



# **CEDCD** Cancer Epidemiology Descriptive Cohort Database

## **Data Collection Form**

**5/16/2017**

Thank you for taking the time to complete this form. The information you provide will populate the Cancer Epidemiology Descriptive Cohort Database (<http://CEDCD.nci.nih.gov>). Users of the CEDCD can access information about Cancer Epidemiology Cohorts, compare cohort characteristics, types of data collected, and tabulate counts of participants, cancer endpoints, and biospecimens. We hope you will find the CEDCD useful in identifying potential collaborators and facilitating future studies.

This form contains pre-filled information (wherever possible) from past entries. Please review for accuracy and update information as needed. The information on this form will be automatically uploaded to the CEDCD database (i.e., no duplicate data entry). Annual updates are planned to ensure that the database reflects accurate up-to-date information about your cohort.

Please return the completed form to Westat ([cedcdhelpdesk@westat.com](mailto:cedcdhelpdesk@westat.com)). If you have questions, please contact the CEDCD Helpdesk or Dr. Joanne Elena ([elenajw@mail.nih.gov](mailto:elenajw@mail.nih.gov)) directly.

**CEDCD**

Cancer Epidemiology Descriptive Cohort Database

**Data Collection Form****5/16/2017****A. Basic Cohort Information** *(If your cohort is comprised of more than one distinct enrollment period or population, please complete separate CEDCD Data Collection Forms to treat them as separate cohorts.)*

A.1a Cohort Name:			
A.1b Cohort Abbreviation:			
A.1c Cohort Website: (if available)			
A.2 Date Form Completed:		_____	
		MM / DD / YYYY	
A.3a Person who completed the form:		A.3b Contact Person for clarification of this form:	
Name:	_____	Is this the person to contact with questions about this form?  <input type="checkbox"/> No <input type="checkbox"/> Yes If no, please provide the name and contact information for correct person in the space below.	
Position with the cohort:	_____		
Phone:	_____		
Email:	_____		
		Name:	_____
		Position with the cohort:	_____
		Phone:	_____
		Email:	_____
A.4 Cohort Principal Investigator(s):			
Name:	_____	Name:	_____
Institution:	_____	Institution:	_____
Email:	_____	Email:	_____
Name:	_____	Name:	_____
Institution:	_____	Institution:	_____
Email:	_____	Email:	_____
Name:	_____	Name:	_____
Institution:	_____	Institution:	_____
Email:	_____	Email:	_____



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### A. Basic Cohort Information (continued)

A.5 If an investigator is interested in collaborating with your cohort on a new project, whom should they contact?

Name:

\_\_\_\_\_

☐ Same as A.3a

Position with the cohort:

\_\_\_\_\_

Phone:

\_\_\_\_\_

☐ Same as A.3b

Email:

\_\_\_\_\_

A.6 What is the procedure for requesting data?

☐ Website, please specify: \_\_\_\_\_

☐ Policy attached (PDF)

☐ We do not have one

A.7 Cohort Description:

Please provide a short paragraph describing your cohort. This will be used as an overall narrative description of your cohort on the CEDCD website. You may provide a link to a description on your cohort's website.

**Data Collection Form****5/16/2017****A. Basic Cohort Information (continued)**

A.8 Eligibility Criteria:

Eligible Gender:

☐ Both genders☐ Males only☐ Females only

Disease State:

☐ Cancer survivors only, specify cancer site: \_\_\_\_\_☐ Generally healthy, no previous cancer diagnosis☐ Other, please specify: \_\_\_\_\_

A.9 Enrollment Information:

Total number of subjects enrolled: \_\_\_\_\_

\_\_\_\_\_ to \_\_\_\_\_  
Year Started (YYYY) Year Ended (YYYY)Is enrollment ongoing? ☐ No ☐ Yes

If still enrolling, please specify the target number you plan to enroll: \_\_\_\_\_

If still enrolling, please specify by when you plan to complete enrollment: \_\_\_\_\_  
YYYY

Age range of enrolled subjects: \_\_\_\_\_ To \_\_\_\_\_

Median age: \_\_\_\_\_ Mean age: \_\_\_\_\_

A.10 Specify time intervals when your questionnaire data were collected. For example, yearly, biannually, 2011-2013.

Specify:

\_\_\_\_\_  
\_\_\_\_\_

A.11 Most recent year when questionnaire data were collected:

\_\_\_\_\_  
Year (YYYY)

A.12 How was information from the questionnaire administered/collected?

In person ☐ No ☐ YesPhone ☐ No ☐ YesPaper ☐ No ☐ YesElectronic / Web-based ☐ No ☐ YesOther: ☐ No ☐ Yes, specify:\_\_\_\_\_  
\_\_\_\_\_

A.13 Were any tools aside from questionnaires used for exposure data collection? (e.g., an accelerometer for recording physical activity)

☐ No ☐ Yes

If yes, specify the instruments:

\_\_\_\_\_  
\_\_\_\_\_

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**A. Basic Cohort Information (continued)**

A.14 Does your cohort have any known restrictions on participating in collaborative projects involving pooling of data or specimens or use of specimens in genomic studies? (For example, restrictions due to the wording of the informed consent?)

- ☐ None  
☐ Require Collaboration with Cohort Investigators  
☐ Require IRB Approvals  
☐ Require Data Use Agreements and/or Material Transfer Agreement  
☐ Restrictions in the Consent Related to Genetic Use  
☐ Restrictions in the Consent Related to Linking to Other databases  
☐ Restriction on Commercial Use  
☐ Other, please specify: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**B. Enrollment Counts (Record actual (not planned) recruitment counts)**

B.1 Racial Categories	Ethnic Categories									Total
	Not Hispanic or Latino			Hispanic or Latino			Unknown/Not Reported Ethnicity			
	Female	Male	Unknown/ Not Reported	Female	Male	Unknown/ Not Reported	Female	Male	Unknown/ Not Reported	
American Indian/Alaska Native										
Asian										
Native Hawaiian or Other Pacific Islander										
Black or African American										
White										
More Than One Race										
Unknown or Not Reported										
Total										

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<b>C. Data on Major Content Domains</b>		
<b>Please specify whether you collected data within these major content domains. Baseline refers to data collected at or near enrollment into the cohort.</b>		
<b>Did you collect data on:</b>	<b>Collected at baseline</b>	<b>Collected during follow-up</b>
C.1 Socio-economic Status (e.g., income)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.2 Education Level	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.3 Marital Status	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.4 Language/Country of Origin	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.5 Employment Status	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.6 Health Insurance Status	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.7 Anthropometry (e.g., weight, height, waist circumference)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.8 Dietary Intake	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.9 Dietary Supplement Use	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.10 Complementary and Alternative Medicine	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.11 Prescription Medication Use (not related to cancer treatment)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.12 Non-prescription Medication Use (not related to cancer treatment)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.13 Alcohol Consumption	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.14 Cigarette Smoking	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes

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<b>C. Data on Major Content Domains (continued)</b>		
<b>Did you collect data on:</b>	<b>Collected at baseline</b>	<b>Collected during follow-up</b>
C.15 Use of Tobacco Products Other than Cigarettes	Cigars <input type="checkbox"/> No <input type="checkbox"/> Yes Pipes <input type="checkbox"/> No <input type="checkbox"/> Yes Chewing tobacco <input type="checkbox"/> No <input type="checkbox"/> Yes E-Cigarettes <input type="checkbox"/> No <input type="checkbox"/> Yes Other <input type="checkbox"/> No <input type="checkbox"/> Yes, specify: _____ _____	Cigars <input type="checkbox"/> No <input type="checkbox"/> Yes Pipes <input type="checkbox"/> No <input type="checkbox"/> Yes Chewing tobacco <input type="checkbox"/> No <input type="checkbox"/> Yes E-Cigarettes <input type="checkbox"/> No <input type="checkbox"/> Yes Other <input type="checkbox"/> No <input type="checkbox"/> Yes, specify: _____ _____
C.16 Physical Activity	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.17 Sleep Habits	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.18 Reproductive History	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.19 Self-Reported Health	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.20 Quality of Life	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.21 Social Support	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.22 Cognitive Function	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.23 Depression	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.24 Other Psychosocial Variables	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.25 Fatigue	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.26 Family History of Cancer	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.27 Family History of Cancer with Pedigrees	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes

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<b>C. Data on Major Content Domains (continued)</b>		
<b>Did you collect data on:</b>	<b>Collected at baseline</b>	<b>Collected during follow-up</b>
C.28 Environmental or Occupational Exposures (e.g. air contaminants/quality, occupational exposures and history, water source)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
C.29 Residential Information (zip code, GIS)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<b>C.31 Co-Morbid Conditions:</b>		
<b>Did you collect data on:</b>	<b>Collected at baseline</b>	<b>Collected during follow-up</b>
a. Diabetes	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
b. Stroke	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
c. COPD and/or Emphysema	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
d. Cardiovascular Disease	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
e. Osteoporosis	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
f. Mental Health	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
g. Cognitive Decline	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<b>C.32 Cancer Related Conditions:</b>		
Do you have information on the following cancer related conditions:		
Acute treatment-related toxicity (e.g., diarrhea, nephrotoxicity) <input type="checkbox"/> No <input type="checkbox"/> Yes		
Late effects of treatment (e.g., cardiotoxicity, lymphedema) <input type="checkbox"/> No <input type="checkbox"/> Yes		
Symptoms management (e.g., fatigue, pain, sexual dysfunction) <input type="checkbox"/> No <input type="checkbox"/> Yes		
Other <input type="checkbox"/> No <input type="checkbox"/> Yes, specify:		
_____		
_____		





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### D. Cancer Information

#### D.1 Cancer Counts

Please enter the number of participants with these cancers by gender

ICD-9	ICD-10/O	Cancer Type	Gender	
			Males	Females
141-149	C00-C14	Oropharyngeal		
150	C15	Esophagus		
151	C16	Stomach		
152	C17	Small intestine		
153	C18	Colon		
154	C19-C21	Rectum and anus		
155	C22	Liver and intrahepatic bile ducts		
156	C23, C24	Gall bladder and extrahepatic bile duct		
157	C25	Pancreas		
162	C33, C34	Trachea, bronchus, and lung		
170	C40	Bone		
172	C43	Melanoma (excluding genital organs)		
174-175	C50	Breast		
180	C53	Cervix		
182	C54	Corpus, body of uterus		
183	C56	Ovary, fallopian tube, broad ligament		
185	C61	Prostate		
188	C67	Bladder		
189	C64-C66, C68	Kidney and other unspecified urinary organs including renal pelvis, ureter, urethra		
191	C71	Brain		
193	C73	Thyroid		
200-202	C81-85	Lymphoma (HL and NHL)		
203	C90	Myeloma		
204-208	C91-95	Leukemia		
		All Other Cancers		

D.2 Most recent year of confirmed cancer case ascertainment:

\_\_\_\_\_  
Year (YYYY)

D.3 How were your cancer cases ascertained?

Self-report ☐ No ☐ Yes  
 Tumor registry ☐ No ☐ Yes  
 Medical record review ☐ No ☐ Yes  
 Other ☐ No ☐ Yes, specify:  
 \_\_\_\_\_  
 \_\_\_\_\_

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<b>D. Cancer Information (continued)</b>	
D.4 Did you collect information about cancer recurrence?	<input type="checkbox"/> No <input type="checkbox"/> Yes
D.5 Do you have second primary cancer diagnosis?	<input type="checkbox"/> No <input type="checkbox"/> Yes
D.6 Do you have cancer treatment data?	<input type="checkbox"/> No ( <b>Go to D.6c</b> ) <input type="checkbox"/> Yes
D.6a Specify the treatment information you have:	Surgery <input type="checkbox"/> No <input type="checkbox"/> Yes Radiation <input type="checkbox"/> No <input type="checkbox"/> Yes Chemotherapy <input type="checkbox"/> No <input type="checkbox"/> Yes Hormonal therapy <input type="checkbox"/> No <input type="checkbox"/> Yes Bone marrow/stem cell transplant <input type="checkbox"/> No <input type="checkbox"/> Yes Other <input type="checkbox"/> No <input type="checkbox"/> Yes, specify: _____ _____
D.6b Specify the data sources the treatment information is from:	Administrative claims data <input type="checkbox"/> No <input type="checkbox"/> Yes Electronic record <input type="checkbox"/> No <input type="checkbox"/> Yes Chart abstraction <input type="checkbox"/> No <input type="checkbox"/> Yes Patient-reported questionnaire <input type="checkbox"/> No <input type="checkbox"/> Yes Other <input type="checkbox"/> No <input type="checkbox"/> Yes, specify: _____ _____
D.6c Would it be possible to collect treatment information from medical records or other sources?	<input type="checkbox"/> No <input type="checkbox"/> Yes
D.7 Do you have cancer staging data?	<input type="checkbox"/> No <input type="checkbox"/> Yes
D.8 Do you have tumor grade data?	<input type="checkbox"/> No <input type="checkbox"/> Yes
D.9 Do you have tumor genetic markers data?	<input type="checkbox"/> No <input type="checkbox"/> Yes If yes, please describe: _____ _____
D.10 Were cancer cases histologically confirmed?	Select only one: <input type="checkbox"/> All <input type="checkbox"/> Some <input type="checkbox"/> None
D.11 Do you have cancer subtyping?	Histological <input type="checkbox"/> No <input type="checkbox"/> Yes Molecular <input type="checkbox"/> No <input type="checkbox"/> Yes



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E. Mortality		
E.1 Most recent year of mortality follow-up:	<div>Year (YYYY)</div>	
E.2 How did your cohort confirm death?	U.S. National Death Index (NDI) linkage <input type="checkbox"/> No <input type="checkbox"/> Yes Death Certificates <input type="checkbox"/> No <input type="checkbox"/> Yes Other <input type="checkbox"/> No <input type="checkbox"/> Yes, specify <div></div> <div></div>	
E.3 Do you have date of death for most subjects?	<input type="checkbox"/> No <input type="checkbox"/> Yes	
E.4 Do you have cause of death for most subjects?	<input type="checkbox"/> No <input type="checkbox"/> Yes	If yes, what type of death code was used?  ICD-9 <input type="checkbox"/> No <input type="checkbox"/> Yes ICD-10 <input type="checkbox"/> No <input type="checkbox"/> Yes Not coded <input type="checkbox"/> No <input type="checkbox"/> Yes Other <input type="checkbox"/> No <input type="checkbox"/> Yes, specify <div></div> <div></div>
E.5 What is the number of deaths in your cohort as of most recent mortality follow-up?	<div></div>	
F. Data Linkage and Harmonization		
F.1 Have you linked your cohort data to any other existing databases (e.g., Center for Medicare and Medicaid Services or NCI's Surveillance, Epidemiology and End Results (SEER) Program)?	<input type="checkbox"/> No <input type="checkbox"/> Yes	If yes, specify: <div></div> <div></div> <div></div> <div></div> <div></div>
F.2 Have you participated in projects that required cross-cohort data harmonization?	<input type="checkbox"/> No <input type="checkbox"/> Yes	If part of a consortium, please specify: <div></div> <div></div> <div></div> <div></div>
F.3 Have you deposited data in an NIH sponsored data repository?	<input type="checkbox"/> No <input type="checkbox"/> Yes	If yes, please select which repositories: CEDR <input type="checkbox"/> No <input type="checkbox"/> Yes dbGaP <input type="checkbox"/> No <input type="checkbox"/> Yes BioLINCC <input type="checkbox"/> No <input type="checkbox"/> Yes Other <input type="checkbox"/> No <input type="checkbox"/> Yes

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<b>G. Specimens Collected</b>		
Specify the types of specimens you collected, whether the specimen was collected at baseline, and/or collected at other time points.		
<b>Did you collect any of the following specimens:</b>	<b>Collected at baseline</b>	<b>Collected at other time points</b>
G.1 Blood	<input type="checkbox"/> No <input type="checkbox"/> Yes If collected, types of aliquots Serum <input type="checkbox"/> No <input type="checkbox"/> Yes Plasma <input type="checkbox"/> No <input type="checkbox"/> Yes Buffy Coat <input type="checkbox"/> No <input type="checkbox"/> Yes Other Blood Derivative <input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes If collected, types of aliquots Serum <input type="checkbox"/> No <input type="checkbox"/> Yes Plasma <input type="checkbox"/> No <input type="checkbox"/> Yes Buffy Coat <input type="checkbox"/> No <input type="checkbox"/> Yes Other Blood Derivative <input type="checkbox"/> No <input type="checkbox"/> Yes
G.2 Buccal/Saliva	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
G.3 Tissue (include tumor and/or normal)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
G.4 If your cohort does not currently collect tumor blocks, do you have information on where the blocks are kept/stored?	<input type="checkbox"/> No <input type="checkbox"/> Yes	
<b>Do you have:</b>		
G.5 Genotyping Data (SNP)	<input type="checkbox"/> No <input type="checkbox"/> Yes	
G.6 Sequencing Data – Exome	<input type="checkbox"/> No <input type="checkbox"/> Yes	
G.7 Sequencing Data – Whole Genome	<input type="checkbox"/> No <input type="checkbox"/> Yes	
G.8 Epigenetic or Metabolic Markers	<input type="checkbox"/> No <input type="checkbox"/> Yes	
G.9 Other “omics” data	<input type="checkbox"/> No <input type="checkbox"/> Yes	



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### H. Technology Use

H.1 In your cohort, have you adopted the use of mobile devices (i.e., tablet computers, personal digital assistants, etc.) for the collection and/or measurement of demographic or lifestyle factors, environmental exposures, and/or other types of information?

☐ Yes, please list or describe:

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☐ No, but we are currently considering it

☐ No, and we do not have any immediate plans to do so.

H.2 Have you adopted the use of cloud-based approaches for the collection, management, analysis, or distribution of any of your study data?

☐ Yes, please list or describe:

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☐ No, but we are currently considering it

☐ No, and we do not have any immediate plans to do so.

### I. Additional Items for Inclusion on the CEDCD Website

As indicated on the CEDCD Approval Form, we are requesting the following items for inclusion on the CEDCD website. If you provided approval to post this information, please attach the documents and return them to Westat with this form. If they are already available on a publicly accessible website, please just provide the website address.

Document	Attached	Website URL (if document is not attached)
Questionnaires	<input type="checkbox"/>	URL:
Main cohort protocol	<input type="checkbox"/>	URL:
Data sharing policy	<input type="checkbox"/>	URL:
Biospecimen sharing policy	<input type="checkbox"/>	URL:
Publication (authorship) policy	<input type="checkbox"/>	URL: