NAACCR CINA Deluxe Application Instructions

Overview

The Cancer Incidence in North America (CINA) Deluxe dataset is intended to promote the use of cancer surveillance data in North America. Application may be made to use these data for descriptive epidemiology, comparative studies, program evaluation, and research. All requests for access to CINA Deluxe data are made through application to the NAACCR Research Proposal Review Subcommittee of the Data Use and Research Committee.

CINA Deluxe data are complex by nature and require working knowledge of cancer surveillance rules and practices. Also, requestors of the CINA Deluxe data must be familiar with SEER*Stat and cancer statistics. Therefore, **access to the dataset is currently restricted to NAACCR members** (or employees of a NAACCR member). Those interested in accessing the data but who are not currently members are strongly encouraged to become members, using the appropriate membership category. Individual members who wish to use the data but have limited knowledge of cancer surveillance should collaborate with an experienced NAACCR member or Registry.

All projects are reviewed by a peer-reviewed panel and awarded competitively. Proposals approved by the Research Proposal Review Subcommittee must also be reviewed by the NAACCR IRB. Following the IRB's approval, the proposal will be circulated to obtain active or passive consent from member registries whose data are eligible for inclusion in the study. Since registries retain ownership of all data, NAACCR must obtain consent for data to be included in the dataset created for each investigator's research project.

General Information

Detailed information regarding the content of the CINA Deluxe file, including the years of data available, data variables and coding schemes, data quality, edits, data access and other file nuances are detailed in the document *Instructions for CINA Deluxe Investigators* included as part of the application packet. It is critical that the Investigator thoroughly review this document before submitting an application. A point of contact for questions is listed in the document.

The CINA Deluxe dataset is available in two formats: 1) CINA Deluxe Standard or 2) CINA Deluxe Customized. These files are described in more detail in the *Instructions for CINA Deluxe Investigators*. Passive registry consent is required for release of the CINA Deluxe Standard file and active consent for the Customized file. Customized datasets that permit access to county level data can be accessed, but individually customized datasets that require additional NAACCR variables are not available at this time. Access to the CINA Deluxe data file for analysis will be available through password-controlled Internet access to a client-server environment for SEER*Stat.

Projects are to be completed within 12 months of approval, unless special permission from NAACCR is obtained. Projects must address one or more of three broad issues- data quality, confidentiality or data use. All projects must include a data quality component in addition to the specific cancer issue being addressed. A project report (or manuscript for publication) is required to be submitted to NAACCR upon project completion.

Applications are accepted quarterly. Limited funding is available semi-annually to non-federal applicants for special approved projects. For completed funded projects, in addition to the project report, detailed written feedback about the data quality of the file as it pertains to the approved use must be provided. Data quality abnormalities must be documented and/or the high quality of data items confirmed. A quality assessment between cancer registries is permitted, but the results will remain confidential unless the Registry authorizes the release of Registry-specific results.

At least thirty (30) days prior to submitting a formal application for access to CINA Deluxe, the Investigator must submit a letter of intent to access the data file. The letter should briefly describe the proposed study title, the expected date of submission, the Investigator's affiliation and if funding is being requested. The letter should be sent electronically or by mail to:

Betsy Kohler, MPH, CTR Executive Director NAACCR 2121 West White Oaks Drive Springfield, IL 62704

Phone: 217-698-0800 Fax: 217-698-0188

Email: bkohler@naaccr.org

The complete CINA Deluxe application packet can be found at: www.naaccr.org.

Guidelines for Application Submission

Submission Requirements and Deadlines

Electronic submission of all application materials is required. Pages must be clearly numbered. All materials must be double-spaced with at least 11 point Arial or Times Roman font and 1" margins. The length may not exceed 10 pages (excluding references and biographical sketches). **Only complete applications will be reviewed.** For each review cycle, applications must be received on or before the publicized deadline. Applications received after the cutoff date will not be reviewed until the next cycle. If the capacity to submit digital signatures or an electronic version of a signature is not available, the signature pages may be faxed.

Application Due Dates

Applications are due at **5 pm CST on August 15, November 15, February 15, and May 15**. Application dates for project funding opportunities will be posted when funds are made available.

Components of a Complete Application

A complete application must include the following:

Cover Letter- signed by the Principal Investigator

NAACCR CINA Deluxe File- Researcher Request for Access Form- completed and signed by required parties

Study Proposal- to include a data quality assessment and total proposal not to exceed 10 pages

Biographical Sketches- for all investigators

Data Confidentiality Agreement for NAACCR Researchers with Access to CINA DELUXE- unmodified and signed and dated by each person with access to the data

Study Proposal Content

In addition to the Cover Letter, Request for Access Form, and Data Confidentiality Agreement, the application should include a brief narrative of the proposed project. Specifically, the study proposal must include:

Study title that is informative.

Background that includes a brief problem statement, an abbreviated literature review, and a discussion of the importance of the project.

Study question/Objectives that will be addressed and are based on the literature review or other knowledge of the subject. The specific hypotheses to be tested in this project should be stated.

Methods that describe the variables that will be used and the level of measurement precision needed for each, the analytic methods and approach, including statistical tests that will be performed and software to be used. Provide sufficient detail for reviewers to assess the approach.

Registry-specific data (if any) that will be analyzed or published/presented in any reports from the project. If registry-specific data will be included in the report, NAACCR must take additional steps to obtain permission from the registries for their data to be included in the project.

Custom or non-standard data item(s) (if any) that is requested or required for the analysis, how it will be analyzed, and whether it will be a critical variable in any reports developed from the project (e.g., county identifier).

Quality assessment plan that describes the proposed assessment of the data quality of the file as it pertains to the research question involved. This assessment should go beyond the known data quality of the file as evaluated by registry certification. Implications on the analysis, results, and study feasibility must be described. The Investigator should briefly describe the quality assurance report that he/she will issue at the end of the study (or if not a separate report, indicate the type of results that will be incorporated into the study report or manuscript). To assist in describing the report, investigators may wish to review the annual summaries of data quality assessments from previous CINA Deluxe users available on the NAACCR website at URL http://www.naaccr.org/index.asp?Col_SectionKey=11&Col_ContentID=52#DataQ.

Names and titles of all personnel who are involved in the study. Describe their role in the project. Include **Biographical Sketches** for the Principal Investigator (PI) and any key personnel responsible for development and implementation of proposed project (maximum of two pages for each person).

Timeframe for project completion that includes major milestones (e.g., analysis, report writing, report submission) of the project and their anticipated start and completion dates.

References that lists only the most salient background articles.

Proposal Review Process

Only **complete** applications will be reviewed. All incomplete applications will be returned to the Investigator and information on what is incomplete will be noted.

All proposals undergo review using established criteria. The proposal review and approval process has five general steps from proposal submission to data access. These include:

- 1) Review Panel determines if proposal meets minimal criteria for scientific merit for a NAACCR research project.
- 2) Applications meeting scientific merit criteria are scored and proposals with an average score of 700 or higher are considered for further review.
- 3) If questions remain after review, investigators of proposals scoring 700 or higher must submit complete and acceptable responses to the reviewers' critique within 60 days before the proposal is considered for NAACCR IRB submission.

- 4) Investigator submits application to the NAACCR IRB and proposals approved by the IRB are considered NAACCR approved projects.
- 5) NAACCR staff request consent from member registries whose data are included in the proposed project and a CINA Deluxe dataset of consenting registries is made accessible to the Investigator.

Proposal Review Criteria and Scoring

Applications will be scored as follows: (total 100 points)

- 1. **Project Objectives (20 points)**
- 2. **Project Methodology (30 points)**
- 3. Quality Assessment Plan (15 points)
- 4. Qualifications of Project Personnel (15 points)
- 5. Adequacy of Resources (10 points)
- 6. **Timeframe (10 points)**

If funding is requested, the budget will be reviewed for appropriate justification but will not be scored.

Investigator Report Requirements

- 1. A written report of the project's findings (positive or negative) must be completed and forwarded to NAACCR within 12 months of the award notification. A brief description of the data quality findings should be included. The report should not exceed 6,000 words. In lieu of a report, a manuscript may be submitted.
- 2. For funded projects, a separate written report of the findings of the quality assessment of the CINA Deluxe data file must be completed and forwarded to NAACCR within 12 months of the award notification. This report is in addition to the final project report. The report should not exceed 6,000 words.

Note: Any and all presentations, abstracts, and publications resulting from this effort must be submitted to the NAACCR Scientific Editorial Board for review and approval before being submitted for presentation or publication. This review process will be completed within six weeks of submission.

Application Checklist

(Cover Letter
F	Request for Access Form completed and signed by required parties
S	tudy Proposal Narrative that does not exceed 10 pages.
L	Data Quality Section in Narrative that addresses issues beyond registry certification data items
В	Siographical Sketches for all investigators
L	Data Confidentiality Agreement for NAACCR Researchers form signed and dated by every
p	erson with access to the data
В	Budget (if funding is requested)