

## NAACCR, Inc. CALL FOR DATA ASSURANCES AGREEMENT

Agreement executed this \_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_, by and between the  
**NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES, INC.** ("NAACCR,  
Inc."), a California corporation, and \_\_\_\_\_ ("REGISTRY") of \_\_\_\_\_.  
*(Name)* *(City)* *(State/Province)*

NAACCR, Inc. is engaged in an annual Call for Data to conduct data evaluation, aggregation, analysis and publication of cancer incidence, specifically described in Attachment A:

NAACCR, Inc. uses and analyzes certain cancer incidence data (the "Data"). NAACCR, Inc. agrees and acknowledges that patient confidentiality is of the utmost importance in the use of the Data and in the manner in which all research results are presented and/or published. Accordingly, in consideration of NAACCR's receipt of the Data from the Registry, NAACCR, Inc. assures REGISTRY as follows:

1. NAACCR, Inc. agrees to treat the Data received from Registry as private, non-public health information. The Data will be used solely for the specified analyses and research described in Attachment A and not for any other purpose. The Data will never be used as a basis for legal, administrative or other adverse actions that can directly affect any individual about whom personal and/or medical information is included in the Data.
2. NAACCR, Inc. understands and agrees that any and all Data which may lead to the identity of any patient, research subject, physician, other person, or reporting facility is strictly privileged and confidential and agrees to keep all Data strictly confidential at all times.
3. If, in the course of evaluation, analysis, and research, NAACCR, Inc. believes it necessary to provide access to the Data to any NAACCR, Inc. researcher, NAACCR, Inc. will not do so unless and until such individual has properly executed a Data Confidentiality Agreement for NAACCR Researchers which has been accepted, in writing, by NAACCR, Inc. NAACCR, Inc. agrees to notify Registry in writing within forty-eight (48) hours of becoming aware of any violation of this Assurances Agreement or any Assurances Agreement executed by any other individual, including full details of the violation and corrective actions to be taken by NAACCR, Inc.
4. NAACCR, Inc. further agrees that all data provided under the provisions of this Assurances Agreement may only be used for the purposes described in Attachment A. Requests for ad hoc uses will only be provided after obtaining consent from each registry for each use.
5. NAACCR, Inc. agrees that (i) any and all reports or analyses of the Data prepared by NAACCR, Inc. shall contain only aggregate data. NAACCR, Inc. further agrees that (ii) at no time will any individual names or other personally identifying information or information which could lead to the identification of any Data subject ever be published, (iii) no report of the Data containing statistical cells with less than six (6) subjects shall be released without the prior written authorization of REGISTRY, (iv) aggregate data that identify individual REGISTRY will not be published without approval from REGISTRY.
6. NAACCR, Inc. further agrees that all data provided under the provisions of this Assurances Agreement shall remain the sole property of REGISTRY and may not be copied or reproduced in any form or manner without REGISTRY's prior written consent. Notwithstanding the foregoing, a NAACCR researcher may copy and maintain the Data on personal computer as long as such computer is secure and accessible only to the NAACCR, Inc. researcher.
7. NAACCR, Inc. will not take any action that will provide any Data furnished by REGISTRY to any unauthorized individual or agency without the prior written consent of REGISTRY.
8. NAACCR, Inc. will not disclose in any manner, to any unauthorized person, information that would lead to identification of individuals described in the Data furnished by REGISTRY. Also, NAACCR, Inc. will not provide any computer password or file access codes which protect the Data to any unauthorized person.

9. Should NAACCR, Inc. become aware of any unauthorized access or disclosure of the Data to other persons, NAACCR, Inc. will report it immediately to REGISTRY.
10. In the event that any attempt is made to obtain from NAACCR, Inc. any or all of the Data provided to NAACCR, Inc. by subpoena or other legal means, NAACCR, Inc. will notify REGISTRY immediately. NAACCR, Inc. agrees that REGISTRY may employ attorneys of its own selection to appear and defend the claim or action on behalf of REGISTRY. REGISTRY, at its option, shall have the sole authority for the direction of the defense and shall be the sole judge of the acceptability of any compromise or settlement of any claims or action against REGISTRY.
11. NAACCR's obligations hereunder shall remain in full force and effect and survive the completion of NAACCR's Call for Data projects described in Attachment A.
12. The terms of this Assurances Agreement shall be binding upon NAACCR, Inc. his/her agents, assistants, and employees.
13. Notwithstanding any contrary language in this Assurances Agreement, NAACCR, Inc. acknowledges and agrees that NAACCR's access to the Data shall at all times be in the sole discretion of REGISTRY.
14. REGISTRY reserves the right to review any and all of NAACCR's reports prior to dissemination or NAACCR's manuscripts before submission for publication to ensure that confidentiality is not violated and the Data are used appropriately.
15. This Assurances Agreement shall be governed by and interpreted under the laws of the State of Illinois.

Dated this 28<sup>th</sup> day of September 2018.

**North American Association of Central Cancer Registries, Inc.**

By:



Its: Executive Director

Print Name: Betsy Kohler  
North American Association of Central Cancer Registries, Inc.

Received and accepted this \_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_.

**REGISTRY** \_\_\_\_\_ ("Registry" Signature)

By: \_\_\_\_\_

Its: \_\_\_\_\_

Print Name: \_\_\_\_\_

Address: \_\_\_\_\_

E-mail address: \_\_\_\_\_

**Please upload on the submission site or fax or scan/e-mail:** Fax 217-698 0188; E-mail: rsherman@naaccr.org

**Attachment A**  
**Uses of Registry Data Submitted to the NAACCR Call for Data**

**1 Summary of Primary and Secondary Data Uses**

Central registry data submitted to NAACCR, Inc. in the Call for Data include data from 1995-2017, as of December 3, 2018. The NAACCR website describes how data releases are approved, with registry consent, and summarizes the variables available for each use; the data release procedure, human subjects protection requirements, and steps to ensure patient confidentiality: <https://www.naacccr.org/cina-data-products-overview/>

**1.1 Cancer in North America Primary uses (registry data included in these activities for all reg provided with signed general DUA except where specific consent is noted)**

- 1.1.1 Produce Cancer in North America (CiNA), 2011-2016 monographs (Vol 1: Combined Incidence; Vol 2: Registry-Specific Incidence, Vol 3: Registry-Specific Mortality, Vol 4: Survival, and associated appendices)
- 1.1.2 NAACCR evaluations of 1995-2017 data to determine fitness for use in cancer surveillance and research projects and make assessments available on the NAACCR website, e.g. 12 month data assessment, completeness of variables, evaluation of area based social measures
- 1.1.3 Produce the Annual Report to the Nation on the Status of Cancer (high quality U.S. registries only)
- 1.1.4 Create surveillance information and respond to data requests using the NAACCR research analytic file for requests of aggregate data of high quality U.S., Canadian, or North American data; state/provincial/territorial-specific data; or cancer site-specific data, which would apply a suppression rule for fewer than six cases for any requested rates and counts by state, province or territory
- 1.1.5 Create aggregated measures by central registry for use in the NAACCR web-based public query system, Quick Cancer Stats, Fast Stats and CiNA+ Online and CI\*Rank (high quality registries only)
- 1.1.6 Produce CiNA Monograph Data in a SAS dataset [CiNA in SAS]
- 1.1.7 Development of a research file to create project-specific datasets for proposals approved by the NAACCR Research Application Review Workgroup (RApR) and the NAACCR IRB. Consent for data inclusion for approved projects will be sent to registries on a project specific basis throughout the year.
- 1.1.8 Utilize data internally within NAACCR and by NAACCR committees to assess quality, fitness for use, and appropriate methodologic approaches.
- 1.1.9 Use of CiNA Deluxe to support the ranking by state and province based on cancer-related health indicators to support comprehensive cancer control
- 1.1.10 Produce a non-confidential, public-use research file with limited variables that will be available upon request after signing a data use agreement. Inclusion in this dataset will require registry consent as well as meeting data quality criteria. Consent for this specific project is included in this document.

**1.2 Cancer in North America Secondary Uses (consent requested for each specific project)**

- 1.2.1 Create project-specific datasets from the 1995-2016 CiNA Deluxe and special analytic files for researchers. Consent will be sent to registries as projects are approved.
- 1.2.2 Produce CiNA Public Use datasets in SEER\*Stat for Public Use. Registry inclusion is dependent upon standard data quality criteria as well as individual registry consent (Active Consent attached).

- 1.2.3 Produce CiNA Deluxe dataset, with a county variable (derived from data items 90, 94, 95, 96, 97), for calculation of incidence projections by the American Cancer Society (ACS) for their annual *Cancer Facts and Figures* publications. (Active Consent attached)
- 1.2.4 Provide aggregated data for medullary thyroid cancer verification (Active Consent attached)
- 1.2.5 Produce CiNA Plus datasets in SEER\*Stat for public use. Registry inclusion is dependent upon standard data quality criteria as well as individual registry consent (Passive Consent attached).
- 1.2.6 Produce an historical dataset annually for NCI collaborators to conduct delay-adjusted incidence rates (Passive Consent attached)

### **1.3 Registry Certification Program**

Upon request, the latest year of cancer diagnoses will be used for Registry Certification. This involves an evaluation of a registry's data to determine whether they meet NAACCR's high quality standards for use in computing incidence statistics. The Data Evaluation and Certification Committee review results annually. A Subcommittee of the Data Evaluation and Certification Committee conducts these reviews.

## **2 Physical and Electronic Data Security**

### **2.1 Certificate of Confidentiality**

The use of CiNA data is covered by a Certificate of Confidentiality (Certificate) that protects the privacy of research participants enrolled in research. The Certificate prohibits disclosure in response to legal demands, such as a subpoena. Effective October 1, 2017, NIH no longer provides documentation that specific NIH-funded studies are covered by a Certificate but NIH funded research activities are automatically issues a certificate under the NIH Policy on Certificates of Confidentiality. This has been confirmed with a Human Subjects Protections Consultant from the NIH Office of Extramural Research. More information is available here: <https://humansubjects.nih.gov/coc/faqs#definitions> If you have any questions, please contact Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org).

### **2.2 File Submissions**

All files are submitted to the NAACCR Statistical Analytic Unit, Information Management Services, Inc. (IMS) through secure electronic channels. Annually, IMS provides an assessment of their Data Security processes using the NAACCR document, *Inventory of Best Practices Assurance of Confidentiality and Security*. The data submissions accessible only by IMS staff under contract with NAACCR, Inc. to process the files and produce the primary analyses of data.

File used for CiNA Monographs and other primary use of data will be deleted 5 years after publication of research. However, historic data will be maintained to support the on-going production of reporting delay-factors.

### **2.2 Secondary Dataset Files**

The NAACCR Executive Office gives client server access to the CiNA Deluxe (NAACCR analytic) or special files to approved NAACCR researchers. Each file is the property of NAACCR, Inc. Data may be exported to other statistical software, such as SAS, for analysis. General information and variables lists for all file types are available on the NAACCR Website: <https://www.naaccr.org/cina-data-products-overview/>.

There are 4 types of CiNA datasets:

- The first file type is the standard CiNA Deluxe file with 19 age-groups and no county identifiers. Depending upon the researcher request, this file may include special variables such as reside in Appalachian County (Y/N) or recodes for breast cancer subtypes. Active Consent is used to obtain registry permission to include data for projects using these types of CiNA files.

- The second file type contains the variables from the CiNA Deluxe file but may contain single years of age, county identifiers, or special variables that could identify a county or lower level of geography. Passive Consent is used to obtain registry permission to include data for projects using these types of CiNA files.
- The third file type are special datasets. Currently, we have CiNA Survival and CiNA Imputed Breast Cancer Subtypes. NAACCR is developing CiNA Geographic file as well. These files are created by NAACCR Workgroups/Taskforces and evaluated for Fitness for Use prior to releasing to outside researchers. Currently, CiNA Survival requires Passive Consent. CiNA Imputed Breast Cancer Subtypes and the anticipated CiNA Geographic files would require Active Consent.
- The fourth type of CiNA file is a limited variable, non-confidential, Public Use dataset. The dataset is available upon request after signing a data use agreement. The dataset automatically suppresses cells less than 6 and many variables are recoded to enable non-researchers to use the data. . There are two options for registry inclusion in the Public Use CiNA file—one will allow data to be exported outside of SEER\*Stat and one will not allow data to be exported outside SEER\*Stat. Registries have the opportunity to consent to each option separately. The Data Use Agreement and a list of included variables and recodes are included with the Call For Data instructions (Appendix A) as well as on the NAACCR website: <https://www.naacccr.org/cina-public-use-data-set/>.

All CiNA files created for research will be deleted 1 year after the project is closed.

### 3 Further Explanation of Secondary Uses of Data

A list of NAACCR IRB approved projects is available on the NAACCR Website: <https://www.naacccr.org/irb-information-for-cina/>. A bibliography is currently available upon request, but NAACCR has an on-line bibliography under development.

#### 3.1 Individual Research Projects

*CiNA Deluxe* is the primary file used to create datasets for specific *ad hoc* research projects. NAACCR also has special datasets, such as CiNA Survival, which can be provided to approved researchers for specific, approved projects. Access to these data requires a submission of a proposal for review and approval by the NAACCR Research Application Review Work Group (RApR). RApR reviews the applications for scientific merit and appropriateness of using CiNA data. If approved by RApR, the proposals then must be approved by the NAACCR IRB. If approved by NAACCR IRB, Consent is requested from all registries eligible for participation in each study. A dataset is created for the Researcher that only includes data from registries that agreed to include their data through the consent process.

After all approvals are in place, but before receiving access to the file, all recipients must sign a Data Confidentiality Agreement for NAACCR Researchers (See Attachment B). A list of all recipients is maintained in the NAACCR Executive Office. The NAACCR IRB monitors all projects annually on the anniversary date of the project IRB approval. Copies of the NAACCR IRB procedures, forms, and meeting minutes are located on the NAACCR Website <https://www.naacccr.org/irb-information-for-cina/> When the studies are completed, researcher access to the SEER\*State file is terminated. CiNA datasets are password protected and may not be accessed by anyone other than approved researchers. All manuscripts for publication resulting from the analysis are reviewed and approved by the NAACCR Scientific Editorial Board before release. For projects requiring IRB Approval, researchers must also seek approval of the manuscript by the IRB. The IRB ensures the researcher publishes the data in accordance of the current DUA and assurances agreements.

## 4 Assurances of Proper Use

NAACCR members approved for access to CiNA Deluxe must sign the Data Confidentiality Agreement for NAACCR Researchers, which specifies in writing the proper protection and use of the data. Limitations on secondary data analyses are stated in the NAACCR Call for Data Assurances Agreement that the recipient of the data must sign.

## 5 Registry Consenting

NAACCR employs two approaches to obtain registry consent for *ad hoc* CiNA projects, summarized below. Both approaches are conducted by email with a consent form sent to the individual designated as the CiNA Approver by the Registry, as well as any alternate registry designates. NAACCR is working towards an electronic consent system to streamline this process.

**Passive Consent:** Registries have 14 days to respond. If no response is received, approval is assumed. Projects qualifying for Passive Consent do not request single-years of age, do not require any County at Dx variables, do not have special requests that are either unique applications of surveillance data, and do not request special variables that increase the potential for identification of individual patients.

**Active Consent:** Registries have 14 days to respond. If no response is received, data from the non-responding data will be excluded from the project. . Project requiring Active Consent either request single-years of age or County at Dx, or both. Active Consent is also used for projects that are either unique applications of cancer registry data or that request special variables that have the potential to identify specific patients or residential locations of patients. Over time, as registries become familiar with projects and there is wide-spread participation, some Active Consents move to Passive Consents. Two examples are the Delay Adjustment Project (now qualifies for Passive Consent) and the CiNA Survival Project (which no longer requires consent because it is now included in CiNA Primary Uses).

dataset

	Passive Consent Process	Active Consent Process
Variable list	Standard File Standard +area-based socioeconomic variables--county or tract-based poverty or urban/rural data <i>without</i> County (requires specific researcher justification)	Customized Request (e.g. Single Year of Age, County Identifier, county or tract-based socioeconomic variables, such as poverty or urban/rural status, released along with a County )
Geographic Presentation	United States, Canada, North America, regional analysis.	County presented individually in publication.
Linked Special Geographic Variables	County-level collapsed data, i.e. Appalachian Region Y/N, CHSDA region Y/N), coded economic or other SES data at does not uniquely identify a county; data appended at the state-level is allowed	Any county-level data linking to continuous variables or coded data that could uniquely identify county

### 5.1 Rescinding Consent

For all primary uses of NAACCR submissions, a registry director has the opportunity to change his or her mind and rescind that consent up to the time that the files go into production to produce the various products. Thus, it is important that every registry be familiar with their data file before it is submitted. We suggest that each registry examine frequency distributions of every variable on the file and check incidence rates to identify outliers.

With regard to special studies, once the dataset has been produced and released to a researcher, consent may be rescinded. However, a researcher may have already conducted analysis on the original file or presented/published data. If a registry rescinds consent, we immediately remove the registry's data from

the research file, instruct the researcher to destroy any exported data for that registry, and instruct the researchers to remove the registry's data from any pending or future presentations/publications.

Attachment B:  
**DATA CONFIDENTIALITY AGREEMENT FOR NAACCR RESEARCHERS**

NOT INTENDED FOR COMPLETION BY REGISTRIES

Agreement executed this \_\_\_\_\_ Day of \_\_\_\_\_ 20 \_\_\_\_

By and between \_\_\_\_\_ ("Researcher") of \_\_\_\_\_

\_\_\_\_\_  
*Organization*

\_\_\_\_\_  
*City*

\_\_\_\_\_  
*State/Province*

and **NORTH AMERICAN CENTRAL CANCER REGISTRIES, INC.** ("NAACCR"), a California corporation. Researcher is engaged in research into the causes, control, or prevention of cancer, specifically described as follows:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
NAACCR collects and maintains certain research data (the "Data") that will or may assist Researcher in this regard. Researcher agrees and acknowledges that patient confidentiality is of the utmost importance in the use of the Data and in the manner in which all research results are presented and/or published. Accordingly, in consideration of his/her receipt of the Data from NAACCR, Researcher agrees as follows:

1. Researcher agrees to treat the Data received from NAACCR as private, non-public health information. The Data will never be used as a basis for legal, administrative or other adverse actions that can directly affect any individual about whom personal and/or medical information is included in the Data.
2. Researcher further agrees that all data provided under the provisions of this Data Confidentiality Agreement may only be used for the purposes described hereinabove and that any other or additional use of the data may result in immediate termination of this Confidentiality Agreement by NAACCR.
3. Researcher understands and agrees that any and all Data which may lead to the identity of any patient, research subject, physician, other person, or reporting facility is strictly privileged and confidential and agrees to keep all Data strictly confidential at all times.
4. If, in the course of his/her research, Researcher believes it necessary to provide access to the Data to any other individual, Researcher will **NOT** do so unless and until such individual has properly executed a Data Confidentiality Agreement that has been accepted, in writing, by NAACCR. And, Researcher agrees to notify NAACCR in writing within forty-eight (48) hours of his/her becoming aware of any violation of this Confidentiality Agreement or any Confidentiality Agreement executed by any other individual, including full details of the violation and corrective actions to be taken by Researcher.
5. Researcher agrees that (i) any and all reports or analyses of the Data prepared by Researcher shall contain only aggregate data. Researcher further agrees that (ii) at no time will he/she ever publish any individual names or other personally identifying information or information which could lead to the identification of any Data subject, and (iii) no report of the Data containing statistical cells with less than six (6) subjects shall be released without the prior written authorization of NAACCR's Executive Director, who has received written authorization from contributing registries.
6. Researcher agrees that linkage to another database is allowed, but not for the purpose of identifying an individual on the file and only as described and specified in the NAACCR IRB approved proposal.
7. Researcher further agrees that all data provided under the provisions of this Confidentiality Agreement shall remain the sole property of NAACCR and may not be copied or reproduced in any form or manner without NAACCR's prior written consent.
8. Researcher shall indemnify NAACCR from any and all liability, loss, or damage (including attorneys' fees) suffered as a result of claims, demands, costs or judgments arising out of the failure of Researcher or those acting in connection with Researcher to conform to and obey the provisions of this Data Confidentiality Agreement. In the event a claim should be brought or an action filed against NAACCR in connection with any such failure, Researcher agrees that NAACCR may employ attorneys of its own selection to appear and defend the claim or action on behalf of NAACCR, at the expense of Researcher. NAACCR, at its option, shall have the sole authority for the direction of the defense and shall be the sole judge of the acceptability of any compromise or settlement of any claims or action against NAACCR.
9. Researcher will not take any action that will provide any Data furnished by NAACCR to any unauthorized individual or agency without the prior written consent of NAACCR.



10. Researcher will not discuss in any manner, with any unauthorized person, information that would lead to identification of individuals described in the Data furnished by NAACCR. Also, Researcher will not provide to any unauthorized person any computer password or file access codes that protect the Data.

11. Should Researcher become aware of any unauthorized access or disclosure of the Data to other persons, Researcher will report it immediately to NAACCR's Executive Director. Researcher understands that failure to report violations of confidentiality by others shall be considered as Researcher's own violation and may result in civil or criminal penalties and termination of current and future access to confidential data.

12. In the event that any attempt is made to obtain from Researcher any or all of the Data provided to Researcher by NAACCR by subpoena or other legal means, Researcher will notify NAACCR immediately. Researcher agrees that NAACCR may employ attorneys of its own selection to appear and defend the claim or action on behalf of NAACCR. NAACCR, at its option, shall have the sole authority for the direction of the defense and shall be the sole judge of the acceptability of any compromise or settlement of any claims or action against NAACCR.

13. Researcher's obligations hereunder shall remain in full force and effect and survive the completion of Researcher's research project described hereinabove.

14. The terms of this Confidentiality Agreement shall be binding upon Researcher, his/her agents, assistants and employees.

15. Notwithstanding any contrary language in this Confidentiality Agreement, Researcher acknowledges and agrees that Researcher's access to the Data maintained by NAACCR shall at all times be in the sole discretion of NAACCR.

16. NAACCR reserves the right to review any and all of Researcher's reports prior to dissemination or Researcher's manuscripts before submission for publication to ensure that confidentiality is not violated and the Data are used appropriately.

17. Researcher understands that access to the Data will be terminated when the report is submitted to the NAACCR Scientific Editorial Board or if no annual progress report is filed with the NAACCR Institutional Review Board. It will also be terminated upon report to the NAACCR IRB that the project is complete.

18. If Researcher is required by any other party or parties, including the state or a state agency, to execute any additional confidentiality agreement(s) as a condition of access to the Data, in the event of a conflict between the provisions of such agreement and this Agreement, Researcher agrees that the most restrictive agreement shall prevail.

19. This Confidentiality Agreement shall be governed by and interpreted under the laws of the State of Illinois.

Dated this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_.

**Researcher** \_\_\_\_\_ ("Researcher" Signature)

\_\_\_\_\_  
(Print Name)

Address: \_\_\_\_\_  
\_\_\_\_\_

E-mail address: \_\_\_\_\_

Phone: ( ) \_\_\_\_\_ ext. \_\_\_\_\_

Received and accepted this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_.

North American Association of Central Cancer Registries, Inc.

By: \_\_\_\_\_

Its \_\_\_\_\_

## Active Consent Form for CiNA Public Use Dataset

NAACCR requests permission from the:

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To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or scan & email or Fax to Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0188 by December 3, 2018. 7. A response must be received by this date for your data to be included in the project.

**Project Title:** **CiNA Public Use Dataset—Case Listing (Exporting from SEER\*Stat)**  
**Allowed**

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

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**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 file to be made available for research. The CiNA Public Use File is a non-confidential, limited, public-use research file 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 new dataset will be to provide non-confidential data to both NAACCR and outside researchers, whose studies require more variables than currently provided in our on-line query systems, but do not need the full CINA Deluxe file, in a timely manner. The dataset includes 6 demographic variables, 12 cancer characteristics variables, and 5 derived variables. No treatment data are included. Many of the variables are recoded to reduce uniqueness and standardize analysis. The CINA Public Dataset is comprised of two datasets. This dataset allows a user to generate counts, rates and trends within the SEER\*Stat system, includes age in the 19 age group categories, and allows the user to export the data as a case-listing to allow regression and other analysis in standard, statistical programs. **There are separate consents for each dataset. This consent is for registry inclusion in the SEER\*Stat accessible database only with case listing allowed.**

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### CiNA Deluxe Variable Set

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- The list of variables and recodes as well as the Data Use 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	1995-2016 CiNA Public Use File; 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](mailto:rsherman@naaccr.org) or 217.698.0800.

Print Name:

Signature:

Title:

Date:

**Active Consent Form for CiNA Public Use Dataset**

NAACCR requests permission from the:

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To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or scan & email or Fax to Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0188 by December 3, 2018. A response must be received by this date for your data to be included in the project.

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

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

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**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 file to be made available for research. The CiNA Public Use File is a non-confidential, limited, public-use research file 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 new dataset will be to provide non-confidential data to both NAACCR and outside researchers, whose studies require more variables than currently provided in our on-line query systems, but do not need the full CINA Deluxe file, in a timely manner. The dataset includes 6 demographic variables, 12 cancer characteristics variables, and 5 derived variables. No treatment data are included. Many of the variables are recoded to reduce uniqueness and standardize analysis. The CINA Public Dataset is comprised of two datasets. This dataset allows a user to generate counts, rates and trends within the SEER\*Stat system, includes age in the 19 age group categories, but does not allow the user to export the data as a case-listing to allow regression and other analysis in standard, statistical programs. **There are separate consents for each dataset. This consent is for registry inclusion in the SEER\*Stat accessible database only with case listing allowed. ; no case listing allowed**

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### CiNA Deluxe Variable Set

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- The list of variables and recodes as well as the Data Use 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:**

<b>Yes</b>	<b>No</b>	1995-2016 CiNA Public Use File; 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](mailto:rsherman@naaccr.org) or 217.698.0800.

Print Name:

Signature:

Title:

Date:

## Active Consent Form for ACS Facts & Figures

NAACCR requests permission from the:

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To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or scan & email or Fax to Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0188 by December 3, 2018. 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:** Ahmedin Jemal, Surveillance & Health Services Research Program (SHSRP),

**Project** ACS

**Description:** A custom version CINA Deluxe with a county variable (data items 90, 94-97 as appropriate ) 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 Americans, 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. The file is released to appropriate staff of IMS who prepare the file(s) and conducts the first steps in the methodology. The output are released to one researcher at ACS (currently Kimberly Miller) who completes 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. Since a county identifier is required for linkage to Census data to compute the projections, active consent is requested, however no county identifying information will be published.

ACS adjusts incidence projections, and reported average annual cancer incidence rates during the most recent 5-year data period using NCI generated registry-specific delay factors as available to provide the most accurate cancer burden. 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 2012 CFF (the projection method used since 2007 was updated in 2012).

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### 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 Deluxe Standard dataset. A county identifier will also be released in order to conduct the state-specific cancer case projections.
- Registry-specific data will be presented. County-specific data will NOT be presented.

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

Yes	No	1995-2016 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](mailto:rsherman@naaccr.org) or 217.698.0800.

Print Name:

Signature:

Title:

Date:

## Active Consent Form for Medullary Thyroid Project

NAACCR requests permission from the:

To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or scan & email or Fax to Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0188 by December 3, 2018. 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 Stemhagen, DrPH, FISPE  
Sr. VP SERRM (Safety, Epidemiology, Registries & Risk Management) at United BioSource Corporation

**Project Description:** As required by the FDA, United BioSource (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, GlaxoSmithKline LLC and Eli Lilly and Company) as the sponsor of the study for GLP-1 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 verify that there are a) 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: Counts by state by year, Counts by sex (M/F) by year (US), Counts by age group by year (US), Stage by year (US), Counts & Rates by age group by year by sex (M/F) US.  
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 Deluxe Standard 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	1995-2016 CiNA Deluxe Custom File <b>without</b> County Identifier
<input type="checkbox"/>	<input type="checkbox"/>	If no, why not?

If you have any questions regarding this project or data uses, please contact Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0800.

Print Name:

Signature:

Title:

Date:

# Active Consent Form for CiNA Synthetic Dataset

NAACCR requests permission from the:

To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or scan & email or Fax to Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0188 by December 3, 2018. A response must be received by this date for your data to be included in the project.

**Project Title:** CiNA Synthetic Dataset

**Principal**

**Investigators:** PI: David Stinchcomb, Chair, NAACCR Synthetic Dataset Task Force

**Goal:** The goal is to create a synthetic dataset with realistic & complete cancer information that can be used for diverse purposes, including training & demos, software testing, & analysis. The CiNA Synthetic Dataset will be about 500,000 cases total, in the current NAACCR layout, will pass edits, & contain a diverse set of sites, stages, & ages with fictitious demographics & place but reflect legitimate diagnostic & treatment possibilities.

**Background:** The NAACCR Synthetic Dataset Task Force has developed a process for creating an annual synthetic dataset. The annual synthetic dataset will include all the current call for data fields populated with synthetic data derived from real CiNA data. An initial version of the CiNA Synthetic Dataset was created based on the December 2017 submission thanks to the active participation of over 40 registries. The dataset has been successfully used in a number of applications including the first NAACCR Hackathon in June. Participants were very impressed with the synthetic dataset and remarked on how realistic it was. Their main request was to have a larger dataset to work with. For this reason, we plan to increase the size from 10,000 records to 500,000 records with this new version. We hope you will continue to or join in the support of this project.

**Methods:** Deidentified tumor data will be combined with synthetic demographic and geographic information. The state in the synthetic person record assigned to each tumor record will be different than the state of the tumor record's originating registry. Sets of dates in the tumor data will be randomly altered within diagnosis year & age group to maintain internal consistency & duration. Combinations of primary site category, stage group, age group, & sex that are rare will be NOT be included in the synthetic dataset. The process also analyzes uniqueness characteristics & removes any records that pose significant risks of identification. Additionally, there is often the need for a Type C (confidential) synthetic dataset (e.g. geocoding training). In this case, fictitious names & non-residential addresses will be added.

## CiNA Deluxe Variable Set

- This consent is for the task force to refine the methodology and create a new release of the CiNA Synthetic Dataset. Applications to use the CiNA Synthetic Dataset for training or other purposes will be reviewed and approved by the NAACCR Program Manager of Data Use and Research.

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

Yes	No	1995-2015 CiNA Deluxe Custom File <b>without</b> 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](mailto:rsherman@naaccr.org) or 217.698.0800.

Print Name:

Signature:

Title:

Date:

# Passive Consent Form for American Lung Association

NAACCR requests permission from the:

To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or scan & email or Fax to Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0188 by December 3, 2018. 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: Zack 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 dashboard using visual graphics and bulleted, 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 (if available), five year survival rate (if available), and number of cases per accredited lung cancer screening center. All results will be based on five years of aggregated data.

This project will be updated annually. More information can be found on NAACCRReview <https://www.naaccr.org/2018-state-lung-cancer-report/>

**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	1995-2015 CiNA Deluxe Custom File <b>without</b> 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](mailto:rsherman@naaccr.org) or 217.698.0800.

Print Name:

Signature:

Title:

Date:

# Passive Consent Form for CiNA Plus in SEER\*Stat

NAACCR requests permission from the:

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To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or scan & email or Fax to Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0188 by December 3, 2018. 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 Plus in SEER\*Stat

**Project Description:** NAACCR receives requests from members who would like to use NAACCR data in their local statistical reports. Without access to these data, these reports can only be compared to SEER rates. Registries want to compare their data to other registries in their own region or to data that reflect more national statistics. By providing access to CiNA+ Online data in SEER\*Stat software, this tool will enable members to produce tables in the same format as their own local statistical reports, and to do some comparative analysis using SEER\*Stat statistical tools.

Registry members who want access to the dataset will need to request the access in writing and sign the NAACCR Researcher Assurance agreement that states they will not use the file to link or attempt to identify individuals.

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## CiNA Deluxe Variable Set

- This project will use a standard subset of variables listed for CiNA Deluxe in the Call for Data. This dataset will only include the variables available on CiNA+ Online, a subset of the CiNA Deluxe dataset: Age (19 age groups only), SEER site groups (see CiNA+ online for complete list), race (W/B/O), ethnicity, sex, year of diagnosis (2011-2016) and registry (state or province only).
- Registry-specific data will be available for this project

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

Yes	No	1995-2016 CiNA + in SEER*Stat
		If no, why not?

If you have any questions regarding this project or data uses, please contact Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0800.

Print Name:

Signature:

Title:

Date:



## Passive Consent Form for Delay Adjustment

NAACCR requests permission from the:

To be included in the project described below, please confirm via the on-line submission, upload a signed copy on the submission site, or scan & email or Fax to Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0188 by December 3, 2018. 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**

**Investigator:** Huann-Sheng Chen, NCI, Rocky Feuer, NCI

**Project Description:** NCI statisticians will use the NAACCR CiNA files to conduct estimates for 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, previously only available for registries in the SEER program. Registries not included in the CiNA combined rates will be included in the analysis in order to create more robust estimates. The earliest data used in the model will be diagnosis year 2005 from the 2007 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 for the US, Canada, and North America may be included in CiNA in addition to traditional rates. Delay adjustment factors will be available in SEER\*Stat for analytic purposes.

### CiNA Deluxe Variable Set

- This project will use the standard variables listed for CiNA Deluxe in the Call for Data
- Registry-specific delay-adjustment factors for non-SEER registries will NOT be published but will be available in SEER\*Stat to generate registry-specific delay-adjusted rates for use by ACS, CDC, NAACCR, NCI.
- Upon request, all registries may have access to their individual delay-adjustment factors in a SEER\*Stat database.
- Registry-specific identifiers, for SEER registries only, are released as specialized databases because cautions are necessary in using estimates for small populations which may be unstable or biased. A data use agreement is necessary for the user to acknowledge that he or she has read and understood the cautions involved in using these databases. More information available [here](#).

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

Yes	No	CiNA Deluxe Standard Files with data from 1997 forward
		If no, why not?

If you have any questions regarding this project or data uses, please contact Recinda Sherman at [rsherman@naaccr.org](mailto:rsherman@naaccr.org) or 217.698.0800.

Print Name:

Signature:

Title:

Date: