|  |
| --- |
| OMB No.: 0925-XXXX  Expiration Date: xx/xx/20xx  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 90 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. |

Thank you for taking the time to complete this form. The information you provide will populate the Cancer Epidemiology Descriptive Cohort Database (give URL). Users of the CEDCD will be able to find information about Cancer Epidemiology Cohorts such as yours in a single unified database. The CEDCD will enable users to learn about existing cohorts, compare cohort characteristics, and tabulate counts of participants, cancers, and specimens across cohorts. We hope you will find the CEDCD useful in seeking collaborators and facilitating projects.

This form is pre-filled with as much information as was possible to locate from available sources. Please review for accuracy and add information as needed.

Please return this form to Westat ([cedcdhelpdesk@westat.com](mailto:cedcdhelpdesk@westat.com)). The information on this form will be electronically loaded to the CEDCD database through an automated process. Annual updates are planned to ensure that the database reflects accurate up-to-date information about your cohort.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. **Basic Cohort Information** *(If your cohort is comprised of more than one distinct enrollment period (such as Physicians Health Study I and II), please complete separate Cohorts Descriptive Database 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.3 Person whom completed the form: | | | | | | | | | Contact Person for clarification of this form: | | |
| Name:  Position on the cohort:  Phone:  Email:  Is this the person  to contact with questions about this form? | | No  Yes  If no, please provide the name and contact information for correct person in the space on the right. | | | | | | | Name:  Position on the cohort:  Phone:  Email: | |  |
| A.4 Cohort’s Principal Investigator(s) and Co-Investigators:  If there is not enough room below to list all of the investigators, please attach a separate document listing all of the investigators with all the information specified below. Please provide title at your home institution. | | | | | | | | | | | |
| Name:  Title:  Institution:  Phone:  Email: |  | | | | | | | Name:  Title:  Institution:  Phone:  Email: | |  | |
| Name:  Title:  Institution:  Phone:  Email: |  | | | | | | | Name:  Title:  Institution:  Phone:  Email: | |  | |
| 1. **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:  Position on the cohort:  Phone:  Email: | | |  | | | | | | | | |
| A.6 Cohort Description:  Please provide a short paragraph describing your cohort. This will be used as an overall narrative description of your cohort on your cohort’s page on the CEDCD website. | | | | | | | | | | | |
| 1. **Basic Cohort Information (continued)** | | | | | | | | | | | |
| A.7 Cohort Design: | | | | | | | Check one:  Risk Cohort – *(initially enrolled participants without cancer)*  Survivor Cohort – *(initially enrolled participants with cancer)*  Lifecycle Cohort – (*multi-generational enrollment within families*) | | | | |
| A.8 Is the cohort a survivor cohort built from a previously established risk cohort? | | | | | No  Yes | | If yes,  Were data collected before enrollment into the survivor cohort?  No  Yes  Were biospecimens collected before enrollment into the survivor cohort?  No  Yes  Please complete the remainder of this form as it pertains only to data and specimens collected from establishment of the survivor cohort; do not include data and specimens collected as part of the previously established cohort. | | | | |
| A.9 Is this a multi-site cohort?  No  Yes  If yes, please list the participating institutions and investigators: | | | | | | | | | | | |
| a. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  b. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  c. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  d. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  e. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  f. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  g. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  h. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  i. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  j. Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. **Basic Cohort Information (continued)** | | | | | | | | | | | | | | | | | |
| A.10 Eligibility Criteria: | | | | | | | Age:  Eligible Age Range: \_\_\_\_\_\_\_\_\_\_\_ to \_\_\_\_\_\_\_\_\_\_\_\_\_  Gender:  Both genders eligible  Males only eligible  Females only eligible | | | | | | | | | | |
| A.11 Enrollment: | | | | | | | \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ to \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Year Started (YYYY) Year Ended (YYYY)  Check if enrollment is ongoing | | | | | | | | | | |
| A.12 Age at Enrollment (range and median): | | | | | | | Range: \_\_\_\_\_\_ To \_\_\_\_\_\_ Median: \_\_\_\_\_\_\_\_\_\_\_\_\_  If your cohort is a lifecycle cohort enrolling multiple generations within families, then specify the age of each generation.  First Generation – Age Range: \_\_\_\_\_\_ To \_\_\_\_\_\_  Second Generation – Age Range: \_\_\_\_\_\_ To \_\_\_\_\_\_  Third Generation – Age Range: \_\_\_\_\_\_ To \_\_\_\_\_\_ | | | | | | | | | | |
| A.13 Specify time intervals when your questionnaire data were collected. For example, yearly, biannually, 2011-2013. | | | | | | | Specify: | | | | | | | | | | |
| A.14 Most recent year when questionnaire data were collected: | | | | | | | \_\_\_\_\_\_\_\_\_\_\_\_  Year (YYYY) | | | | | | | | | | |
| A.15 How was information from the questionnaire administered/collected? | | | | | | | Check all that apply:  In person  Paper  Electronic / Web-based  Other, specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | | | |
| A.16 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:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | | | |
| A.17 Most recent year of confirmed cancer case ascertainment: | | | | | | | \_\_\_\_\_\_\_\_\_\_\_\_  Year (YYYY) | | | | | | | | | | |
| **A. Basic Cohort Information (continued)** | | | | | | | | | | | | | | | | | |
| A.18 Most recent year of mortality follow-up: | | | | | | | | \_\_\_\_\_\_\_\_\_\_\_\_  Year (YYYY) | | | | | | | | | |
| A.19 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?) | | | | | | | | No  Yes  If Yes, please describe briefly:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | | |
| 1. **Current Enrollment Counts** | | | | | | | | | | | | | | | | | |
| B.1 Total number of subjects enrolled: \_\_\_\_\_\_\_\_  If still enrolling, please specify the target number you plan to enroll: \_\_\_\_\_\_\_\_\_\_\_  If still enrolling, please specify by when do you plan to enroll subjects: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ YYYY | | | | | | | | | | | | | | | | | |
| B.2 Number of Males enrolled: \_\_\_\_\_\_\_\_\_\_\_ | | | | | | B.3 Number of Females enrolled: \_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | | | | |
| B. 4 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** |  |  | |  | |  | |  | | |  | | |  |  |  |  |
| **C. Data on Major Content Domains** | | | | | | | | | | | | | | | | | |
| **Specify whether you collected data within these major content domains. Baseline refers to data collected at or near enrollment into the cohort. If a lifecycle cohort, include all exposure data for all generations as follow-up.** | | | | | | | | | | | | | | | | | |
| **Did you collect data on:** | | | **Check all that apply** | | | | | | | | | | | | | | |
| **Collected at baseline** | | | | | | | | | **Collected during follow-up** | | | | | |
| C.1 Marital Status | | | Collected | | | | | | | | | Collected | | | | | |
| C.2 Socio-economic status (e.g., income) | | | Collected | | | | | | | | | Collected | | | | | |
| C.3 Education Level | | | Collected | | | | | | | | | Collected | | | | | |
| C.4 Anthropometry (e.g., weight, height, waist circumference, or BMI) | | | Collected | | | | | | | | | Collected | | | | | |
| C.5 Cigarette smoking | | | Collected | | | | | | | | | Collected | | | | | |
| C.6 Use of tobacco products other than cigarettes | | | Collected  If collected, specify other tobacco products:  Cigars  Pipes  Chewing tobacco  Other, specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | | Collected  If collected, specify other tobacco  products:  Cigars  Pipes  Chewing tobacco  Other, specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | |
| C.7 Alcohol consumption | | | Collected | | | | | | | | | Collected | | | | | |
| C.8 Dietary intake | | | Collected | | | | | | | | | Collected | | | | | |
| C.9 Dietary supplement use | | | Collected | | | | | | | | | Collected | | | | | |
| C.10 Physical activity | | | Collected | | | | | | | | | Collected | | | | | |
| C.11 Reproductive history | | | Collected | | | | | | | | | Collected | | | | | |
| C.12 Quality of life or other psychosocial variables | | | Collected | | | | | | | | | Collected | | | | | |
| 1. **Data on Major Content Domains (continued)** | | | | | | | | | | | | | | | | | |
| **Did you collect data on:** | | | | **Check all that apply** | | | | | | | | | | | | | |
| **Collected at baseline** | | | | | | | | | **Collected during follow-up** | | | | |
| C.13 Prescription medication use (not related to cancer treatment) | | | | Collected | | | | | | | | | Collected | | | | |
| C.14 Non-prescription medication use (not related to cancer treatment) | | | | Collected | | | | | | | | | Collected | | | | |
| C.15 Family history of cancer | | | | Collected  If collected, was data collected on:  First degree relatives only  First and second degree relatives  All relatives  Do you have pedigrees?  No  Yes | | | | | | | | | Collected  If collected, was data collected on:  First degree relatives only  First and second degree relatives  All relatives  Do you have pedigrees?  No  Yes | | | | |
| C.16 Environmental or occupational exposures (e.g. air contaminants/quality, occupational exposures and history, water source) | | | | Collected | | | | | | | | | Collected | | | | |
| C.17 Geocoding Information | | | | Collected | | | | | | | | | Collected | | | | |
| **C.18 Non-Cancer Illness:** Check all that apply. | | | | | | | | | | | | | | | | | |
| **Illness** | | | | **Prevalent Illness** | | | | | | | | **Incident Illness** | | | | | |
| 1. Diabetes | | | | Collected | | | | | | | | Collected | | | | | |
| 1. Heart and Vascular Diseases | | | | Collected | | | | | | | | Collected | | | | | |
| 1. Lung Diseases | | | | Collected | | | | | | | | Collected | | | | | |
| 1. Digestive and/or Genitourinary Diseases | | | | Collected | | | | | | | | Collected | | | | | |
| 1. Osteoporosis/Bone related conditions | | | | Collected | | | | | | | | Collected | | | | | |
| 1. **Data on Major Content Domains (continued)** | | | | | | | | | | | | | | | | | |
| **C.18 Non-Cancer Illness:** Check all that apply. | | | | | | | | | | | | | | | | | |
| **Illness** | | | | **Prevalent Illness** | | | | | | | | **Incident Illness** | | | | | |
| 1. Neurodegenerative Disorders and/or Mental Illnesses | | | | Collected | | | | | | | | Collected | | | | | |
| 1. Autoimmune diseases | | | | Collected | | | | | | | | Collected | | | | | |
| **D. Cancer Information:** This section is to capture the extent of cancer information that your cohort collects or currently has available. Please limit your response to data that have already been collected or are part of ongoing collection, and not to include planned collection that has yet to begin. Please include in your consideration data that you ascertain from participants or other data sources as well as derived data (e.g. algorithms to differentiate recurrent vs second primary cancer). | | | | | | | | | | | | | | | | | |
| D.1 How were your cancer cases ascertained? | | | | | | | | | Check all that apply:  Self-report  Tumor registry  Medical record review  Other, specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | |
| D.2 Do you have recurrent cancer diagnosis? | | | | | | | | | No  Yes | | | | | | | | |
| D.3 Do you have second primary cancer diagnosis? | | | | | | | | | No  Yes | | | | | | | | |
| D.4 Do you have cancer treatment data? | | | | | No  Yes  If no, would it be possible to collect this information from medical records or other sources?  No  Yes | | | | If yes, specify treatment and data source:  Treatment: Check all that apply  Surgery  Radiation  Chemotherapy  Hormonal therapy  Bone marrow/stem cell transplant  Other, specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Data source: Check all that apply  Administrative claims data  Electronic record  Chart abstraction  Patient-reported questionnaire  Other, specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | |
| **D. Cancer Information (continued)** | | | | | | | | | | | | | | | | | |
| D.5 Do you have cancer staging data? | | | | | | | | | No  Yes | | | | | | | | |
| D.6 Do you have tumor grade data? | | | | | | | | | No  Yes | | | | | | | | |
| D.7 Do you have tumor genetic markers data? | | | | | | | | | No  Yes  If yes, please describe:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | |
| D.8 Were cancer cases histologically confirmed? | | | | | | | | | Select only one:  All  Some  None | | | | | | | | |
| D.9 Do you have cancer subtyping? | | | | | | | | | Check all that apply:  Histological  Molecular | | | | | | | | |
| D.10 Do you have information on cancer-related conditions? | | | | | | | | | No  Yes | | | | | | | | |
| If yes, check all that apply: | | | | | | | | | | | | | | | | | |
| Acute treatment-related toxicity (e.g., diarrhea, nephrotoxicity) | | | | | | | | | | | | | | | | | |
| Late effects of treatment (e.g., cardiotoxicity, lymphedema) | | | | | | | | | | | | | | | | | |
| Symptoms management (e.g., fatigue, pain, sexual dysfunction) | | | | | | | | | | | | | | | | | |
| Other, specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | | | | | | | | | | | | | | | |
| D.11 If you **did not collect** the information requested in D.2 to D.10, are the data available to be retrieved at a later point in time? | | | | | | | | | | No  Yes | | | | | | | |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **E. Mortality** | | | | |
| E.1 How was death confirmed by your cohort? | | | | Check all that apply:  National Death Index (NDI) linkage  State death certificates  Other, specify  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| E.2 Do you have date of death for most subjects? | | | | No  Yes |
| E.3 Do you have cause of death for most subjects? | No  Yes | | | If yes, is the cause of death coded?  No  Yes  If yes, what type of death code was used? Check all that apply:  ICD-9  ICD-10  Other, specify  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| E.4 What is the number of deaths in your cohort as of most recent mortality follow-up? | | | | \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| **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, Surveillance, Epidemiology and End Results)? | | | No  Yes | If yes, specify: | | |
| F.2 Has your cohort participated in any cross-cohort data harmonization projects not limited to NCI? | | | No  Yes | If yes, specify: | | |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **G. Specimens Collected** | | | | | | | | |
| Specify the types of specimens you collected, whether the specimen was collected at baseline, and/or collected at other time points. | | | | | | | | |
| **Did you collect any of the following specimens:** | | **Collected at baseline** | | | | | | **Collected at other time points** |
| G.1 Blood | | Collected  If collected, types of aliquots (Check all that apply):  Serum  Buffy Coat  Plasma  Other Blood Derivative | | | | | | Collected  If collected, types of aliquots (Check all that apply):  Serum  Buffy Coat  Plasma  Other Blood Derivative |
| G.2 Buccal Swab | | Collected | | | | | | Collected |
| G.3 Saliva | | Collected | | | | | | Collected |
| G.4 Lymphocytes | | Collected | | | | | | Collected |
| G.5 Other Specimen types not listed above (e.g., urine, sputum). Do not include tumor tissue.  Specify below: | |  | | | | | |  |
| a. | | Collected | | | | | | Collected |
| b. | | Collected | | | | | | Collected |
| c. | | Collected | | | | | | Collected |
| G.6 Did you collect tumor tissue? | | | | | | No (Skip to question G.10)  Yes | | |
| G.7 Did you also collect normal tissue? | | | | | | No  Yes | | |
| G.8 How were the tumor tissue samples prepared/ stored? | | | | | | Check all that apply:  Formalin Fixed Paraffin Embedded (FFPE)  Fresh/Flash Frozen  Diagnostic slides  Other, specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | |
| **G. Specimens Collected (continued)** | | | | | | | | |
| G.9 How was the tumor tissue collected? (Include collection of the same tumor at different time points) | | | | | | | Check all that apply:  Core Biopsy  Fine Needle Aspirations (FNA)  Surgery  Other, specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |
| G.10 If your cohort does not currently collect tumor blocks, did you collect information on where the blocks are kept/stored? | | | | | | | No  Yes | |
| **Do you have:** | | |  | | | | **Approximately How Many Participants** | |
| G.11 Genotyping Data (SNP) | | | No  Yes | | | |  | |
| G.12 Sequencing Data – Exome | | | No  Yes | | | |  | |
| G.13 Sequencing Data – Whole Genome | | | No  Yes | | | |  | |
| G.14 Epigenetic or metabolic markers | | | No  Yes | | | |  | |
| G.15 Other “omics” data | | | No  Yes | | | |  | |
| **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:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  No, but we are currently considering it or will consider it in our next renewal.  No, and we do not have any immediate plans to do so. | | | |
| H.2 Most studies store all of their study data on local servers that are maintained at their institution. Cloud computing refers to storing data on the internet. Have you adopted the use of cloud-based approaches for the collection, management, or distribution of any of your study data? | | | | | Yes, please list or describe:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  No, but we are currently considering it or will consider it in our next renewal.  No, and we do not have any immediate plans to do so. | | | |
| 1. **Technology Use (continued)** | | | | | | | | |
| H.3 If the answers were "No, and we do not have immediate plans to do so" for either of the prior 2 questions, please indicate the possible reasons. | | | | | Check all that apply:  Limited funding  Limited support from department/institution  Limited technical infrastructure or support  Security concerns  Other and/or please describe:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | | |
| 1. **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 |  | | | URL: | | | | |
| Main cohort protocol |  | | | URL: | | | | |
| Data sharing policy |  | | | URL: | | | | |
| Biospecimen sharing policy |  | | | URL: | | | | |
| Publication (authorship) policy |  | | | URL: | | | | |
| CEDCD Biospecimen and Cancer Count Information Spreadsheet |  | | | Attached Only | | | | |
| Separate List of investigators (if needed) |  | | | Attached Only | | | | |