

For Office Use:

Date request received: _____

Date request completed: _____

Person receiving request: _____

DISTRICT OF COLUMBIA CANCER REGISTRY (DCCR) DATA REQUEST

Any person or institution, agency or office interested in using DCCR cancer data must submit a completed data request form to the DCCR for review and approval. The DCCR has promulgated rules, which establish specific criteria for reviewing requests for registry data; therefore, each potential requester must review the request form to determine whether the intended use of the data conforms to established standards of confidentiality.

The request form is designed to obtain assurances from the requester that the confidentiality of the data obtained from the Cancer Registry is maintained, and that the data requested will be used only for the proposed study.

A separate data request must be submitted and approved for each project proposing to use registry data. An additional request for data for the same project requires the submission and approval of an updated request form.

If data will be used for research, data requests from non-DC Government agencies or individuals must be accompanied by a copy of an approved IRB received from the District of Columbia's Department of Human Services' Board for the Protection of Human Subjects, constituted according to federal guidelines for the protection of human subjects as laid out in the National Research Act, PL-93-348, July 12, 1974. The forms for IRB approval can be found at <https://dchealth.dc.gov/service/institutional-review-board-public-health>.

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RELEASE OF CONFIDENTIAL INFORMATION

Regulations outlined in D.C. Official Code § 7-302 prohibit the DCCR from releasing confidential patient information, regardless of whether IRB approval is obtained.

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.

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CONFIDENTIALITY

The DCCR is required by the Cancer Registries Amendment Act to maintain confidentiality of cancer data registered in the District of Columbia.

Confidential data may include, but is not limited to:

- Any information that can be used to identify an individual, such as: name, date of birth, address, social security number
- Rare cancers
- Small numbers within a cell

No information obtained from the DCCR in the course of research or project activities shall be used for any purpose other than requested. In the case of information obtained for health statistics or epidemiologic studies, such information shall not be published or released in the form that will permit identification of District residents.

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.

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LEVELS OF DATA

The DCCR recognizes three categories/levels of security with regard to its release of data 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 I. Reports of aggregate data stratified by non-confidential data fields (i.e. aggregated incidence and mortality rates by race, sex, , etc.). – **No IRB required**

Level II. Files containing 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, or any other information that could potentially be used to identify individual patients. (for cancer research activities, i.e. publications, manuscripts). – **IRB required**

Level III. For purposes of record linkage (but not direct patient contact) the requestor must submit to DCCR a file containing individual record level data with personal identifiers to be used for the linkage. – **IRB required**

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APPLICANT ASSURANCES

As the official or principal investigator of the program or research study named on this application, I agree to abide by the provisions of this agreement regarding the use and release of DCCR data. I will take all steps necessary to ensure that all those involved with the specified program or research project also abide by the provisions of this agreement, and that the data received are not used for any purpose other than that specified in the Application. The undersigned hereby agrees to the following terms and conditions related to this data request and to the use of the information obtained from the District of Columbia Cancer Registry (DCCR).

1. Any and all data obtained from the DCCR shall be used for research and statistical purposes only, and for the purpose described in this data request. Use of the information for any other purpose shall not be undertaken until after a separate application form for that project has been submitted to, and approved by DCCR.
2. No data shall be published or released in any form if a particular individual is identifiable.
3. A copy of any publication(s), abstract(s), and PowerPoint or poster presentation emanating from the use of the data **must** be sent to the Program Manager at DCCR for review and approval prior to submission.
4. Any publication or report produced from the use of the data will be in accordance with the terms of this application and will include the following citation:

“The information contained in this publication or report was provided by the District of Columbia Cancer Registry, District of Columbia Department of Health, program funded by the National Program of Cancer Registries (NPCR) – CDC, agreement 1 NU58DP007155”.

5. If the results of the project utilizing DCCR data will be published, the DCCR Program Manager must receive notification when the manuscript or other type of report is published, to include the full citation and DOI number, if applicable.
6. Linkages with other data bases, if planned, are essential for the administrative purposes specified in the application and will not lead to unauthorized disclosure of restricted data.
7. Adequate procedures are in place to secure restricted data from unauthorized access or use for purposes other than those for which they were requested; secured when not in use and accessed only by authorized individuals for the purposes stated in the application.

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8. I shall report in writing to the DCCR any unauthorized use or accidental dissemination of confidential information within 24 hours of notice or knowledge of the unauthorized use of dissemination.
9. All data and any copies of the data shall be destroyed at the conclusion of the study. An assurance statement that the data has been destroyed, including both the date of data destruction and the method(s) used to destroy the data, shall be provided to the DCCR Program Manager. Final disposition of restricted and identifiable data will be made in a manner that will not permit unauthorized disclosure. Data may also be returned to the DCCR for destruction.

Principal Investigator, Program Director, or Other Responsible Individual:

Signature:

Printed Name and Title:

Organization:

Title of Program or Study:

Date:

****The Department of Health does not discriminate based on race, color, religion, national origin, sex, age, marital status, personal appearance, sexual orientation, family responsibilities, physical handicap, matriculation, or political affiliation. ****

Disclaimer: The District of Columbia Cancer Registry (DCCR) is not responsible for data that is misrepresented or altered, and does not assume any liability or responsibility from the conclusions generated from the data. No warranties are implied regarding the method that serves to approve publications. The research results do not represent the views of the Department of Health or District of Columbia Cancer Registry (DCCR).

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District of Columbia Cancer Registry (DCCR) Data Request Form

Date of request: _____

1. Person Requesting Data: _____

Title: _____

Organization _____

Address: _____

City/State: _____ Zip: _____

Telephone: _____ Fax: _____

E-mail: _____

2. Contact Person (if different from Requestor):

Name: _____

Telephone: _____ Fax: _____

E-mail: _____

3. Purpose of study or program:

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4. Summary of study/program protocol/how requested data will be used. Please be as succinct as possible; your complete study protocol or program and detailed descriptions of your project and background are not necessary.

a. Description of health or medical problem addressed, or administrative purpose served by the program, demonstrating that data requested are essential, and stating primary study or program objectives and hypotheses to be tested, if applicable.

b. Describe analysis plan, if applicable, indicating how data will be used and level of aggregation.

c. Describe procedures for maintaining confidentiality and security of restricted data received.

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5. Type of Request Submitted (check all that apply)

____ Cancer Research ____ IRB Proposal ____ Amendment to IRB (Include IRB No:)

____ Grant Proposal ____ IRB Continuation/Renewal IRB No: _____

____ Incidence/Mortality Rates ____ Other aggregated data (please explain purpose) - 1 to 2 sentences

6. Level of Data (see description above)

____ Level I ____ Level II ____ Level III

7. Information to be used to select records of interest:

Diagnosis Years:

Sites of Cancer:

Demographic/Other variables (sex, race, etc.):

Response requested by (month/day/year): _____

8. Procedures and timetable for disposition of any restricted data received.

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Data Destruction Agreement

Upon completion of research, data linkage, and/or receipt of linked data results, all data received from DCCR must be destroyed. There must not be any individually identifiable information, dataset copies, or parts thereof, retained when the files are destroyed.

My signature below certifies that all Department of Health, District of Columbia Cancer Registry data related to the

project _____ will be

destroyed on (date)_____. The method for data destruction will be

Printed Name: _____

Signature: _____

Phone: _____

E-mail: _____

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Send completed/signed documents (Data Request Form, Data Destruction Agreement with estimated date of destruction) to:

Claudine Samanic, PhD

Public Health Analyst, DC Cancer Registry

Community Health Administration

DC Department of Health

899 North Capitol St., NE, 3rd floor

Washington, DC 20002

Phone 202-596-4964

Fax 202-442-9388

claudine.samanic@dc.gov

****Upon completion of data destruction, a revised data destruction agreement must be submitted to DCCR that includes actual date and method of destruction. ****
