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 30th day of August 2012.

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: _____

<u>Please fax to:</u>

Fax: (217) 698-0188

Attachment A
Uses of Registry Data Submitted to the NAACCR 2013 Call for Data

1 Summary of Primary and Secondary Data Uses

Central registry data submitted to NAACCR, Inc. in the 2013 Call for Data include data from 1995-2010, as of December 3, 2012. The NAACCR document, *Checklist for Reviewing Consent Requirements for all NAACCR Data Uses,* summarizes the variables available for each use; the data release procedure, human subjects protection requirements, and steps to ensure patient confidentiality.

1.1 *Cancer in North America* Primary uses

1.1.1 Produce Cancer in North America (CINA), 2005-2010 monograph
1.1.2 NAACCR evaluations of 1995-2010 data to determine fitness for use in cancer surveillance and research projects
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 or 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 (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 IRB.
1.1.8 Utilize poverty status, survival and treatment data internally within NAACCR and by NAACCR committees to assess quality and fitness for use.

1.2 *Cancer in North America* Secondary Uses

1.2.1 Create project-specific datasets from the 1995-2010 CINA Deluxe analytic for researchers
1.2.2 Produce CINA Plus in SEER*Stat.
1.2.3 Produce an historical dataset annually for NCI collaborators to conduct delay-adjusted incidence rates
1.2.4 Use of CINA Deluxe, with a county variable (data item 90), for calculation of incidence projections by the American Cancer Society (ACS) for their annual *Cancer Facts and Figures* publications.
1.2.5 Provide SEER and ACS with access to a copy of the CINA Deluxe file under the following conditions:
   a. Custody will be limited to a designated individual within the organization.
   b. NAACCR will be notified of all uses of the data and this information would be passed on to NAACCR members.
   c. Re-release of the file will be prohibited.
   d. If state or province-specific data are released in response to a request, the state or province will be notified immediately.
   e. Cell suppression rules described in item 1.1.4 will be observed.

1.3 Registry Certification Program

Upon request, the last 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 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.

2.2 Secondary Dataset Files

The NAACCR Executive Office gives client server access to the CINA Deluxe (NAACCR analytic) file 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.

The second format of the CINA Deluxe involves a customized file. Variables in the CINA Deluxe Custom File can include a county identifier or any of the variables in the standard data file, which have had the variable values re-categorized to meet the specific needs of a research proposal. All uses of the Custom file format require an active consent by participating registries.

3 Further Explanation of Secondary Uses of Data

A list of NAACCR projects and their status is provided in the NAACCR Research List and NAACCR Annotated Bibliography of Research and Publications, available at the URL address http://www.naaccr.org/DataandPublications/EpiReports.aspx, on the NAACCR website.

3.1 Individual Research Projects

CINA Deluxe is the primary file used to create data sets for specific *ad hoc* research projects. All projects require a submission of a proposal for review and approval by the NAACCR Date Use or Research Committee's Research Proposal Review Subcommittee. CINA Deluxe applications that do not request funding from NAACCR will be reviewed and approved by DURC. Those approved for scientific merit are then reviewed and must be approved by the 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 provided consent.

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 approval. Copies of the NAACCR IRB procedures, protocols, and forms are located on the website. When the studies are completed, access to the file is terminated. CINA Deluxe is password protected and may not be accessed by anyone other than approved researchers. All manuscripts for publication and oral presentations,

resulting from the analysis are reviewed and approved by the NAACCR Scientific Editorial Board before release.

3.2 American Cancer Society Facts and Figures

A custom version CINA Deluxe with a county variable (data item 90) is produced for the American Cancer Society and NCI to calculate incidence projections for the ACS's annual publication, *Cancer Facts and Figures*. The file is released under controlled IRB approved protocols to the appropriate staff of ACS, or their designee, to conduct the analysis and computations.

3.3 Medullary Thyroid Cancer Verification

As required by the FDA, United BioSource (UBC) is conducting post-marketing surveillance on a medication 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, 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. The following variables would be included: Gender, Race 1, Computed Ethnicity, Spanish / Hispanic Origin, Primary Site Code, Topography of Cancer, Morphology of Cancer Code, and Age at Diagnosis.

3.4 CINA Plus in SEER*Stat

This data analysis tool includes all the data from CINA+ Online, except that the data are available in SEER*Stat software to enable more flexible queries that can include statistical testing. Access to this data set is discretionary; only requests from NAACCR members will be considered. An application form to access the file must be submitted.

3.5 Delay Adjustment

Data available in CINA Deluxe data files from the 1999 submission forward will be used to develop delay-adjusted trend statistics for the United States, and if possible, Canada. The data will be provided to the National Cancer Institute to develop these estimates, currently only available for data from the NCI-SEER program.

3.6 Creation of CINA Deluxe for NCI and ACS

NCI and ACS would be provided with access to a confidential file of CINA Deluxe data from consenting registries in order to develop national data on issues so as to enable responding to requests from the media, legislators, policy makers, scientists, and the general public for cancer statistics in North America. The data will be stored at IMS. Following appropriate data security standards, access would be given to a single individual at NCI and up to two individuals at ACS (a primary and a back-up) who could run these types of tabulations using SEER*Stat with the following conditions:

a. Custody will be limited to the designated individual/s within the organization.
b. NAACCR will be notified of all uses of the data and this information would be passed on to NAACCR members.
c. Re-release of the file will be prohibited.
d. If state or province-specific data are released in response to a request, the state or province will be notified immediately.
e. Cell suppression rules for cells with fewer than 6 observations will be followed.

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* projects, summarized in the table below. Both approaches are conducted by email with a consent form sent to all Registry Directors and their alternate for research consenting. In the first approach, a passive consenting process, registries have 14 days to respond. If no response is received, approval is assumed. In the second approach, an active consent is required for all projects. This approach is used when the proposed projects require a county identifier or other customized data set; linkage with other datasets; presentation of state-specific results; or use of any county-based variable (e.g., percent of persons in the county living below the poverty level).

	Passive Consent Process	**Active Consent Process**
Variable list	Standard	Customized Request (e.g. Single Year of Age, County Identifier, County or Census Tract Based Socioeconomic Variable)
Geographic Presentation	United States, Canada, North America	State or Provinces Identified
Linkage	None	Linkage Requested with Another Data File

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 data set has been produced and released to a researcher, consent may not be rescinded.

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 Secondary Data Uses
CINA Deluxe Projects

NAACCR requests permission from the:

_____

To be included in the project described below, please scan and email or fax your response to Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0188 by **December 3, 2012.** 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 of the ACS**

Project Description: A custom version CINA Deluxe with a county variable (data item 90) is produced for the American Cancer Society and IMS to calculate incidence projections for the ACS's annual publication, *Cancer Facts and Figures (CFF),* ACS's publications, *Cancer Facts and Figures (CFF), Cancer Facts and Figures for African Americans, and Cancer Facts and Figures for Hispanics/Latinos*. The file is released under controlled IRB approved protocols to the appropriate staff of IMS to conduct the analysis and computations. The output/summary projects are released to ACS. Registries have previously agreed that the value of this project to the cancer surveillance community is sufficiently great to make this a standing use of the NAACCR data submissions. Since a county identifier is required for linkage to Census data to compute the projections, an active consent is requested.

In addition, ACS, NAACCR, and NCI would like to use the 2010 observed cases to check model predictions by comparing the estimated cases published in 2010 *CFF* with the observed cases in 2010. The new case projection method was used beginning with the 2012 CFF (the projection method used since 2007 was updated in 2012).

Yes	No	CINA Deluxe Variable Set
√		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.

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

Yes	No	1995-2010 CINA Deluxe Custom File with County Identifier
		If no, why not?

If you have any questions regarding this project or data uses, please contact Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0800.

Please fax to: 217.698.0188

Print Name:	Signature:
Title:	Date:

Active Consent Form for Secondary Data Uses
CINA Deluxe Projects

NAACCR requests permission from the:

_____

To be included in the project described below, please scan and email or fax your response to Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0188 by **December 3, 2012.** A response must be received by this date for your data to be included in the project.

Project Title:	**Medullary Thyroid Cancer Verification**
Principal Investigator:	Kelly D. Davis, M.D. Vice President, Safety, Epidemiology & Risk Management United BioSource Corporation
Project Description:	As required by the FDA, United BioSource (UBC) is conducting post-marketing surveillance on a medication 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, 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. The following variables would be included: Diagnosis Year, State of Residence, Gender, Race 1, Computed Ethnicity, Spanish / Hispanic Origin, Primary Site Code, Topography of Cancer, Morphology of Cancer Code, and Age at Diagnosis.

Yes	No	CINA Deluxe Variable Set
√		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.

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

Yes	No	1995-2010 CINA Deluxe Custom File with County Identifier
		If no, why not?

If you have any questions regarding this project or data uses, please contact Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0800.

Please fax to: 217.698.0188

Print Name:	Signature:
Title:	Date:

Passive Consent Form for Secondary Data Uses
CINA Deluxe Projects

NAACCR requests permission from the:

_____

If you do NOT consent to the use of your data in the project described below, please scan and email or fax your response to Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0188 by **December 3, 2012.** If a response is not received by this date, it will be assumed that consent is given and the data will be included in the project.

Project Title: **CINA Plus in SEER*Stat**

Project Description: NAACCR has received 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.

Your consent will apply to the 2013 Call for Data Submission. Registry members who want access to the data set 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. NAACCR will inform all registries when a member has been granted access to the file.

Yes	No	CINA Deluxe Variable Set
√		Project will use a standard subset of variables listed for CINA Deluxe in the Call for Data**.** This data set will only include the variables available on CINA+ Online, a subset of the CINA Deluxe data set: Age (19 age groups only), SEER site groups (see CINA+ online for complete list), race (W/B/O), ethnicity, sex, year of diagnosis (2006-2010) and registry (state or province only).
√		Registry-specific data will be available

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

Yes	No	If no, why not?

If you have any questions regarding this project or data uses, please contact Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0800.

Please fax to: 217.698.0188

Print Name:	Signature:
Title:	Date:

Passive Consent Form for Secondary Data Uses
CINA Deluxe Projects

NAACCR requests permission from the:

_____

If you do NOT consent to the use of your data in the project described below, please email or fax your response to Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0188 by **December 3, 2012.** If a response is not received by this date, it will be assumed that consent is given and the data will be included in the project.

Project Title:	**Delay Adjustment**
Principal Investigator:	**Huann-Sheng Chen, NCI**
Project Description:	NCI statisticians will use the NAACCR CINA files created since 1999, with incidence data from 1997 through the current year to conduct estimates for delay adjustments needed in trend data for the US and Canada.. These data will be used to adjust trend analyses. 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. Delay factors may be estimated based on groups of registries, or individual registries, but no registries will be identified in analyses.

Yes	No	CINA Deluxe Variable Set
√		Project will use the standard variables listed for CINA Deluxe in the Call for Data
√		Registry specific data will NOT be presented.

Please indicate 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 Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0800.

Please fax to: 217.698.0188

Print Name:	Signature:
Title:	Date:

Passive Consent Form for Secondary Data Uses
CINA Deluxe Projects

NAACCR requests permission from the:

_____

If you do NOT consent to the use of your data in the project described below, please email or fax your response to Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0188 by December 3, 2012. A response must be received by this date for your data to be included in the project.

Project Title: **Creation of CINA Deluxe File for use by NCI and ACS for routine inquiries.**

Project Description: NCI and ACS periodically receive requests from the media, legislators, policy makers, scientists, and the general public for cancer statistics in North America. For example a scientist asked ACS this year how many yolk sac cancers of the testes there were in the US. In order to respond to their constituent, ACS asked NAACCR to run the tabulations. In order to provide more timely and efficient responses to questions such as these, a confidential file will be created and stored at IMS. Following appropriate data security standards, access would be given to a single individual at NCI and up to two individuals at ACS (a primary and a back-up) who could run these types of tabulations using SEER*Stat with the following conditions:

f. Custody will be limited to the designated individual/s within the organization.
g. NAACCR will be notified of all uses of the data and this information would be passed on to NAACCR members.
h. Re-release of the file will be prohibited.
i. If state or province-specific data are released in response to a request, the state or province will be notified immediately.
j. Cell suppression rules for cells with fewer than 6 observations will be followed.

CDC accesses NPCR data for these types of requests, and ACoS would use NCDB data. Your consent will apply to the 2013 Call for Data Submission.

Yes	No	CINA Deluxe Variable Set
√		Project will use the standard variables listed for CINA Deluxe in the Call for Data
√		Registry-specific data will be available

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

Yes	No	If no, why not?

If you have any questions regarding this project or data uses, please contact Jim Hofferkamp at jhofferkamp@naaccr.org or 217.698.0800.

Please fax to: 217.698.0188

Print Name:	Signature:
Title:	Date: