

NAACCR IRB

The NAACCR IRB was established in August 2002. It is fully compliant with all federal regulations regarding the protection of human subjects. The NAACCR IRB number is IRB00002589 and the NAACCR Federal Wide Assurance number (FWA) is FWA00003090. The NAACCR IRB has developed extensive and detailed guidelines directing its operations and the process for reviewing research proposals.

The guidelines, application forms, and current membership of the NAACCR IRB can be found on the NAACCR website at <http://www.naacr.org/irb>.

Security & Confidentiality

All data files are accessed by researchers through a secure internet client-server environment. *CINA Deluxe* files are tailored for each research project and include data only from registries that have given consent to have their data included in the study.

Promoting Cancer Research

The NAACCR Research Program web page serves as a clearinghouse of information for researchers. It includes information on how to access individual member registries' data, and also includes contact information, a description of their infrastructure, and capacity for data availability for various types of research protocols and topics (e.g., rapid case ascertainment studies, record linkage studies or studies involving patient contact). The information about member registries will be updated annually in December. In addition, the page includes information on how to access the NAACCR CINA Deluxe file.

Epidemiologic Reports

For a complete list of all NAACCR research and surveillance reports, and publications, refer to the following NAACCR publications available on the NAACCR website.

NAACCR Research Publications List: Multi-Registry Cancer Incidence and Mortality Data in the United States and Canada

NAACCR Annotated Bibliography of Research and Publications: Multi-Registry Cancer Incidence and Mortality Data in the United States and Canada

NORTH AMERICAN ASSOCIATION
OF CENTRAL CANCER REGISTRIES, INC.

NAACCR

Cancer Research

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Introduction

NAACCR has an annual call for data from its registry members. These data are evaluated for quality in producing accurate incidence rates, and they are compiled into analytic files to produce:

- An annual statistical monograph of cancer incidence in the United States and Canada (CINA), including an electronic version available as a SAS data set;
- An online query system of cancer incidence data for the previous 5 years from member registries meeting NAACCR standards of high quality (CINA+ Online);
- A data file for NAACCR researchers to conduct cancer surveillance research (CINA Deluxe);
- Annual Report to the Nation - NAACCR data are used in the annual updates of fixed interval trends and current incidence estimates and the annual feature.

CINA

Cancer Incidence in North America (CINA) is released annually in April. Case counts and rates are produced for individual NAACCR member registries. Data from registries meeting NAACCR high-quality standards are aggregated to produce NAACCR Combined Incidence rates for the United States and Canada. The monograph is released in four volumes: incidence, mortality, combined (including pediatric) rates, and incidence in U.S. Hispanic/Latino populations.

CINA+ Online

CINA+ Online provides incidence counts and rates for high-quality NAACCR member registries in flexible formats defined by queries of the user. Results can be requested in tables, graphs, or maps. The system is available at <http://www.naacr.org/cinap>.

CINA Deluxe

CINA Deluxe is an aggregated research data file of incidence data from NAACCR member registries. Research proposals from NAACCR members are reviewed on a quarterly basis. Data are available from 1995 forward, but a registry may be included with at least three consecutive years of data that meet NAACCR standards.

Research Tools

To assist with data analysis, the following are examples of programs available on the NAACCR website:

NAACCR Method to Enhance Hispanic/Latino Identification version 2

This algorithm uses information on ethnicity from the medical record, information reported to the cancer registry, and an evaluation of the strength of the birthplace race and surname (including maiden name, when available) associated with Hispanic ethnicity status.

Poverty and Census Tract Linkage Program

This program is used with a NAACCR standard data exchange file format with confidential information, including a census tract identifier. The program will link the census tract identifier with the percent of the residents in the census tract that live below the poverty level. This information is based on the 2000 US Census.

NAACCR Asian/Pacific Islander Identification Algorithm

This algorithm uses information on Asian race Not Otherwise Specified (NOS) as reported to the cancer registry based on information from the medical record, and using gender, birthplace, first name, and surname (including maiden name, when available), assigns an Asian NOS race status to a more specific Asian race group.

NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm

This algorithm combines NHIA v2 and NAPIIA in to a single SAS program.

Record Uniqueness

The Record Uniqueness Program was developed by Howe, Lake, and Shen to assess electronic data files for risk of confidentiality breach based on unique combinations of key variables.