational safety and health stakeholders.

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

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.

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, and prevention and dissemination processes are included in the evaluation.

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

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Kentucky Trauma Registry
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Coordinator and Data Contact

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State Web Site: http://www.kentuckyhealthfacts.org/Resources.aspx

Sources of Information for the Database

The Kentucky Trauma Registry is an initiative of the Kentucky chapter of the American College of Surgeons' (ACOS) Committee on Trauma and the Kentucky Board of Emergency Medical Services. Data are collected by ACOS-verified trauma facilities and reported to the Kentucky Injury Prevention and Research Center (KIPRC) at least annually. Data are also collected for Kentucky residents who are treated at Ohio verified trauma facilities and will soon be collected from their counterparts in Tennessee. Thanks to a three-year statewide initiative Kentucky is expanding the number of reporting trauma facilities to a projected total of 12 in year 2012. These facilities are required to report in compliance with the National Trauma Data Bank standards as a condition of their new status. KIPRC has an important role in synthesizing and analyzing statewide trauma registry data and producing statewide trauma registry reports. The Kentucky Trauma Registry is currently funded by the Foundation for a Healthy Kentucky and the Kentucky Transportation Cabinet.

Description of the Data Collected

Trauma registry data include hospital name, patient gender, sex, 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.

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 CDC. Evaluation of quality is determined through quarterly and annual reports of these performance standards.

Data Limitations

There is one important limitation that keeps the trauma registry from achieving its full potential. It only includes data from facilities that are either ACOS-verified or self-designated trauma centers. 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.

Data Set Availability

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

Data Release Policy

Spreadsheet versions of Kentucky Trauma Registry (KTR) data are available upon request from the Kentucky Injury Prevention and Research Center (KIPRC) at the University of Kentucky College of Public Health. 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

The Kentucky Trauma Registry (KTR) Report 2008 is a publication of KIPRC. This report presents trauma data collected by the state's Level I trauma facilities, the University of Kentucky Hospital (UK) and the University of Louisville Hospital (UL), and the freestanding Kosair Children's Hospital (KO). This information was gathered by each hospital and submitted to KIPRC, where it has been analyzed as a whole. This report of 2008 Kentucky Trauma Registry data is intended to provide a baseline for assessment of the input from newly verified facilities in subsequent years.

Kentucky Trauma Registry reports as well as Kentucky Inpatient and ED Traumatic Injury Data reports can be found on the KIPRC website http://www.kiprc.uky.edu/projects/trauma.

The most current reporting on traumatic injuries in the state can be found and is available for downloading at the following website, operated by the funding source: http://www.kentuckyhealthfacts.org/Resources.aspx.

Traumatic injury data reports are included in the Kentucky Trauma Care System Annual Report to the Kentucky General Assembly.

Suggested Data Citation

Costich JF, Slavova SS, Beaven S, Kentucky Trauma Registry Report 2008, Kentucky Injury Prevention and Research Center, Lexington, KY, July 2011

Costich JF, Slavova SS, Beaven S. Kentucky Trauma Registry Report. Kentucky Trauma Advisory Council Report to the General Assembly, December 2010

Contributing Authors

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Svetla Slavova, PhD, Kentucky Injury Prevention and Research Center

Kentucky Violent Death Reporting System (KVDRS)

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Data Contact:	Kory Bays or Ashley Bush Kentucky Injury Prevention and Research Center 333 Waller Ave, Suite 200 Lexington, KY 40504 (859) 323-8591 k.bays@uky.edu ambush32@gmail.com
State Web Site:	http://www.kvdrs.ky.gov

Sources of Information for the Database

Information is collected from death certificates, coroner/medical examiner reports, police reports, crime laboratory reports, toxicology reports, and child fatality review team 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 seventeen funded states. Together, this information provides a more complete picture of violent death. 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 NVDRS. The Division of Maternal and Child Health (MCH) within the Department for Public Health collects CFR data and provides information to the KVDRS.

Strengths of the Data

To improve coroner reporting *The Coroner Investigation Reporting System* (CIRS) has been designed, developed, and distributed to almost 72% of county coroners. This system is 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. To date 17 counties participate in a web-based version of the CIRS, making reporting more efficient and timely in those counties.

The KVDRS has teamed up with the DPH/MCH to collect the state mandated CFR form when a child less than 18 years of age dies. If coroners use the KVDRS web-based data collection system and if the death is a child, the state mandated form becomes activated and common fields are programmed to automatically fill from the CIRS form to the CFR form. This simplifies the process of documenting investigative information for the coroner, and the DPH can access those reports through the KVDRS web site. This streamlines statewide coroner reporting.

Specific Uses of Information

A local minister requested statistics on teen suicide to use in a sermon following a teen suicide death within the community. Frequencies of teenage suicides were provided. The immediacy of the response allowed for a poignant “teaching moment” on teenage suicide in a Kentucky community.

KVDRS’s project manager was interviewed for a statewide public television program about the KVDRS and Intimate Partner Violence. The program aired on *KET’s Kentucky Health* on KET1 in 2006 and has been shown again since then. The program can also be downloaded from the web site. The interview focused on violence in Kentucky homes and the problem of homicides followed by suicides and intimate partner violence (IPV). The KVDRS annual report is available on the KVDRS web site (www.kvdrs.ky.gov). Copies have been distributed to various requestors, such as local, state and federal government agencies, legislators and advocacy groups.

Data Limitations

KVDRS reports include only deaths occurring within Kentucky. The lag time to receive death certificate data for Kentucky residents who have died outside of Kentucky does not allow for their inclusion. 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.

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, beyond summaries in the annual report, 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 2009. National data are also available following the approval of a 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 Re-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	800-900
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 Walsh, sabrina.walsh@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 an annual statewide statistical summary of all homicides, suicides, and unintentional firearm fatalities, peer-reviewed publications, and contributes to state and national reports each year.

Suggested Data Citation

Kentucky Injury Prevention and Research Center (KIPRC) and Centers for Disease Control and Prevention (CDC). *Kentucky Violent Death Reporting System Data*. Lexington, Kentucky: University of Kentucky, College of Public Health, [data year].

Contributing Author

Sabrina Walsh, DrPH, Kentucky Injury Prevention and Research Center

Kentucky Women's Cancer Screening Program (KWCSP)

Interim Program Director:	Joy Hoskins, RN, BSN, BA Director, Division of Women's Health Assistant Director of Nursing Kentucky Department for Public Health (502) 564-3970 ex. 3107
Data Contact:	Sivaram "Ram". Maratha, M.Sc, MPA Data Manager & Epidemiologist Division of Women's Health Kentucky Department for Public Health (502) 564-3236 ex. 3772 sivaramr.maratha@ky.gov

State Web Site: http://chfs.ky.gov/dph/info/dwh/cancerscreening.htm
National Web Site: http://www.cdc.gov/cancer/nbccedp/

Sources of Information for the Database

Kentucky Women's Cancer Screening Program (KWCSP) collects surveillance data from all 120 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 KWCSP has collected MDEs continuously since 1998. The KWCSP 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

The Minimum Data Elements (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. 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 Kentucky state program's screening outcomes, and respond to the information needs of CDC stakeholders and partners. The data at present are 99% complete. Screening data are available after 3 1/2 months and diagnostic data are available 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.

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

Data Limitations

Data are available only for women ages 40-64, below 250% poverty level and not eligible for Medicare, Medicaid, and have no private insurance.

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 are 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	14,000
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 Author

Sivaram "Ram" Maratha, MSc, MPA, Kentucky Department for Public Health

Perinatal Hepatitis B Screening
(Perinatal Hep B)

Coordinator / Data Contact:	Julie Miracle, RN Kentucky Department for Public Health Division of Epidemiology and Health Planning Immunization Program (502) 564-4478 ex. 4038

Sources of Information for the Database

System data is 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. The data also includes the Estimated Date of Confinement (EDC), name of hospital, name of local health department and contact nurse, the private provider's name and the outcome of the pregnancy. Kentucky State Law and Kentucky Regulation 902 mandates that all pregnant women must be screened for hepatitis B surface antigen testing. KAR 2:020 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) and hepatitis B vaccine series receipt and date and the result of post serology testing which include surface antibody and surface antigen testing for hepatitis B virus. 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.

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 vaccine to prevent disease
- Monitor for vaccine failures in infants of hepatitis B positive mothers who receive the preventive regimen

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. A web database is currently under development.

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 is submitted 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. A web-based registry is currently being developed. LHDs contact the providers for the information and forward to the state coordinator. Kentucky has a three year average average of 71 infants born to HBsAg positive mothers. CDC estimated that in 2011, Kentucky could have between 92 to 156 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. Kentucky follows the integrated security and confidently guidelines for HIV, STD, viral hepatitis and TB surveillance programs mandated by the CDC.

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 uses this 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 Author

Julie Miracle, RN, Kentucky Department for Public Health

Pregnancy Risk Assessment Monitoring System (PRAMS)

Coordinator and Data Contact:	Elizabeth Kelty, MPH Kentucky Department for Public Health Division of Maternal and Child Health (502) 564-4830 ex. 3340 elizabeth.kelty@ky.gov
National Web Site:	http://www.cdc.gov/PRAMS

Sources of Information for the Database

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a population-based health surveillance system. PRAMS utilizes mixed mode system consisting of mail and telephone surveys to collect data. The survey distribution 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, adoptions, surrogate 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. Participation in the survey is strictly voluntary, and data are deidentified prior to analysis. The Kentucky PRAMS is a pilot project that has been conducted twice, once in 2008 and again in 2010. The first pilot project was funded by a community grant through the March of Dimes, and the second pilot was funded through the Title V Maternal and Child Health Block Grant. PRAMS 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 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, employment status of the mother, government assistance, pregnancy intent, 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. Kentucky is not a CDC funded PRAMS state; however, both pilot projects were conducted following the PRAMS model surveillance protocol for CDC funded states and consists of three types of 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.

Strengths of the Data

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

Specific Uses of Information

- Provide data not available from other sources about pregnancy and the first few months after birth
- Investigate emerging maternal and child health issues
- Provide data to plan and review policies focused on improving maternal and child health
- Provide data for grant applications
- Identify emerging issues that could affect maternal and child health program planning
- Evaluate health disparities

System Evaluation

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

Data Limitations

There are some limitations in the PRAMS data: recall bias, non-response bias, small sample size, and inability to compare to other states. 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. In addition, surveys are only printed in English. Transient populations and non-English speaking populations are therefore 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 200 women are selected each month to participate in the survey and only 50-60% of participants respond. The first pilot project garnered a total sample size of 356 while the second project, which ran for a longer time, included 844 participants.

Inability to Compare to Other States: Kentucky PRAMS is not funded through the CDC. CDC funded states conduct continuous surveillance, follow the same protocol, and data are weighted by CDC statisticians. While Kentucky PRAMS follows CDC protocol for surveillance and data weighting, surveillance is not continuous and weighting is completed by the University of Kentucky.

Data Set Availability

Kentucky PRAMS data are available for 2008 and 2010. The data are available in SAS and comma delimited format. A weighting variable is 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 who will forward a data request sheet to be filled out and returned (See Appendix F). National data are available on the CDC PRAMS website.

Average Yearly Sample Size	840
2010 Response Rate	55.2%
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 produces a statewide summary for each survey year. The report for the 2008 data can be found on the Kentucky Cabinet for Health and Family Services, Maternal and Child Health website: http://chfs.ky.gov/NR/rdonlyres/888F8BBC-3DF7-47A4-B34E-8BD7BABA1E09/0/PRAMSREPORT08final withcovers.pdf.

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].

Contributing Authors

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Reportable Disease Surveillance System (RDSS)

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Data Contact:	T.J. Sugg, MPH Kentucky Department for Public Health Division of Epidemiology and Health Planning (502) 564-3418 ex.3520 tennis.sugg@ky.gov
State Web Site:	http://chfs.ky.gov/dph/epi/reportablediseases.htm
National Web Site:	http://www.cdc.gov/osels/ph_surveillance/index.html

Sources of Information for the Database

Information in the system is based on demographic, clinical, laboratory, and risk factor information on each occurrence of any one of sixty-eight reportable diseases. The data are taken from the EPID 200 Reportable Disease Form or the Kentucky Electronic Public Health Records System (KYEPHRS) from selected Centers for Disease Control and Prevention (CDC) disease supplemental forms and from clinical laboratory reports. Disease reporting is a required activity by health care providers, hospitals, clinics, and laboratories and is mandated and regulated by the State of Kentucky through the Kentucky Disease Surveillance Administrative Regulation 902 KAR 2:020, Disease Surveillance. This activity is supported by a combination of federal and state funds.

Description of the Data Collected

The Reportable Disease Surveillance System (RDSS) collects data on demographics, clinical symptoms, risk factors, and outbreak associations. Demographic data collected include gender, age, race, ethnicity, and place of residence. Information from supplemental forms for some diseases is also entered into the system. This information is sent from hospitals, clinics, local health departments, private practice physicians, and commercial laboratories electronically through a web-based system [KYEPHRS-Disease Surveillance Module or (NBS) National Electronic Telecommunications System for Surveillance (NETSS) base system] as well as by mail or by fax.

Strengths of the Data

The major strength of this data comes from the fact that certain diseases are required, by law, to be reported to the Department for Public Health. However, the level of compliance in the state of Kentucky varies widely depending on the disease.

Specific Uses of 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

The data collection is routinely monitored utilizing quality control standards developed by CDC. Yearly checks are done before the CDC data files are closed.

Data Limitations

- Data on the EPID200 form and KYEPHRS or NBS are often incomplete.
- Follow-up is difficult and may not result in obtaining the needed information.
- Data are often sent to the local health department or state weeks and sometimes months after the reportable event. This makes follow-up even more difficult.
- Data are not readily available to all. Data must be transferred to another program such as Epi-Info. Gleaning the data wanted can be cumbersome and is usually done by reportable disease employees. It is then sent out electronically to the requestor.
- Data collection is dependent on health care providers reporting the data to the state.

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 that the requestor has signed a confidentiality/security agreement with the Department for Public Health. Occasionally approval by the Institutional Review Board is necessary. Most data will be released as an Excel file although other formats may be available.

Data Release Policy

Any data released to the public will be de-identified data. Data requests are taken by phone and by e-mail.

Data Publications

The Reportable Disease Program produces a yearly statewide summary. Yearly summaries can be found on the Data Warehouse web site http://chfs.ky.gov/dph/surv.htm. Data are also periodically posted on Epidemiologic Notes and Reports.

Suggested Data Citation

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

Contributing Author

Peggy Ellis, MPH, Kentucky Department for Public Health

Vital Statistics Surveillance System (Vital Stats)

Registrar:

Paul F. Royce
Kentucky Department for Public Health
Division of Epidemiology and Health Planning
Office of Vital Statistics
(502) 564-3418

Data Contact:

Hollie R. Sands, MPH
Epidemiologist
Kentucky Department for Public Health
Division of Epidemiology and Health Planning
Office of Vital Statistics
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State Web Site: http://chfs.ky.gov/dph/vital/vitalstats.htm
National Web Site: http://www.cdc.gov/nchs/nvss.htm

Sources of Information for the Database

Information in the vital statistics system is based upon birth, death, stillbirth, marriage, and divorce certificates collected and maintained by the Office of Vital Statistics. Almost 99% of birth records are reported electronically from birthing facilities via the Electronic Birth Registration System (EBRS). On July 1, 2010 the office implemented an Electronic Death Registration System (EDRS). As of July 1, 2011 approximately 22% of all death certificates were reported electronically through the EDRS. The remainder of birth record, death record, stillbirth, marriage, and divorce certificate data is reported on paper, and is keyed to the Office of Vital Statistics' (OVS) electronic data systems. KRS 213.016 mandates the establishment of the OVS. Various other sections of KRS 213 mandate what certificate data are to be collected and how they are to be managed by OVS. KRS 213.141 prescribes the fees that are to be paid for certified copies of certificates or records and for searches of records when copies are not made. 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 Collected

On births (and stillbirths), the system collects identifying information on the newborn and parents; demographic data such as address, age, race, and Hispanic origin of the parents; 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). Data are collected on all births that occur in Kentucky or that occur to a Kentucky resident out-of-state. On deaths, the system collects 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, or contributing causes. Data are collected on all deaths that occur in Kentucky or that occur to a Kentucky resident out-of-state. On marriages and divorces, the system collects identifying information on the husband and wife, and the date and county of the event on all marriages and divorces that occur in Kentucky.

Strengths of the Data

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. Electronic data have been maintained in a reasonably consistent format since 1977, and tabulated statistical data on births and deaths are available going back to 1911. Collection protocols and formats are similar among states, so the data are comparable.

Specific Uses of Information

- Provide data used to estimate population statistics by age, race, gender, and place of residence
- Provide birth and death statistics for a variety of purposes and programs of government, business, and other organizations
- Provide data to assess the health status of the population, e.g., birth weight, infant mortality, and leading causes of death, by both government agencies and other healthcare researchers
- Provide denominators for the calculation of rates and ratios of health events
- Provide data to the National Center for Health Statistics (NCHS) for incorporation into the National Vital Statistics System

Data Limitations

In general, there are three main limitations to the vital statistics data.

Incompleteness of residence data: Each state registers vital events that occur within its jurisdiction. In order to collect data on vital events that occur to its residents in other states, the state of residence must depend upon the state of occurrence to transmit these records, known as intransfers, back to the state of residence. Even though numerous attempts are made to collect these records, OVS rarely receives 100% of them from the other states. Consequently, the total number of records in OVS's files is usually less than nationally published statistics for Kentucky. However, the difference is ordinarily less than one percent of the total number of events.

Timeliness: Due primarily to the time spent waiting for other states to transmit intransfer records, plus the time spent to complete a final edit of the data, there is currently a delay of as much as three to five years in establishing a "complete" annual database. Additionally, due to budget cuts which eliminated several staffing positions, OVS no longer has the resources required to produce the numerous tables in the *Annual Vital Statistics Report*. The last year for which these reports were available was 2005.

Accessibility: The data are housed on a mainframe system requiring special software, such as SAS, for access. In addition, the arcane structure of the files and the coding conventions usually require a user to develop considerable familiarity with the data before useful analyses can be made. So far, funds have not been made available to develop an online query system. In addition, marriage and divorce data are often incomplete because the collection method relies on submissions from **county clerk** offices in the county where the marriage license was issued and divorce certificate submissions from the **circuit county clerk** that granted the divorce decree.

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 Set Availability

No identifiable birth (>50,000 records annually), death (>40,000 records annually), or stillbirth data sets are available to the public. However, for a cost, these data can be made available to research organizations pending approval from the Cabinet's Institutional Review Board. De-identified, aggregate data sets can be made available to the public, the smallest geographic unit of analysis varying among data sets and stratification. All data is generated in either an Excel workbook or text file for release. Data can be transferred to the end user through file transfer protocol, FTP, or burned to a password protected disc and mailed with instructions for password retrieval. The vital statistics data contact can supply further information regarding instructions for requesting the data. National data are available on the NCHS web site.

Data Release Policy

Although under review, the current data release policy states that all numerators less than 5 be suppressed if the denominator is less than 1,000 for all data sets. 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 http://chfs.ky.gov/dph/vital/vitalstats.htm. 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 [data year].

Contributing Authors

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Youth Risk Behavior Surveillance System (YRBSS)

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State Web Site:
http://www.education.ky.gov/KDE/Administrative+Resources/Coordinated+School+Health/Youth+Risk+Behavior+Survey.htm

National Web Site: http://www.cdc.gov/HealthyYouth/yrbs/index.htm

Sources 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 and 2011, the Kentucky Department of Education collaborated with the Family Resource 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 collected during the spring of odd-numbered years. The YRBS is a self-reported survey given to the selected sample of students.

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, 2007, and 2009 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.

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 2010 objectives and other program indicators

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.

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, 2007 and 2009 for high schools, and 2009 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.

2009 Sample Size	**High school**	2,071
	Middle school	2,137
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 2009 Kentucky YRBSS results are highlighted in the latest report and can be found on the YRBSS website: http://www.cdc.gov/HealthyYouth/yrbs/index.htm. The website also includes a tool called Youth Online, that can analyze and create tables and graphs and perform statistical tests on high school and middle school results from 2001-2009 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].

Contributing Authors

Stephanie Bunge, M.Ed., Kentucky Department of Education
Kate Jones, MA, Kentucky Department for Public Health

Youth Tobacco Survey
(YTS)

Coordinator and Data Contact:	Dennis Peyton, MPH, CCRP, CHES Epidemiologist Health Promotions Branch Division of Maternal and Child Health Kentucky Cabinet for Health and Family Services (502) 564-7996 ex. 3824 dennis.peyton@ky.gov
State Web Site:	http://chfs.ky.gov/dph/info/dpqi/hp/tobacco.htm
National Web Site:	http://www.cdc.gov/tobacco/

Sources of Information for the Database

The Youth Tobacco Survey (YTS) is a questionnaire administered to middle and high school students in Kentucky and is made possible by a grant to the Kentucky Department for Public Health (KDPH) from the Centers for Disease Control and Prevention (CDC). The survey sample is a two-stage cluster design. In the first stage, schools are selected randomly within the grade range specified with a probability proportional to enrollment size. At the second stage, classes are randomly selected from within the selected school and all the students within a selected class are surveyed. Participation in YTS is voluntary. Personal identifying information, such as name or address, is not collected. The YTS has been conducted biennially since 2000 by local health department tobacco coordinators and health educators. The YTS is also conducted nationally in even-numbered years with a sample size of approximately 300 schools in the United States.

Along with federal funds, the Kentucky Tobacco Prevention and Cessation Program (KTPCP) receives state funds through the Master Settlement Agreement. With these resources, KTPCP supports local health departments in building community capacities to prevent and eliminate harm from tobacco use. The successful administration of the KYTS by local health departments obtains information useful in monitoring the progress toward achieving each of the four goals listed above. Evaluation of the activities conducted to prevent and control tobacco use in Kentucky will result in a greater knowledge of how to direct resources in the future.

Description of the Data Collected

The YTS collects data on prevalence of tobacco use among young people, including cigarettes, smokeless tobacco, cigars, bidis (hand-rolled cigarettes wrapped in a leaf and tied with string), and kreteks (clove cigarettes). The survey also collects information on secondhand smoke exposure, youth cessation of tobacco use, the role of media and advertising in tobacco use, minors' access to tobacco products, tobacco use in schools, tobacco-related attitudes of young people, and the influence of peers and family members to use tobacco products.

Strengths of the Data

The YTS provides data on risk behaviors associated with tobacco use across the state. The data collected are comparable to results from the Youth Tobacco Surveys of other states and also to the national YTS results. Data from the YTS can be used to monitor components of CDC's Best Practices for Comprehensive Tobacco Control Programs, including surveillance and evaluation, community programs to reduce tobacco use, school programs, enforcement, counter-marketing, and cessation programs.

Specific Uses of Information

- Monitor *Healthy Kentuckians 2010* goals
- Provide data to enhance the capacity of the state to design, implement, and evaluate the comprehensive tobacco control program
- Provide data for tobacco grant applications
- To evaluate health disparities

Data Limitations

The main limitation to YTS data is self-report bias. Therefore, the prevalence estimates are strictly based on each respondent's answers to the questions. The tendency to report a healthier lifestyle may occur. Another limitation is that no over-sampling procedures were taken in previous surveys so that regional data could be obtained.

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

YTS data from 2002 and 2006, 2008, and 2010 for both middle and high schools are available to the public; data from 2004 is available for high school only (middle school data were not weighted). The data are available in SPSS, SAS, and comma delimited formats.

Sample Size		
	High School	3,500
	Middle School	4,200
Smallest Geographic Level Released		Statewide
Cost of Data Set		Free

2010 OVERALL RESPONSE RATES (High School):

Schools - 89.47% 85 of the 95 sampled schools participated.

Students- 83.32% 3592 of the 4311 sampled students completed usable questionnaires

Overall response rate - 89.47% * 83.32% = 74.55%

2010 OVERALL RESPONSE RATES (Middle School):

Schools - 83.33 % 90 of the 108 sampled schools participated.

Students - 86.81 % 4275 of the 4924 sampled students completed usable questionnaires

Overall response rate - 83.33% * 86.81% = 72.34%

Data Release Policy

Contact the YTS coordinator if requesting data from the YTS.

Data Publications

The Kentucky Tobacco Prevention and Cessation Program produces a report of the YTS results for every year the survey is administered. Fact sheets for the 2010 YTS can be found at the Kentucky Tobacco Prevention and Cessation Program website: http://chfs.ky.gov/dph/info/dpqi/hp/tobacco.htm.

Suggested Data Citation

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). *Kentucky Youth Tobacco Survey.* Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, [survey year].

Contributing Author

Mr. Dennis Peyton, Epidemiologist, Tobacco Cessation Program.

Appendices

Additional Resources

The public health data sources presented in this guide are very valuable to public health decision making. In many instances, however, to be most effective these sources need to be supplemented with population data as well as data pertaining to social and economic indicators. Listed below are specific links to certain national and state websites that will provide population and economic related data. Specific sites that include county level data are also included.

Population Data

U.S. Census Bureau http://www.census.gov

This is the main source for all population data. The most recent complete census was conducted in 2010.

Kentucky State Data Center http://ksdc.louisville.edu/

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

Economic Data

Statistical Abstract of the United States http://www.census.gov/compendia/statab/

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.

County Level Data

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.

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.

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.

Atlas of Rural and Small-Town America http://www.ers.usda.gov/data/ruralatlas/

The Atlas of Rural and Small-Town America is a mapping application that provides a spatial interpretation of county-level, economic and social conditions along four broad categories of socioeconomic factors.

Glossary

Area Development District (ADD) - Kentucky has 120 counties that are divided into 15 ADDs for the planning of a variety of programs.

Health Information 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.

Public Health Surveillance - the ongoing systematic collection, analysis, interpretation and dissemination of health data. Specific types of surveillance are listed below.

- **Active Surveillance** - the health department regularly contacts reporting sources (e.g. once per week) to elicit reports, including negative reports (no cases)

- **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.

Kentucky Behavioral Risk Factor Surveillance System (BRFSS)

Data Set Request Form

BRFSS
Behavioral Risk Factor Surveillance System

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: ____________

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Appendix C

The undersigned investigator agrees to the following with respect to BRFSS data sets:

I will not release the data set I receive to any other persons.
I will not use these data for any purpose other than statistical reporting.
I will not attempt to contact or re-identify any respondents to the survey.
I will acknowledge the Centers for Disease Control and Prevention (CDC) as the original source of the data.
I will send a copy of any published reports using BRFSS data to the address listed below.

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:

Kentucky BRFSS Coordinator
Chronic Disease Prevention & Control Branch
Kentucky Department for Public Health
275 East Main St, HS2WE
Frankfort, KY 40621

Phone # (502) 564-9358 Ext 4284
Fax # (502) 564-2983

BRFSS
Behavioral Risk Factor Surveillance System

Kentucky Behavioral Risk Factor Surveillance System (BRFSS)

Data Request Form

BRFSS
Behavioral Risk Factor Surveillance System

Name: ____

Organization: ____

Address:____

City: ____

State: ______________ Zip Code:

E-mail: _______________________________

Telephone #: __________________ Fax # : _____________________

Year(s) of data requested:___________________________________

Topic(s) of data requested: __________________________________

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How will data be used:_______________________________________

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Date data request should be completed ___________________________

If you are producing a report, please send a copy of all printed and published materials using Kentucky BRFSS data to the address listed below.

Please mail or fax this form to:

Kentucky BRFSS Coordinator
Chronic Disease Prevention & Control Branch
Kentucky Department for Public Health
275 East Main St, HS2WE
Frankfort, KY 40621

Phone # (502) 564-9358 Ext 4284 Fax # (502) 564-2983

EDUCATION PAYS

Data Request Form
HIV/AIDS Branch - Epidemiology

Date of Request: ____________________ Date Requested By: __________________

Date Completed: ____________________

For Office Use Only

Name: ____

Organization: _______________________________________

Address: ____

Address: ____

Zip Code: ______________

****

Email Address: _________________________________

Home Phone (if applicable): _______________________

Work Phone (if applicable): _______________________

Fax (if applicable): __________________________

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Type of Request: ____
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Would you like to be on the mailing list? YES NO
Would you like to receive the semi-annual/annual reports? YES NO

Pregnancy Risk Assessment Monitoring System (PRAMS)

SAS Dataset 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: ____

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

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Appendix F

The undersigned investigator agrees to the following with respect to PRAMS datasets:

I will not release the data I receive to any other persons.
I will not use these data for any purpose other than statistical reporting.
I will acknowledge the Kentucky Department for Public Health as the original source of the data.
I will send a copy of any published reports using PRAMS data to the address listed below.

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:

Kentucky PRAMS Coordinator
Kentucky Department for Public Health
Division of Maternal and Child Health
275 East Main St. HS2W-A
Frankfort, KY. 40621

Phone # (502)- 564-4830 Fax # (502) 564-8389

Agreement for Use of Kentucky Health Claims Data

This agreement between the Kentucky Cabinet for Health and Family Services, Office of Health Policy, and the individual whose signature appears below, applies to all health claims data collected in compliance with KRS 216.2920-216.2947, including but not limited to subsets of patient level records in full or in part, and any and all summaries or aggregations of data which may be derived from original data or any subset thereof.

Personal identifiers: Patient level health claims data have been purged of name, address, social security number, and other direct personal identifiers to prevent individual patient identification. Nevertheless, the undersigned agrees that no attempt will be made to identify individual patients through any means or methods without expressed written permission of the Kentucky Cabinet for Health and Family Services. Furthermore, the undersigned agrees that information derived or summarized from patient-level data which could result in the identification of any specific individual will not be released or made public.

Establishment identifiers: Identifiers for hospitals, clinics, physicians, and other health care providers have been included on patient level records in compliance with the aforementioned statute for the purpose of making cost, quality, and outcome comparisons among providers. Such purpose does *not* include the use of information concerning individual providers for commercial or competitive purposes involving those providers, or to determine the rights, benefits, or privileges of such providers. Providers shall not be identified directly or by inference in disseminated material. Under this agreement, users of data shall not contact providers for the purpose of verifying received data or summaries derived therefrom.

The undersigned gives the following assurances with respect to data obtained under the terms and conditions of this agreement:

- I will not attempt to link or permit others to attempt to link the hospital stay records of persons in this data set with personally identifiable records from any other source without prior written approval from the Kentucky Cabinet for Health and Family Services;

- I will not attempt to use or permit others to use the data sets to learn the identity of any person included in any set;

- I will not release or permit others to release any information based on these data that identifies individuals, either directly or indirectly;

- I will not attempt to use or permit others to use the data to learn the identity of any provider that may be represented in the data;

- I will not contact or permit others to contact providers or persons represented in the data;

- I will not use or permit others to use data concerning individual health care providers
  (1) for commercial or competitive purposes involving those providers,
  (2) to determine the rights, benefits, or privileges of individual providers, or
  (3) to report, through any medium, data that could identify individual providers, either directly or by inference;

- I will require others in the organization specified below who use the data to sign this agreement and will keep those signed agreements and make them available upon request;

- I will not release or permit organizations or individuals outside my direct control or the control of the organization specified below to release the data sets or any part of them to any person who is not a member of the organization specified below;

- I will make no statement nor permit others to make statements implying or suggesting that interpretations drawn are those of health care providers that may be identified in the data, either individually or as a group, or the Kentucky Cabinet for Health and Family Services; and

- I will acknowledge the "Kentucky Cabinet for Health and Family Services, Office of Health Policy " as data source in any and all publications based on these data.

Violation of this agreement will result in action by the Kentucky Cabinet for Health and Family Services. Violations deemed unlawful may be referred to the Commonwealth Attorney, the police, the Federal Bureau of Investigation, or other appropriate legal authority for investigation and/or prosecution.