

(For office use only) KCR Data Request Number: _____

APPLICATION TO ACCESS KCR DATA

This form must be completed and submitted with each proposal to use data from the Kentucky Cancer Registry. This is to assure that appropriate procedures are implemented for the use of KCR data.

Type of Proposal Submitted:
<input type="radio"/> New
<input type="radio"/> Amended

The Kentucky Cancer Registry recognizes four categories/levels of security with regard to its release of data for cancer surveillance and research purposes.

- I. Reports of aggregate data stratified by non-confidential data fields (i.e. case counts by race, sex, county, etc.).
- II. Files contain individual, record-level data with no personal identifiers. The file 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 file may contain zip code and county of residence.
- III. Files contain individual, record-level data with personal identifiers, to be used for purposes of record linkage, but not direct patient contact. Once the record linkage is complete, the personal identifiers will be removed from the data set.
- IV. Files contain individual, record-level data with personal identifiers, to be used for research purposes involving direct patient or family contact.

Please choose the category/level that best fits your research request.

- Level I
- Level II
- Level III
- Level IV

LEVEL III CHECKLIST

The data set to be linked includes personal identifiers, however, once the record linkage is completed, the personal identifiers will be removed from the linked data set before it is sent to the requesting party.

Therefore, in order initiate the release of a Level III data set from the Kentucky Cancer Registry, there are three items that must be included for the request to be considered.

- 1. Completed Level III Application Form**
- 2. Signed Assurance Form**
- 3. Copy of approved review by an appropriate Institutional Review Board (IRB).**

*As part of the application, the Kentucky Cancer Registry requests a brief description of the research project as well as a brief description of the Principal Investigator's credentials, education and research interests to be included in the Kentucky Cancer Registry's Annual Report. By signing the application, you are giving the Kentucky Cancer Registry permission to use this information in the report. The Registry does reserve the right to edit the submitted descriptions for formatting purposes.

Please enclose the requested documents and mail, fax or email them to:

*Kentucky Cancer Registry
Jaclyn McDowell, DrPH**
Epidemiologist
2365 Harrodsburg Road, Suite A230
Lexington, KY 40504-3381*

FAX: 859.257.4177

Email: jnee@kcr.uky.edu

***Contact Jaclyn McDowell at 859.218.2228 with any questions regarding the application process.*

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APPLICATION FORM FOR LEVEL III DATA

The data set to be linked includes personal identifiers, however, once the record linkage is completed, the personal identifiers will be removed from the linked data set before it is sent to the requesting party.

I. ORGANIZATION OR INDIVIDUAL REQUESTING ACCESS

A. Date of Request: _____

B. Name of Person Requesting Data: _____

C. Title, Degree and Rank: _____

D. Organization: _____

E. Address: _____

F. City, State, Zip Code: _____

G. Telephone number: _____

H. E-mail Address: _____

I. Fax number: _____

J. Other Person who should be contacted if more information is needed:

1. Name: _____

Telephone: _____

E-mail: _____

Address (if different from above):

K. Is this study externally funded? Yes No

L. If yes, what is the name of the funding organization(s) for this project?

M. Date data are needed: _____

II. THE RESEARCH PROJECT

A. Type of cancer(s) or issue(s) being studied:

B. List specific data items requested:

C. Check (✓) the year(s) of data requested

<input type="checkbox"/> 1995	<input type="checkbox"/> 1999	<input type="checkbox"/> 2003	<input type="checkbox"/> 2007	<input type="checkbox"/> 2011	<input type="checkbox"/> 2015*
<input type="checkbox"/> 1996	<input type="checkbox"/> 2000	<input type="checkbox"/> 2004	<input type="checkbox"/> 2008	<input type="checkbox"/> 2012	<input type="checkbox"/> 2016*
<input type="checkbox"/> 1997	<input type="checkbox"/> 2001	<input type="checkbox"/> 2005	<input type="checkbox"/> 2009	<input type="checkbox"/> 2013	<input type="checkbox"/> 2017*
<input type="checkbox"/> 1998	<input type="checkbox"/> 2002	<input type="checkbox"/> 2006	<input type="checkbox"/> 2010	<input type="checkbox"/> 2014	

*2014 is the most recent year for which data is complete. Data collection is ongoing for 2015-2017.

D. Check (✓) how you would like to receive the data. All data will be transferred over the KCR secure file transfer site. A username and password for access to the site will be set up when the application is approved.

Format
<input type="radio"/> Fixed width text file (ASCII)
<input type="radio"/> Delimited text file (ASCII)
<input type="radio"/> Other, please specify

E. Describe the study proposal and objectives. *(This description will be included in the KCR Annual Report).* A copy of your **IRB application**, along with the **approval letter MUST** be attached.

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F. Provide a brief description of the Principal Investigator (i.e. credentials, education, research interests, etc.). *(This description will be included in the KCR Annual Report).*

G. How will you maintain the confidentiality and security of identifiable data obtained from the Kentucky Cancer Registry records? *(Identifiable data refers to any information that could permit the identification of any individual. This is not only name and address, but also individual case record data where other demographic items such as age, sex, race and place of residence could also be used to identify subjects.)*

III. APPLICANT ASSURANCES

The undersigned hereby agrees to the following terms and conditions related to this application and to the use of information obtained from the Kentucky Cancer Registry.

- A. The data obtained following written approval from the Kentucky Cancer Registry shall be used only for the study proposed and the purposes described in the “Research Project” section of this application. Use of the information for a project or purpose other than that described previously shall not be undertaken unless a separate application form for the subsequent project has been submitted to, and approved by, the Kentucky Cancer Registry.
- B. No attempts will be made to further link any data set provided by the Kentucky Cancer Registry in order to identify the individuals contained in the data set. **No attempt will be made to contact any individual contained in the data set, or to contact any such individual’s health care provider(s).**
- C. The identity of the individuals contained in the data set will be kept confidential and the data will be stored in a secure manner.
- D. Data will only be used by the people listed below (attach additional sheets if necessary):

Name, Rank/Degree _____
Responsibility in Project _____

Name, Rank/Degree _____
Responsibility in Project _____

Name, Rank/Degree _____
Responsibility in Project _____

Name, Rank/Degree _____
Responsibility in Project _____

Name, Rank/Degree _____
Responsibility in Project _____

- E. This project will be completed by the following date: _____

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- F. A letter signed by the person receiving these data must be sent to KCR on or before the completion date verifying that all copies of the data, either paper or electronic have been destroyed. This letter will be sent to the following address:

*Kentucky Cancer Registry
Jaclyn McDowell, DrPH
Epidemiologist
2365 Harrodsburg Road, Suite A230
Lexington, KY 40504-3381*

- G. If data from the Kentucky Cancer Registry are used in any publication (or presentation), the following statement must be included.

Data used in this publication (or presentation) were provided by the Kentucky Cancer Registry, Lexington, KY.

A copy of any publication or presentation outline using data from the Kentucky Cancer Registry should be mailed to the Registry at the address listed previously.

- H. All statements entered in this application are true, complete and correct.

Name of Person Requesting Data: _____

Title: _____

Organization: _____

Signature of Person Requesting Data: _____

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IV. KENTUCKY CANCER REGISTRY RESPONSE

A. Date Request Made: _____

B. Request was accepted: Yes No

C. If no, reason for denial

D. Date data set released: _____

E. Data provided from KCR:

F. Keywords:

G. Cost of request: _____

H. Date of payment: _____

I. Request reviewed by: _____Thomas C. Tucker _____Frances Ross

_____Eric Durbin

J. Authorized signature: _____