



# CEDCD Cancer Epidemiology Descriptive Cohort Database

Collection of this information is authorized by The Public Health Service Act, Section 411 (42 USC 285a). Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private to the extent provided by law. Names and other identifiers will not appear in any report of the study. Information provided will be combined for all study participants and reported as summaries. You are being contacted by email to complete this instrument so that we can develop a database and keep the website up to date.

Public reporting burden for this collection of information is estimated to average 30 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-XXXX). Do not return the completed form to this address.

[Date]

[Principal Investigator Name]

[Institute and Contact Information]

Dear Dr. [Investigator],

The Epidemiology and Genomics Research Program (EGRP) of the National Cancer Institute (NCI) is currently developing an exciting new resource for Cancer Epidemiology Cohorts. We are developing the Cancer Epidemiology Descriptive Cohort Database (CEDCD) [website URL], a public, descriptive database of cancer epidemiology cohorts with the goal to facilitate collaborative research efforts among cancer epidemiology cohorts and highlight contributions to cancer research and public health.

As the Scientific Cohort and Consortia Coordinator of the NCI's EGRP, I am contacting you to ask permission to provide and publicly share descriptive information of the [FULL COHORT NAME] (for e.g. descriptive cohort characteristics, study protocols, basic counts of participants with various characteristics, etc.) in this database that will be publicly available and searchable. The CEDCD will contain only descriptive information; it will not contain any participant-level data. After initial data collection, this database will be updated annually.

If you, your CO-PI's, and your respective institutions, will permit EGRP to publicly share this information, indicate your approval on the enclosed Approval Form. Otherwise, please identify any information you would like us to remove before posting on the website.

Please indicate your approval by signing the next page and returning this to us, along with any special instructions regarding information you would not want publicly shared.

If you have any questions or need additional information, please feel free to email me at [seminard@mail.nih.gov](mailto:seminard@mail.nih.gov) and my colleague Gabriel Lai at [gabriel.lai@nih.gov](mailto:gabriel.lai@nih.gov). Thank you for your consideration of this request.

Sincerely,

Daniela Seminara, Ph.D., M.P.H.  
Senior Scientist and Consortia Coordinator  
Office of the Associate Director  
Epidemiology and Genomics Research Program  
Division of Cancer Control and Population Sciences  
National Cancer Institute

**Approval to publicly share [FULL TITLE] Cohort Information for the Descriptive Cohort Database (DCD) Website**

Please indicate your approval to publicly share information for each item.

**Descriptive Data:**

Cohorts Descriptive Database Collection Form and CEDCD Biospecimen and Cancer Count Information Spreadsheet

- Agree to publicly share
- Do not agree to publicly share

Roster of Cohort Investigators/Institutions

- Agree to publicly share
- Do not agree to publicly share

**Attachments:** [if available]

Cohort Data Sharing Policy

- Agree to publicly share
- Do not agree to publicly share

Ancillary Proposals Submission Guidelines and Processes

- Agree to publicly share
- Do not agree to publicly share

Authorship and/or Publication Policy

- Agree to publicly share
- Do not agree to publicly share

Questionnaires and SOPs (including biospecimen collection SOPs)

- Agree to publicly share
- Do not agree to publicly share

We agree to publicly share data of the above indicated cohort information within the web-based Cancer Epidemiology Descriptive Cohort Database (CEDCD), with any additional instructions we have provided.

\_\_\_\_\_  
Principal Investigator Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Business Official Signature (if needed)

\_\_\_\_\_  
Date

**Please return signed copy and any special instructions to:**

Westat, Inc.

Email: [CEDCDHelpdesk@westat.com](mailto:CEDCDHelpdesk@westat.com)

Fax: 301-315-5910

Mail: Attn: CEDCDHelpdesk, Westat, 1600 Research Boulevard, Room TB361, Rockville MD 20850