

For Office Use:  
Date request received: \_\_\_\_\_  
Date request completed: \_\_\_\_\_  
Person receiving request: \_\_\_\_\_

Community Health Administration

District of Columbia Cancer Registry (DCCR) Data Request Form

Date of request: \_\_\_\_\_

Person Requesting Data: \_\_\_\_\_ Title: \_\_\_\_\_

From (agency, facility, general public, etc.) \_\_\_\_\_

Address: \_\_\_\_\_

City/State: \_\_\_\_\_ Zip: \_\_\_\_\_

Telephone: \_\_\_\_\_ Fax: \_\_\_\_\_

E-mail: \_\_\_\_\_

**Type of Request Submitted (check all that apply)**

\_\_\_\_ Cancer Research      \_\_\_\_ IRB Proposal      \_\_\_\_ Amended IRB (Include IRB No.)      \_\_\_\_ Grant Proposal  
\_\_\_\_ IRB Continuation/Renewal      IRB No: \_\_\_\_\_      \_\_\_\_ Incidence/Mortality Rates  
\_\_\_\_ Student      \_\_\_\_ University Affiliation \_\_\_\_\_

**Level of Data (see description below)**

\_\_\_\_ Level I      \_\_\_\_ Level II      \_\_\_\_ Level III

Level I: Non-confidential aggregate data – No IRB required      Level II: Record-level data w/o identifiers – No IRB required  
Level III: Record-level data w/identifiers (record linkage only) – IRB required

**Brief Description of Purpose for Data Request:** (ex: researching incidence of pancreatic cancer in DC for possible publication)

Diagnosis Years: \_\_\_\_\_

Sites of Cancer: \_\_\_\_\_

Ward(s) at diagnosis: \_\_\_\_\_

Response requested by (month/day/year): \_\_\_\_\_ (Please allow at least 14 business days for request completion)

Submit DCCR Data Request Form by fax, e-mail or mail to:

DC Department of Health  
899 North Capital Street NE, 3<sup>rd</sup> floor  
Attn: Betelihem Tobo, PhD, District of Columbia Cancer Registry (DCCR)  
Washington, DC 20002

Telephone: (202) 442-9188  
Fax: (202) 442-9388  
E-mail: [Betelihem.tobo@dc.gov](mailto:Betelihem.tobo@dc.gov)

For Office Use:  
Date request received: \_\_\_\_\_  
Date request completed: \_\_\_\_\_  
Person receiving request: \_\_\_\_\_

Community Health Administration

## RELEASE OF CONFIDENTIAL INFORMATION

Due to the following DC regulations, the District of Columbia Cancer Registry (DCCR) is not allowed to release any information that contains confidential patient information. Even if an approved IRB is obtained, D.C. Official Code § 7-302 would not allow the release of the names and addresses of patients in the DC Cancer Registry. The requestor must contact the physician's offices, clinics, etc. and ask them to inform the patients about the research project.

The **yellow** highlight language in the statute allows the Director to release identifying information only when essential to protect public health (such as in response to an outbreak).

The **teal** highlighted language allows disclosure if:

1. The patient gives prior written permission (which has not happened but could happen as discussed below);
2. A court order meeting all the requirements has issued (which has not happened and is unlikely to happen; or,
3. There is an exchange with another state registry that has sufficient confidentiality

See regulation listed below

### D.C. Official Code § 7-302 provides:

"The Commissioner of Public Health shall use the records incident to a reported case of cancer for statistical and public health purposes only, and identifying information contained in these records shall be disclosed only when essential to safeguard the physical health of others. No person shall otherwise disclose or redisclose identifying information derived from these records unless:

(1) The person reported gives his or her prior written permission;

(2) A court finds, upon clear and convincing evidence and after granting the person reported an opportunity to contest the disclosure, that disclosure is essential to safeguard the physical health of others; or

(3) The identifying information is exchanged with a cancer registry that is maintained by a state and the Commissioner of Public Health receives a satisfactory assurance from the cancer registry that the confidentiality of the identifying information shall be preserved."

For Office Use:  
Date request received: \_\_\_\_\_  
Date request completed: \_\_\_\_\_  
Person receiving request: \_\_\_\_\_

Community Health Administration

## CONFIDENTIALITY AGREEMENT

The District of Columbia Cancer Registry (DCCR) of the Community Health Administration, is required by the Cancer Registries Amendment Act to maintain confidentiality of cancer data registered in the District of Columbia. Data permitting identification of particular individuals and establishments can be disclosed only under specified conditions designed to protect privacy or potential harm to those who provided the data.

Confidential data referred include:

- Births
- Deaths (including fetal deaths)
- Any other vital record or cancer data used to amend a record

No information obtained from the DCCR in the course of research or project activities may be used for any purpose other than the purpose for which it was supplied. In the case of information obtained in the course of health statistical or epidemiological activities, such information may not be published or released in the form that will permit identification of a particular establishment or person supplying the information. The information may not be described in a manner that such establishment or person supplying the information can be identified.

The DCCR does not release cancer data for use as a basis for legal, administrative, or other actions, which may directly affect particular individuals or establishments.

Due to the sensitive nature of the information on these confidential documents and restrictions placed upon release or access to them, each request must be reviewed to determine conformity to provisions of privacy and confidentiality.

Requesters of cancer data must submit a completed Cancer Registry Data Request Form. Requester(s) must sign the form agreeing to all assurances listed in the *application form*.

I have read and agree to the confidentiality requirements.

Applicant Name: \_\_\_\_\_

Applicant Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Please submit form with completed Data Request Application.

For Office Use:  
Date request received: \_\_\_\_\_  
Date request completed: \_\_\_\_\_  
Person receiving request: \_\_\_\_\_

Community Health Administration

## LEVELS OF DATA

The District of Columbia Cancer Registry (DCCR) provides three (3) categories, levels, or types of data that can be released for cancer surveillance and research purposes. As you prepare to submit your data request forms to DCCR, please review the criteria for each level. The three levels/categories are:

### Level 1:

Reports of aggregate data stratified by non-confidential data fields (i.e. case counts by race, sex, county, etc.).  
**(No IRB required)**

### Level 2:

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. **(No IRB required)**

### Level 3:

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. **(IRB required)**