

Kentucky Cancer Registry (KCR)

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State Website: <https://www.kcr.uky.edu/>

Why is it used?

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

What data is collected?

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

How is data collected?

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

Data Strengths:

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

Data Limitations:

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

How is the system evaluated?

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

Data Set Availability:

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

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



Data Release Policy:

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

Data Publications:

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

Suggested Citation:

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