

Active Consent Form for CiNA County-Level Maps (US Only)

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. A response must be received by this date for your data to be included in the project.

Project

Title:

CiNA County-Level Maps [US only]

Principal

Investigator:

Recinda Sherman, NAACCR

Project

Description:

We currently map standard cancer rates by state in NAACCR Maps: <https://www.cancer-rates.info/naaccr/> as part of Primary Data Use for the CiNA data submission. We would also like to visualize county-level cancer burden nationally.

We will present age standardized cancer rates by county. We will aggregate the most recent 5 years of CiNA data by sex and by race/ethnicity using the same categories (including site groups) as our current state-based mapping tool. We will suppress at <16 incidence cases and for counties <20,000 in population.

CiNA Research Data Set

- This project will present maps by county-level for counties >20,000 denominator and >15 cancer cancers.

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

Yes	No	1995-2022 CiNA Research Dataset
		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.

Active Consent Form for Mayo Clinic Catchment Area (US Only)

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. A response must be received by this date for your data to be included in the project.

Project

Title:

Mayo Clinic Catchment Area

Principal

Investigator:

James Cerhan, MD, PhD, Mayo Clinic (Rochester, Minnesota)

Project

Description:

The Mayo Clinic Comprehensive Cancer Center (MCCCC) has three campuses: Mayo Rochester in Minnesota, Mayo Arizona, and Mayo Florida. We are working to define and describe our campus-specific catchment areas and the larger impact areas that surround the three catchment areas and then compare them to national data. This information is critical to plan strategically, understand cancer health disparities (e.g., by age, sex, race/ethnicity, geography, rurality), set priorities, and allocate resources for the MCCCC's myriad research and clinical programs, community outreach and engagement (COE), education initiatives, and policy activities.

Our aims are two-fold. First, in preparation for the 2024 NCI Cancer Center Support Grant (CCSG) competitive renewal, we aim to define the MCCCC catchment area as 3 geographic areas that MCCCC serves or intends to serve in the research it conducts, the communities it engages, and the outreach it performs. In defining a catchment area, we also define the corresponding impact area such that each regional catchment area is a targeted subregion of the larger regional impact area. Each area will be a set of contiguous counties. Because of our national patient base, we seek national data. Second, in order to serve programmatic research and COE, we aim to characterize the cancer burden of MCCCC catchment and impact areas by calculating age-adjusted cancer incidence rates within each catchment and impact area.

Objectives:

The purpose is to characterize the cancer burden in the counties within the MCCCC catchment and impact areas as well as to evaluate the cancer burden and disparities in reference to the cancer burden seen nationally.

Analysis Plan:

We will estimate, tabulate, and graphically display age standardized (2000 US Standard Population) cancer-specific incidence rates. We will further examine the data by sex, age group (<18, 18-39, 40-64, 65+), race, and Hispanic ethnicity at the county level when possible (some counties have small numbers of cases). These will be evaluated across our catchments, impact areas, and nationally. We will present analysis by catchment area within the 5 states and will suppress at <16 incidence cases.

Catchment Areas

Mayo Arizona: Maricopa County.

Mayo Florida: Duval, Saint Johns, Flagler, Clay, Baker, Nassau, Putnam, Brevard and Volusia counties.

Mayo Rochester: 65 counties within Iowa, Minnesota and Wisconsin.

Iowa	Minnesota	Wisconsin
Allamakee	Blue Earth	Barron
Cerro Gordo	Brown	Buffalo
Chickasaw	Carver	Chippewa
Clayton	Cottonwood	Crawford
Emmet	Dakota	Dunn
Fayette	Dodge	Eau Claire
Floyd	Faribault	La Crosse
Hancock	Fillmore	Monroe
Howard	Freeborn	Pierce
Kossuth	Goodhue	Saint Croix
Mitchell	Houston	Trempealeau
Winnebago	Jackson	Burnett
Winneshiek	Le Sueur	Clark
Worth	Martin	Grant
	Mower	Jackson
	Nicollet	Juneau
	Olmsted	Pepin
	Renville	Polk
	Rice	Richland
	Scott	Rusk
	Sibley	Sawyer
	Steele	Taylor
	Wabasha	Vernon
	Waseca	Washburn
	Washington	
	Watonwan	
	Winona	

CiNA Research Data Set

- This project will present analysis by catchment and state-level.
- State-specific data will be presented.

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

Yes	No	1995-2022 CiNA Research Dataset
		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.

Active Consent Form for Medullary Thyroid Project (US Only)

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. A response must be received by this date for your data to be included in the project.

Project Title: Medullary Thyroid Cancer Verification

Principal Investigators: Annette Stenhagen, 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 Research Dataset

- 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. Unsuppressed tabular data at registry level is requested (<6 case count). County-specific data will NOT be presented.

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

Yes	No	1995-2022 CiNA Tabular Data without County
		If no, why not?

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

Passive Consent Form for American Lung Association (US Only)

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. 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: 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	1995-2022 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.

Passive Consent Form for CiNA Public Use Dataset

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. 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: **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 both the 19 and 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. **Results/Output are 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/>
-

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

Yes	No	1995-2022 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.

Passive Consent Form for Spatial-temporal Small Area Estimation Models for Cancer Incidence

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. 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: Spatial-temporal Small Area Estimation Models for Cancer Incidence

Principal Investigator: Benmei Liu, Surveillance Research Program, NCI

Project Description: Mapping is essential for analyzing and visualizing cancer incidence across specific geographic areas. While most studies have mapped cancer incidence by state, there is limited publicly available information at the county level, particularly for less common cancer sites. Counties with sparse data often face issues of data masking due to instability and confidentiality concerns. Spatio-temporal models can be used to predict missing counts and smooth small or zero counts.

The NCI and the ACS have recently updated the spatio-temporal methods used to estimate historical cancer cases needed for current year projections. Results indicated that methods based on standard Poisson assumption perform worse for rarer cancers due to sparse data. Some studies have suggested using hurdle models for county-level age-adjusted cancer rates, but these have focused on single cancer registries and used few covariates.

This project aims to develop spatio-temporal hierarchical models for all U.S. counties, incorporating a large set of covariates to predict counts and derive county-level age-adjusted rates. The input data will use the CiNA ACS F&F file. The study plans to cover all cancer site combined and the same 28 specific cancers as in the ACS' F&F. Different model assumptions will be tested and compared, the final model will be used to produce yearly counts and age-adjusted rates. Estimates for non-participating registries will be predicted using covariate data from similar counties.

These modeled county-level age-adjusted rates for each cancer site will be used to create annual maps, which will be available on NCI's GIS website. No observed data will be disclosed. Only analysts involved in data curation - Joe Zou (IMS)- and model development Zhuoqiao Wang (IMS), Benmei Liu (NCI), Li Zhu (NCI) – will have access to the raw data.

CiNA Research Data Set

- County-specific *modeled* data will be presented.
- County-specific observed data will be used in the model but *will not* be presented.

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

Yes	No	1995-2022 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.

Passive Consent Form for Delay Adjustment

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. 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: 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.

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

Yes	No	1995-2022 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.

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

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. 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: The Affordable Care Act and cancer outcomes

Principal

Investigators: 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. non-expansion 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 Research Dataset

- 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	1995-2022 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.

Active Consent Form for ACS Facts & Figures (US Only)

NAACCR requests permission from the (enter registry name):

To be included in the project described below, please sign via DocuSign by December 3, 2024. 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 Cancer Facts & Figures report and Cancer Statistics article, along with biennial Cancer Statistics articles on breast cancer; colorectal cancer; African American/Black people; Asian American/Pacific Islander/Native Hawaiian people; Hispanic/Latino people; and cancer treatment & survivorship published in *CA: A Cancer Journal for Clinicians*. For the projections, 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 Rebecca Siegel, Nikita Wagle, Tyler Kratzer, Angela Giaquinto, and Anatu Saka) 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 delay-adjusted rates by cancer site, and race/ethnicity to produce longitudinal trends and state rates using a composite national delay factor. 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. The projection methodology was last updated for the 2021 estimates, with previous updates in 2012 and 2007.

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	1995-2022 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: