

Active Consent Form for ACS Facts & Figures

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or email to Recinda Sherman at rsherman@naaccr.org or 217.698.0188 by December 5, 2023. A response must be received by this date for your data to be included in the project.

Project

Title: ACS Facts and Figures [US ONLY]

Principal

Investigator: Rebecca Siegel, MPH, Surveillance & Health Equity Science, ACS

Project

Description: A custom version CiNA Research Dataset is produced for ACS and IMS to calculate incidence projections for the ACS's signature annual, biannual, & triennial Facts & Figures publications: Cancer Facts and Figures (CFF); Cancer Facts and Figures for African American/Black People; Cancer Facts & Figures for Asian, Pacific Islanders, and Native Hawaiians; Cancer Facts and Figures for Hispanics/Latinos; Breast Cancer Facts & Figures; Colorectal Cancer Facts & Figures; Cancer Treatment & Survivorship Facts & Figures' and the accompanying statistics articles published in the CA- A Cancer Journal for Clinicians.

For the projection, the file is released to appropriate staff of IMS who prepare the file(s) and conduct the first steps in the methodology. IMS also adjusts incidence counts in the file using NAACCR registry-specific delay factors as available to provide the most accurate cancer burden. The augmented output is then released to designated researchers at ACS (currently Nikita Wagle, Tyler Krazter, Angela Giaquinto, and Rebecca Siegel) who complete the final steps to generate the national and state-level projections published in the reports. This is a standing use of the NAACCR data submissions.

The CiNA Researcher data set is also used to disseminate cancer incidence rates nationally (stratified by state and/or race), as well as various other national-level statistics (e.g., age distribution) for the most common cancer types. ACS also requests access to a dataset with composite national-level delay factors by cancer site, sex, and race/ethnicity (no registry-specific data) to produce longitudinal trends. ACS, NAACCR, and NCI also plan to use the CiNA observed cases to check model predictions, by comparing with the estimated cases published in historical CFF for the corresponding years, and assist in the development of improved projection methods. A new case projection method was adopted beginning with the 2021 CFF (the projection method used since 2007 was updated in 2012).

CiNA Research Data Set

- This project needs the reported values for all data variables; rather than the aggregated variables that are available in the CiNA Research Standard dataset.
- State-specific data will be presented.

Please indicate yes or no to indicate your consent for this project:

| | | |
|------------|-----------|-----------------------------|
| Yes | No | 1995-2021 CiNA ACS F&F File |
| | | If no, why not? |

If you have any questions regarding this project or data uses, please contact Recinda Sherman at rsherman@naaccr.org or 217.698.0800.

Print Name:

Signature:

Title:

Date:

Active Consent Form for Medullary Thyroid Project US Only

NAACCR requests permission from the (enter registry name):

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Project Title: Medullary Thyroid Cancer Verification

Principal Investigators: Annette Stemhagen, DrPH, FISPE
SVP, Chief Scientific Officer, SERRM (Safety, Epidemiology, Registries & Risk Management) at United BioSource LLC (UBC)

Project Description: As required by the FDA, United BioSource LLC (UBC) is conducting post-marketing surveillance on behalf of the MTC Registry Consortium (currently consisting of the following members: Novo Nordisk Inc., AstraZeneca Pharmaceuticals LP and Eli Lilly and Company) as the sponsor of the study for long-acting GLP-1 receptor agonist medications to monitor any increase in medullary thyroid carcinoma which may be associated with its use. UBC has entered into surveillance agreements with many statewide registries on behalf of the Sponsors and needs to a) verify that there are no missing MTC cases in the participating states, and b) monitor the incidence of MTC in the remaining states. NAACCR will release tabular aggregate data to UBC to assist in this important study. Since this is such a rare cancer, many cells may be smaller than 6 on a state level. We are requesting to release tabular data with counts less than 6. These data are for internal use by UBC only and will not be published or presented. The following variables are reported for adults: Counts by State by Year, Counts by Sex (M/F) by Year (US), Counts by Age by Year (US)—includes 0-17 age category, single ages for adults, Stage by Year (US), Counts & Rates by Age-group by Year by Sex (M/F) US, Counts & Rates by Year (separately for US and participating State Cancer Registries), Counts & Rates by Sex by Year, and Counts & Rates by Age-group and Year.
Note: This consent is to cover the national data shared. States actively participating in the MTC Registry will have a separate consent and/or state agreement for the data shared specifically for the registry.

CiNA Deluxe Variable Set

- This project needs the reported values for all data variables; rather than the aggregated variables that are available in the CiNA Research dataset.
- Registry-specific data will be presented. County-specific data will NOT be presented.

Please indicate yes or no to indicate your consent for this project:

| | | |
|------------|-----------|--|
| Yes | No | 1995-2021 CiNA Deluxe Custom File without County Identifier |
| | | If no, why not? |

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Print Name:

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Passive Consent Form for American Lung Association US Only

NAACCR requests permission from the (enter registry name):

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Project Title: State-level lung cancer burden

Principal

Investigators: PI: Zach Jump, American Lung Association Dataset Task Force

The goal of this project is to describe each state's lung cancer burden in a consumer-friendly online report using visual graphics and simple text explanations. Burden will be represented by lung cancer incidence rate, percent of cases diagnosed by stage, percent of cases first treated with surgical resection or untreated (if available), five year survival rate (if available), number of cases per accredited lung cancer screening center, and by race/ethnicity. All results will be based on five years of aggregated data.

This project will be updated annually. Current report can be found here: <https://www.lung.org/research/state-of-lung-cancer>

CiNA Deluxe Variable Set

- Project does not need the reported values for all data variables. Project will use the aggregated variables that are available in the CiNA Deluxe Standard dataset.
- Registry/state-specific data WILL be presented. County-specific data are NOT requested. Single-years of age NOT requested.

Please indicate yes or no to indicate your consent for this project:

| Yes | No | 1995-2021 CiNA Research Dataset without County Identifier |
|-----|----|--|
| | | If no, why not? |

If you have any questions regarding this project or data uses, please contact Recinda Sherman at rsherman@naaccr.org or 217.698.0800.

Print Name:

Signature:

Title:

Date:

Passive Consent Form for The Affordable Care Act and cancer stage at diagnosis US Only

NAACCR requests permission from the (enter registry name):

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Project Title: The Affordable Care Act and cancer outcomes

Principal

Investigators: PI: Xuesong Han, American Cancer Society

The Affordable Care Act substantially increased health insurance coverage in the US, but the impact of ACA on cancer care and outcomes is largely unknown. We aim to examine the impacts of ACA on insurance coverage and cancer stage at diagnosis, cancer treatment and survival. The following data analysis steps will be conducted:

- Monthly insurance rates for cancer patients at the time of cancer diagnosis will be calculated and graphed from 2007 through the most recent year, nationally and by state.
- Using patients from non-Medicaid-expansion states as a control group, the changes in Medicaid coverage among the patients from Medicaid-expansion states will be evaluated and adjusted by sociodemographic factors.
- Calculate percent of early stage diagnosis, receipt of standard care, and treatment within 30 days pre and post ACA in expansion and nonexpansion states, for all cancer patients and those with common cancers and adjusted for sociodemographic factors.
- Survival analysis will be conducted by diagnosis period and Medicaid expansion status and adjusted for sociodemographic factors.

A sensitivity analysis replacing county-level-poverty with census-tract-level-poverty will be conducted for the patients whose census-tract-level-poverty information is available.

Main presentation of the results will be for adult patients 18-64 years old, and will include estimates of the outcomes (percent uninsured, percent early stage diagnosis, percent receiving timely treatment, survival rate) pre/post ACA for expansion vs. nonexpansion states, for all cancer combined and by common cancer types.

As a secondary aim, we also consider presenting the results for children and adolescent patients 0-18 years. However, given the wide coverage of CHIP program pre-ACA, the effect from the Medicaid expansion provision will be limited. Therefore, for patients 0-18 years old, the results will not be presented by Medicaid expansion status, instead will be presented for the whole country.

CiNA Deluxe Variable Set

- Project does not need the reported values for all data variables. Project will use the aggregated variables that are available in the CiNA Research dataset.
 - Registry/state-specific data WILL be presented. County-specific data are NOT requested. Single-years of age are NOT requested but to 2 additional categories (15-17; 18-19) will be provided
 - Project is requesting derived poverty codes (at both the county and tract-level; but county will NOT be released and tract is NOT available in CiNA data).
 - Project is requesting data for survival, but Cause of Death is NOT requested.
-

Please indicate yes or no to indicate your consent for this project:

| | | |
|------------|-----------|---|
| Yes | No | 1995-2021 CiNA Research File without County Identifier |
| | | If no, why not? |

If you have any questions regarding this project or data uses, please contact Recinda Sherman at rsherman@naaccr.org or 217.698.0800.

Print Name:

Signature:

Title:

Date

Passive Consent Form for CiNA Public Use Dataset

NAACCR requests permission from the (enter registry name):

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Project Title: **CiNA Public Use Dataset—Case Listing (Exporting from SEER*Stat) NOT Allowed**

Contact Person: **Recinda Sherman, PhD MPH CTR, NAACCR**

Project Description: Cancer registry data is designed to be used at both local and national levels to improve our understanding of cancer pathology, clinical progression, etiology, and to describe populations at risk. Our cancer surveillance system is considered the “gold standard” for public health disease surveillance, and our data allow for the systematic analysis of cancer data to identify burdens, trends, and to generate hypotheses about cancer risk and etiology.

To this end, we produce the CiNA Public Use dataset to be made available for research. The CiNA Public Use Dataset is a non-confidential, limited, public use research dataset from 1995 forward for U.S. and Canada. It will be available to all researchers upon request after signing a Data Use Agreement, similar to the procedures currently used to access SEER data. The purpose of the dataset is to provide non-confidential data to both NAACCR and outside researchers, whose studies require more variables than currently provided in our on-line query. No treatment data are included. Many of the variables are recoded to reduce uniqueness and standardize analysis.

The CiNA Public Dataset allows a user to generate counts, rates, and trends within the SEER*Stat system, and includes age in the 20 age group categories. CiNA Public Dataset **DOES NOT** allow the user to export the data as a case-listing to support regression or other analysis in standard, statistical programs. **Output is automatically suppressed at <16.**

CiNA Data

- The list of variables and recodes, as well as the Data Assurance Agreement, is available here: <https://www.naaccr.org/cina-public-use-data-set/>
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Please indicate yes or no to indicate your consent for this project:

| Yes | No | 1995-2021 CiNA Public Use Dataset; no case listing allowed |
|-----|----|--|
| | | If no, why not? |

If you have any questions regarding this project or data uses, please contact Recinda Sherman at rsherman@naaccr.org or 217.698.0800.

Print Name:

Signature:

Title:

Date:

Passive Consent Form for Delay Adjustment

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or email to Recinda Sherman at rsherman@naaccr.org or 217.698.0188 by December 6, 2023. If a response is not received by this date, it will be assumed that consent is given and your data will be included in the project.

Project Title: Delay Adjustment

Principal

Investigators: PI: Huann-Sheng Chen, NCI, Rocky Feuer, NCI

NCI statisticians in collaboration with IMS will use the NAACCR CiNA files to estimate delay adjustments needed in trend data for the US and Canada. Delay adjustment has been demonstrated to be an important and significant correction in the analysis of cancer incidence trends. This project will enhance trend analyses in all cancer incidence data, including NPCR, SEER, and Canadian registry data. All registries will be included in the analysis in order to create more robust estimates. The earliest data used in the model will be diagnosis year 2009 from the 2011 submission, but earlier years of data will be included in the database. Delay factors may be estimated based on groups of registries, or individual registries and delay adjusted rates can be produced for the US, Canada, and North America, individual registries, or any selected registry group.

Observed and delay-adjusted counts and rates are available for each registry that meets the data quality criteria by race, sex, for all sites combined and the five most common cancer sites.

ACS: ACS uses delay factors as part of the methodology to produce projections of cancer incidence counts for Cancer Facts and Figures. IMS staff compiles delay adjusted incidence counts prior to passing them to ACS for them to run the projections models, ACS does not have access to registry-specific delay factors. ACS uses composite delay factors that are nationwide (not registry-specific) by cancer site, sex, and race/ethnicity to produce longitudinal trends. These longitudinal trends may be for all ages combined, or by a selected age group.

NAACCR: NAACCR presents national-level, delay adjusted rates—in the CiNA monographs, Annual Report to the Nation, and CiNA Explorer. Registry-level delay adjusted factors are only released back to the reporting registry (when requested via the NAACCR Data Request Tracking (DaRT) System). In addition, state-level delay factors are used to calculate completeness rates for NAACCR Certification.

NPCR: IMS provides the delay factors to NPCR. NPCR creates an internal database each year with the combined NPCR and SEER registries with delay factors, and this database does contain state/registry/county. Access to this database is strictly limited and is only available for approved projects.

In addition, starting with dx year 2020, NPCR will use state-level delay factors to calculate completeness rates.

SEER: Registry-level, delay adjustment factors are available in for SEER Registries according to an agreement with NCI/SEER. NCI does release a registry-specific delay database to any user with “Research Plus” access, which requires additional user authentication over the Research Data (<https://seer.cancer.gov/data/access.html>). Users accessing delay databases get a warning in SEER*Stat that indicates that users should have a full understanding of the use of delay factors and provides a link to cautions and a guide to their proper use (especially the use of registry-level factors).

In addition, state-level delay factors are used to calculate completeness rates for SEER registries.

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| | | |
|------------|-----------|---|
| Yes | No | 1995-2021 CiNA Research File without County Identifier |
| | | If no, why not? |

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