



**GOVERNMENT OF THE DISTRICT OF COLUMBIA
DEPARTMENT OF HEALTH
COMMUNITY HEALTH ADMINISTRATION
BUREAU OF CANCER AND CHRONIC DISEASE
D. C. CANCER REGISTRY**

TELEPHONE: (202)442-9414
FAX NUMBER: (202)442-4947

MAILING ADDRESS
899 NORTH CAPITOL STR, NE.
THIRD FLOOR
WASHINGTON, D. C. 20002

**GUIDELINES FOR REQUESTING DATA OR
ACCESS TO CONFIDENTIAL CANCER DATA**

INTRODUCTION

Any person or institution, agency or office interested in using cancer Registry Data should submit a completed "*application form* (enclosed)" to the Cancer Registry. The Program Director has promulgated rules, which established specific criteria for reviewing requests for *registry data*; therefore, each potential requester must review the *application form* to determine whether the intended use of the data conforms to established standards of confidentiality.

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

An *application form* is enclosed. Additional copies of the application form can be obtained from the DC Cancer Registry at 899 North Capitol Street, N.E., 3rd Floor, Room 350, Washington, D.C. 20002, Telephone Number: (202) 442-5878 or (202) 724-7703; Fax Number: (202) 442-9432.

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

Each *application form* must be completed and the information submitted must be sufficient to permit determination of whether the application meets specified criteria for approval. Providing the requested information is voluntary; however, *failure to supply sufficient detail may delay review of the application or cause it to be disapproved*.

Each submission of the *application form* received from a D. C. Government agency should be accompanied by a copy of the approval received from the District of Columbia's Department of Human Services' Board for the Protection of Human Subjects. Applications from non-DC Government agencies or individuals must be accompanied by a copy of the approval received from any IRB 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.

CONFIDENTIALITY

The Program Director, D. C. Cancer Registry 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 D. C. Cancer Registry 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 Program Director 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*.

The original application form, when completed, should be sent to:

Rachel Lay Khoo, PhD

Program Director
DC Cancer Registry
Cancer & Chronic Disease Bureau
Community Health Administration
DC Department of Health
899 N. Capitol St. NE, 3rd floor,
Washington, DC 20002
Phone 202-442-9216
Fax 202-442-4947
lay.khoo@dc.gov

APPLICATION FOR USE OF DATA WITH IDENTIFIERS

D. C. Cancer Registry
Bureau of Cancer and Chronic Disease
Community Health Administration
D. C. Department of Health
District of Columbia Government

FOR OFFICE USE ONLY

Application No.: _____
Date Received: _____
Date Reviewed: _____
Approved: *Conditionally* _____
 Unconditionally _____
 Pending _____
 Disapproved _____

I. ORGANIZATION OR INDIVIDUAL REQUESTING USE OF CANCER DATA WITH IDENTIFIERS

- 1. Project Director: _____
- 2. Title: _____
- 3. Organization: _____
- 4. Street Address: _____
- 5. City/State/Zip Code: _____
- 6. Telephone No.: _____ E-Mail: _____
- 7. Type of data requested: _____
- 8. Expected date for completion of study: _____
- 9. Expected date for data destruction (data with identifiers): _____
(Please, complete certification and return after data destruction has taken place)

Please check the box which best describes your organization:

- Federal Government State/Local Gov't Health Provider
- College or University Media Congress
- Other Commercial Other

II. SUMMARY OF STUDY PROTOCOL OR PROJECT ACTIVITIES

1. Title of study or project:

2. Name and address of sponsor (s) for this project, if any: _____

3. Institutional Review Board (IRB) for the Protection of Human Subject:

a) Has this project been reviewed and approved by the D. C. Government Institutional Review Board for the Protection of Human Subject or any Institutional Review Board 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?

YES: ____ NO: ____

b) If YES, give the date of approval below and attach a copy of the approval application.

If NO, state reason:

4. Include the following information in the description of your research plan or project activities. (Failure to provide this information may cause the Program Director to disapprove the application.):

a) Statement of the problem addressed by your study or project.

b) Objectives, including hypotheses to be tested, if any, or research questions to be answered.

c) A brief summary of analyses or project activities that will be performed, indicating specifically how data obtained from the D. C. Cancer Registry (DCCR) will be used. If there has to be contact with individuals whose data are requested, state so.

d) Describe any data files that will be linked with the DCCR data and specify the source of these data files.

- e) Indicate how the results of your study or activities will be released. (DC Government agencies must submit the results of the study or project for review by the appropriate Department— Department of Health— or Commission— Social Services or Mental Health— D. C. Cancer Registry before publication.)
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III. OTHER DATA USERS AND USES

1. For the purpose of this research or project, as described in section II above, will any of the data with identifiers be used by other organizations; for example, other divisions, agencies, consultants, contractors and/or subcontractors?

YES: ____ NO: ____

- a) If YES, indicate the name (if known, otherwise indicate the type of organization) of any other organization and its role in this research project. Also describe safety precautions that exist (or will be implemented) to insure that the data will be used solely for the purposes of this research or project.
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2. Will any of the data with identifiers be used as a basis for legal, administrative, or other actions, which may directly affect particular individuals or establishments as a result of their specific identification in this project?

YES: ____ NO: ____

- a) If YES, please explain: _____
-

3. Will the data with identifiers be used either directly or indirectly for any research project other than the one described in section II above?

YES: ____ NO: ____

- a) If YES, briefly describe the other research project(s) or purpose(s) for which these data will be used. (Attach a separate application form for each research or project, which will be using identifiable data obtained from the Program Director.)
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IV. DATA ITEMS REQUESTED

List in detail all data items you are requesting: (example: year of diagnosis, cancer site, stage at diagnosis, histology, behavior, sex, race, age at diagnosis, Hispanic, treatment etc.) **ONE DATA ITEM OR PER LINE**. Indicate if you are requesting **Incidence or**

Mortality data. Information is for **DC residents only**.

1. **Which** Years of diagnosis _____
2. **Which** Cancer sites _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____

APPLICANT ASSURANCES

The undersigned hereby agrees to the following terms and conditions related to this application and to the use of the information obtained from the D. C. Cancer Registry Database with identifiers files.

1. The data with identifiers obtained from the Program Director will be used only for research and statistical purposes. No data will be published or released in any form if a particular individual or establishment supplying the information or described in it is identifiable. Furthermore, the identifiable information will not be used as a basis for legal, administrative, or other actions, which directly affect those particular individuals or establishments as a result of their specific identification in this project.
2. The data with identifiers obtained from the Program Director will be used only for the study proposed and the purposes described in section II: "Summary of Study Protocol or Project Activities." Use of the information for any purpose other than stipulated and described in section II, will not be undertaken until after a separate application form for that project has been submitted to, and approved by the Program Director.
3. A copy of any publication(s), abstract(s), and PowerPoint or poster presentation emanating from the use of the data will be sent to the Program Director at the D. C. Cancer Registry, D. C. Department of Health, 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 statement:

“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”.
5. I agree that when individuals have made a substantial contribution to the conduct of the study, writing or revising of the manuscript, they shall be listed as authors.
6. If you are using DCCR data in a research manuscript that will be published, please notify us the status of your publication.
7. All data and copies of the data will be destroyed at the conclusion of the study. An assurance statement that the data has been destroyed, the date of data destruction, and the method(s) used to destroy the data (for example, use of software programs such as electronic File Shredder, Eraser 5.1 or Evidence Eliminator; burn, pulverize, or shred hard copies, to prevent reconstruction; or returned to DCCR) will be issued to the Program Director at the D. C. Cancer Registry.
8. All the statements made in this application are true, complete, and correct to the best of my knowledge and belief.

9. The appropriate Department, Commission, and D. C. Cancer Registry will review D. C. Government agency reports emanating from use of these data prior to publication.

Name: _____

Title: _____

Organization: _____

Signature: _____

Date: _____

Please send this application to:

Rachel Lay Khoo, PhD
Program Director
DC Cancer Registry
Cancer & Chronic Disease Bureau
Community Health Administration
DC Department of Health
899 N. Capitol St., NE 3rd floor
Washington, DC 20002
lay.khoo@dc.gov

For additional information, please call: (202) 442-9216 or (202) 724-7703; Fax: (202) 442-4947.

The Department of Health does not discriminate on the basis of 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 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 DC Cancer Registry.



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Certification of Data Destruction

Upon completion of data linkage and confirmed receipt of linked data results, the data 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, Cancer Registry data related to the project “_____” will be destroyed on _____. The method for data destruction will be _____.

Signed

Print Name

Title

Organization

Address

City

State

Zip Code

Phone

E-mail

Please complete the method and estimate the date of destruction and send the original signed form with your application to:

Rachel Lay Khoo, PhD
Program Director
DC Cancer Registry
Cancer & Chronic Disease Bureau
Community Health Administration
DC Department of Health
899 N. Capitol St., NE 3rd floor
Washington, DC 20002
Phone 202-442-9216
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