

Kentucky Cancer Registry (KCR)

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Source of Information for the Database

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

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

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

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

Description of the Data Collected

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

Strengths of the Data

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

Data Limitations

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

Specific Uses of Information

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

System Evaluation

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

Data Set Availability

Kentucky Cancer Registry recognizes four categories, levels, or types of data that can be released for cancer surveillance and research purposes.

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

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

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

Data Release Policy

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

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

Data Publications

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

Suggested Data Citation

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

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