

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

APPLICATION TO ACCESS ECPEGT' TGI KVT[DATA

This form must be completed and submitted with each proposal to use data from the Tqugo ct{ " Y ktkco u'Ecpegt 'Registry'*TY ET+. This is to assure that appropriate procedures are implemented for the use of TY CR data.

Type of Proposal Submitted:
New
Amended
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The TY ET 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

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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 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

1995	1998	2001	2004	2007	2010*
1996	1999	2002	2005	2008	2011*
1997	2000	2003	2006	2009	2012*

*2009 is the most recent year for which data is complete. Data collection is ongoing for 2010-2012.

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>
Fixed width text file (ASCII)
Delimited text file (ASCII)
Other, please specify

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E. Describe the study proposal and objectives. (*This description will be included in the TY ET 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 TY ER Annual Report*).

G. How will you maintain the confidentiality and security of identifiable data obtained from the 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 thg'Registry.

A. The data obtained following written approval from the 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, thg 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<

*Tqugo ct { 'Y knko u' Cancer Registry
.....'e lq' Crt gf c 'Y qqf u 'DU' EJ GU' EVT. 'O cpci gt
.....'4263' I gqt i kc 'C xg. 'PY . 'Uwkg' 442
.....'Y cuj kpi vqp. 'FE' 42282*

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- F. If data from the 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 Togo Cancer Registry, J. Y. E.

"

A copy of any publication or presentation outline using data from the 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: _____

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IV. CANCER REGISTRY RESPONSE

A. Date Request made: _____

B. Request was accepted Yes No

C. If no, reasons for denial:

D. Date non-confidential data set released: _____

E. Data provided from TY CR:

F. Keywords: _____

G. Cost of Request: _____

H. Date of Payment: _____

I. Request reviewed by _____ aaaaaaaaaaaaaaaaaaaaaaaaaaaaaaaaaaaaa

J. Authorized Signature: _____

Authorized Signature: _____