

(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:

- New
- 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 IV CHECKLIST

This data set will include personal identifiers for the purposes of direct patient contact.

In order to initiate the release of a Level IV data set from the Kentucky Cancer Registry, there are four items that must be included for the request to be considered.

1. **Completed Level IV Application Form**
2. **Signed Assurance Form**
3. **Copy of approved full review by an appropriate Institutional Review Board (IRB).**
4. **Copy of the consent form to be used in the research project.**

\*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 them to:

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

**No individual identifying information will be released to researchers for the purpose of contacting the patient until the Kentucky Cancer Registry completes two procedures.**

1. **Physician notification:** The physician receives information about the study and the patient's potential participation. The physician is asked to inform the Kentucky Cancer Registry if there is any reason why the patient should not be contacted. If there is a substantive reason why a patient should not be contacted, he or she will not be included in the second procedure. All other eligible cases will be contacted in step two.
2. **Patient notification:** The Kentucky Cancer Registry will send eligible cases a letter informing them of their eligibility for the research study. They are provided a pre-addressed postage-paid response card which they may use to select whether or not they want their names to be released to investigators. If a response card is not received within two weeks, five phone calls will be made in an attempt to get verbal consent. Only those who agree to have their names released will have their contact information released to the researchers.

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

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## APPLICATION FORM FOR LEVEL IV DATA

This data set will include personal identifiers for the purposes of direct patient contact.

### 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 (include relevant inclusion criteria):

B. Requested data:

**Note:** Following physician and patient notification, contact information, including name, address, and telephone number of eligible cases, will be released to the investigator for the purpose of patient contact. If further individual record-level data is required, the investigator must obtain written informed consent from participating individuals that includes consent for the release of personal data from the Kentucky Cancer Registry.

If registry data will be requested for study participants, please specify the items needed. Due to the sensitive nature of the information, please request the minimum number of data fields necessary to conduct your research. Provide justification for each data field 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.

<u>Format</u>
<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, including informed consent form and a copy of the approval letter, MUST be attached.
- 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. The identity of the individuals contained in the data set will be stored in a secure manner. Only staff associated with this study will have access to individual identifiers.
- C. 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 \_\_\_\_\_

- D. This project will be completed by the following date: \_\_\_\_\_

- E. 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  
2365 Harrodsburg Road, Suite A230  
Lexington, KY 40504-3381*

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- F. 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.*

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

Name of Person Requesting Data: \_\_\_\_\_

Title: \_\_\_\_\_

Organization: \_\_\_\_\_

Signature of Person Requesting Data: \_\_\_\_\_

