

## **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 or any other third party 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 3<sup>rd</sup> day of December 2024.

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

By: 

Its: Executive Director

Print Name: Karen L. Knight, M.S.  
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 submit using DocuSign via the submission site. This version is for reference only. Contact Recinda Sherman with questions at: [rsherman@naacccr.org](mailto:rsherman@naacccr.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 1995-2022, as of December 3, 2024, and 2023 as late as January 31, 2025. Primary data use activities do not require additional consent from registries. Secondary data use activities do require additional, project-specific consent from the registries.

##### **1.1 Cancer in North America Primary Use (registry data included in these activities for all registries based on signed, general DUA except where specific consent is noted)**

- 1.1.1. Produce Cancer in North America (CiNA), 2018-2022 statistics including incidence, survival, prevalence, and population attributable risk factors (PARF).
- 1.1.2. NAACCR evaluations of 1995-2023 data to determine fitness for use in cancer surveillance and research projects and make assessments available on the NAACCR website and to the NAACCR community, e.g. 12 month data assessment, completeness of variables.
- 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 CiNA research datasets 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 using 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 systems available here <https://www.naacr.org/interactive-data-online/>.
- 1.1.6. Development of datasets to create project-specific datasets for proposals approved by the NAACCR Research Application Review Workgroup (RApR) (consent from registries required prior to release of any data to researchers).
- 1.1.7. Utilize data internally within NAACCR and by NAACCR committees to assess quality, fitness for use, and appropriate methodologic approaches.
- 1.1.8. Use of CiNA Research datasets to support the ranking by state and province based on cancer-related health indicators to support comprehensive cancer control.
- 1.1.9. Produce a non-confidential, Public Use Dataset with limited variables to be available upon request after signing a data assurances 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.
- 1.1.10. Produce an historical dataset annual to create delay factors based on multiple submission datasets to be used by NCI, CDC, ACS, and NAACCR. Consent for this project is included in this document.
- 1.1.11. Produce a new CiNA Geographic dataset, for US data only, which includes census tract, for the purposes of data quality and methodology evaluation by NAACCR only. These data will never be released without specific consent from the registries.

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

The NAACCR website describes how data releases are approved, with registry consent, and summarizes the variables available for each use; the data release procedure, and steps to ensure patient confidentiality: <https://www.naacccr.org/cina-data-products-overview/>. The NAACCR Data Request Tracking (DaRT) System tracks all data requests, data release, and associated processes: <https://apps.naacccr.org/dart>.

- 1.2.1 Create project-specific datasets from the 1995-2022 CiNA (e.g CiNA Research, CiNA Survival/Prevalence) and special CiNA Research datasets for researchers-- consent for inclusion will be sent to registries as projects are approved.
- 1.2.2 Produce CiNA Research dataset for calculation of incidence projections by the American Cancer Society (ACS) for their annual *Cancer Facts and Figures* publications (Active Consent attached, US Only)
- 1.2.3 Provide data for mapping county-level data as a CiNA product (Active Consent attached, US Only)
- 1.2.4 Provide data for Mayo catchment area analysis (Active Consent attached, US Only)
- 1.2.5 Provide aggregated data for medullary thyroid cancer verification (Active Consent attached, US Only)
- 1.2.6 Provide data for the National Childhood Cancer Registry (Active Consent attached, US Only)
- 1.2.7 Produce CiNA Research dataset for American Lung Association Annual Report (Passive Consent attached, US Only)
- 1.2.8 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 (Passive Consent attached)
- 1.2.9 Provide data for mapping modeled, county-level data (Passive Consent attached, US Only)
- 1.2.10 Produce CiNA Research dataset for evaluation of stage at diagnosis and impact of the Affordable Care Act by the American Cancer Society (Passive Consent attached, US Only)
- 1.2.11 Produce an historical dataset annually for NCI/CDC/ACS collaborators to conduct delay-adjusted incidence rates (Passive Consent attached)

## 1.3 Registry Certification Program

Diagnosis year 2022 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 Certification Committee review results annually.
- NAACCR Executive Office conducts the evaluation.

## 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 *Data Assurances Agreement updated September 16, 2024*

funded research activities are automatically issued 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 NAACCR Program Manager of Data Use & Research (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 are accessible only by IMS staff under contract with NAACCR, Inc. to process the files and produce the primary analyses of data.

Datasets used for CiNA Products and other primary and secondary uses of data will be deleted 5 years after publication of research. However, historic data will be maintained to support the ongoing production of reporting delay-factors.

## 2.3 Standard File Submission Workflow

- Registry personnel log in via the MyNAACCR Login service and can only upload files on the NAACCR CFD Portal. The CFD Portal does not offer the ability to download any files by the registry or NAACCR staff.
  - All data in transmission from a registry to IMS are encrypted using industry standard TLS 1.2 technologies.
  - Each file received by IMS is automatically encrypted by AES 256 encryption with a unique, randomly generated key per submission year.
- To download the files from the NAACCR CFD Portal, a single approved IMS staff member runs a script that connects to the web server. The script can only be run from within the secure IMS network.
  - The files are downloaded to a secure, privileged-access directory on an internal IMS server.
  - During the download process, each registry file is unencrypted.
  - Each file is run through Edits and then IMS SEER\*Recode program and additional fields added on to the data record. An output file in CSV format is created.
  - Country-specific (US or Canada) SAS programs are run on the registry CSV files that check for invalid records to produce two CSV files:
    - One containing all the registry exclusion records
    - One containing all the records to be used
    - Additional SAS programs are run that add in additional fields (e.g., collapsed summary stage) and recodes certain counties (for example for AK, CO, CT and HI to match populations).
- The CSV file containing all the records to be used for the submission is read in via SEER\*Prep and two SEER\*Stat databases are created. They are used for NAACCR's CiNA and Certification work. The Patient IDs in SEER\*Stat are changed and are not the registry submitted Patient IDs.
- Once all the data are processed, the encrypted files on the NAACCR CFD Portal are deleted.

## 2.4 Special Handling of Census Tract for CiNA Geographic Dataset (US Only)

- All data in transmission from a registry to IMS are encrypted using industry standard TLS 1.2 technologies. Submission files can only be uploaded to the NAACCR Call for Data Portal and are not accessible for download. Each file received by IMS is automatically encrypted upon upload with a unique key per submission year.
- When the data are ready to be processed by IMS, a single, approved IMS staff member downloads the encrypted registry files to a secure privileged-access directory on an internal IMS server. Each registry file is then unencrypted, and the data processed.
- A limited dataset containing census tract is created for SEER\*Stat, separate from the standard CiNA dataset. Once the SEER\*Stat file is created, all unencrypted, processing files are deleted. The encrypted, registry submission files that are stored on the secure IMS network are kept for one year and then deleted. All backups are deleted one year later.
- A single, approved IMS Staff member will have access to census tract information. However, the IMS SEER\*Stat administrators have the capacity to access any dataset in SEER\*Stat. However, no IMS personnel will access the CiNA census tract data without written permission from NAACCR.
- As with all SEER\*Datasets, census tract information will be accessible by the NAACCR Program Manager of Data Use & Research.
- As with all datasets, no data will be released for any purpose without the approval of the NAACCR Program Manager of Data Use & Research.
- To support the development of a national dataset that can support geospatial and area based health equity research, census tract may be made available member of the CiNA Geographic Taskforce under Primary Data Use item 1.1.11.

## 3 Secondary Datasets

The NAACCR Executive Office provides permission for client server access to the CiNA Research, CiNA Survival/Prevalence, or CiNA special datasets to approved NAACCR researchers. Each dataset 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 dataset types are available on the NAACCR Website: <https://www.naacr.org/cina-data-products-overview/>.

There are 2 types of CiNA Research datasets:

- The first dataset type is made available only to approved researchers who are NAACCR members, have a NAACCR approved protocol, and have signed a data confidentiality agreement. These include the standard CiNA Research dataset and CiNA Survival/Prevalence and NAACCR is investigating the development of a CiNA Geographic dataset. Datasets with county identifiers, single-years of age, special variables, new methodology, or sensitive research (e.g. HIV) require ACTIVE CONSENT (see section 5) from individual registries to be included in the researcher's specific CiNA dataset. Datasets with the standard 19 age-groups and no county identifiers with well understood methodology and no special variables or sensitive research require PASSIVE CONSENT from individual registries to be included in the researcher's dataset. PASSIVE CONSENT may also be used for some special variables such as "reside in Appalachian County (Y/N)" or recodes for breast cancer subtypes. Resources to understand the datasets are available here: <https://www.naacr.org/cina-research/> .

- The second dataset is the limited variable, non-confidential, Public Use dataset. The dataset is available upon request after signing a data assurance agreement. The dataset automatically suppresses cells less than 16 and variables are recoded to enable all users to use standard analysis. This dataset does not allow data to be exported outside of SEER\*Stat. Resources to understand the Public Use Dataset are available here: <https://www.naaccr.org/cina-public-use-data-set/>.

All CiNA datasets created for research will be deleted 1 year after the project is documented as closed or 5 years after known publication date.

## **4 Further Explanation of Secondary Uses of Data**

A bibliography of peer reviewed publications based on CiNA datasets is available on our website.

### **4.1 Individual CiNA Research Projects**

Access to CiNA Research datasets 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. Due to changes in the Common Rule, NAACCR IRB is no longer required. If RApR approves a project, 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 consent to include their data through the consent process.

After all approvals are in place, but before receiving access to the dataset, all recipients must sign a Data Confidentiality Agreement for NAACCR Researchers (See Attachment B). The NAACCR IRB monitors all projects annually. Copies of the NAACCR IRB procedures, forms, and meeting minutes are located on the NAACCR Website <https://www.naaccr.org/irb-information-for-cina/>. CiNA datasets are password protected and may not be accessed by anyone other than approved researchers.

All manuscripts for publication resulting from the individual CiNA Research Projects are requested to be reviewed and approved by the NAACCR Scientific Editorial Board before release. Part of that review ensures the researcher publishes the data in accordance with the data agreement and approved proposal. When the studies are completed, researcher access to the SEER\*Stat dataset is terminated except for Public Use Datasets. Access to the Public Use Datasets is automatically terminated annually after the release of the latest CiNA Public Use dataset—users must sign a new data assurances agreement to gain access to the latest dataset. The NAACCR Data Request Tracking (DaRT) System tracks all data requests, data release, and associated processes: <https://apps.naaccr.org/dart>.

### **4.2 Assurances of Proper Use of CiNA data by Researchers**

NAACCR members and their collaborators that approved for access to CiNA Research datasets must sign the NAACCR Data Confidentiality Agreement, which specifies the proper protection and limitations on use of the data. Recipients of the Public Use Dataset must initial and sign a Data Assurance Agreement.

### **4.3 Registry Consenting**

NAACCR employs two approaches to obtain registry consent for *ad hoc* CiNA projects (Secondary Data Use) which are summarized below. Both approaches are now conducted

through the NAACCR DaRT system with a consent request sent the individual designated as the CiNA Approver by the Registry, as well as any alternate registry designates.

**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 request County at Dx, are not 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 registry will be excluded from the project. Projects requiring Active Consent may contain 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).

	<b>Passive Consent Process</b>	<b>Active Consent Process</b>
Variable list	Standard Dataset; Standard +area-based socioeconomic variables--county or tract-based poverty or urban/rural data <b>without</b> 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, state-level analysis.	County
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 area-level data linking to continuous variables or coded data that could uniquely identify county

## 5 Rescinding Consent

For all primary uses of NAACCR submissions, a registry director has the opportunity to rescind 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 before it is submitted.

With regard to special studies (secondary data uses), once the dataset has been produced and released to a researcher, consent **may still 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 SEER\*Stat dataset, 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.

## 6 Submitting DAY of Dates



To properly assess a registry's tumor-level duplicate rate for the purposes of NAACCR Certification, registries will need to submit DAY of diagnosis date. NAACCR\*Prep provides multiple levels of suppression. Regardless of what level of suppression is applied in NAACCR\*Prep, registries will also be able to determine to how the DAY data will be used in the CFD Portal.

Specific details are updated annually in the CFD *General Instructions* available here: <https://www.naacr.org/call-for-data/>.

**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 province or any state or provincial 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 \_\_\_\_\_