

**NORTH AMERICAN ASSOCIATION OF
CENTRAL CANCER REGISTRIES
(NAACCR)
MISSION AND OBJECTIVES RELATED TO GOALS
2006 – 2010
*As of June 14, 2005***

MISSION

The North American Association of Central Cancer Registries (NAACCR) is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America.

OBJECTIVES

GOAL 1: Provide consensus standards for coding, editing, and data exchange and promote best practices for the collection and use of cancer and patient information.

- 1-1 Evaluate changes to all existing standards as recommended by standard setters, using the committee process to determine the appropriateness of modification of NAACCR standards.
- 1-2 Based on changes to the standards, the Edits Subcommittee of the Uniform Data Standards Committee will review, modify, and release NAACCR Version 10 Edits metafiles and future versions as needed, using established dissemination protocol.
- 1-3 The Uniform Data Standards committee will maintain a log (or list) of all proposed standard revisions or additions and monitor on a monthly basis the status of all recommended data changes.
- 1-4 Disseminate data standard changes through the NAACCR Website and NAACCR Listserv, using established dissemination protocol, with posting by June of each year.
- 1-5 The Registry Operations Committee will promote best practices for the collection and use of cancer and patient information, specifically death clearance practices; tumor linkage and data consolidation in record consolidation processes in 2005-2006.

GOAL 2: Coordinate the implementation of standards to promote continuity in data collection and exchange, and analysis.

- 2-1 By February of each year, the UDS Committee will complete review and revision of Volumes I and II of the NAACCR standards documents.
- 2-2 By March of each year, the Board of Directors will review and approve the revised Volume II of the standards documents.
- 2-3 By June of each year, NAACCR membership will be provided copies of the revised standard documents.

GOAL 3: Provide educational resources related to registry operations and data utilization.

- 3-1 Preceding the annual meeting, measures of data quality indicators collected from the *CINA* Call for Data (from DQI sub-committee chair), Registry Certification (from committee chair), and standards revisions and additions (UDS committee chair) will be summarized and submitted to the Education Committee to define and develop training needs for the next year. The format for these reports will include at a minimum, a summary interpreting the most important needs or issues for training.

- 3-2 The Education Committee will review using their established protocol all education/training materials for use by NAACCR.
- 3-3 A summit will be planned regarding employee retention and compensation.
- 3-4 Hold an annual 3-5 day Institute on cancer registry operations.
- 3-5 Conduct a Toolkit Workshop in the fall 2005.
- 3-6 In January 2006, plan and hold a 4th Cancer Surveillance Institute I: Principles and Public Health Applications (CSI I).
- 3-7 By October 2006, plan and hold a second Cancer Surveillance Institute II: Statistics and Methods (CSI II).
- 3-8 NAACCR will hold an advanced course in conjunction with the annual meeting.

GOAL 4: Provide technical assistance to NAACCR member organizations.

- 4-1 Provide technical assistance opportunities for all NAACCR members regardless of their source of federal support.

GOAL 5: Facilitate the exchange of technical information among NAACCR members.

- 5-1 By January 2006, have 75% of the members on at least one NAACCR committee.
- 5-2 Beginning in FY 2003, the chair meetings will be convened by the President and will include quarterly teleconferences and two in-person meetings to increase awareness, cooperation, and collaboration on all projects.
- 5-3 Committee Chairs, the President, and the Executive Director will inform the membership on key issues and solicit their comments through the newsletter (each quarter) and listserv (as appropriate).

GOAL 6: Improve, monitor, and report the completeness and quality of data collected throughout North America.

- 6-1 By January 2006, increase to 100% the proportion of registries that complete the NAACCR protocol to evaluate duplicates on submission for the *Call for Data*.
- 6-2 By January 2006, increase to 100% the proportion of registries that achieve the NAACCR standard duplicate rate of 1 duplicate per 1,000 records (0.1%) (two years to improve)
- 6-3 By January 2006, increase to 100% the proportion of registries that achieve no inter-record EDITS errors on their file submission.
- 6-4 By January 2008, increase to 100% the proportion of registries that perform death clearance on the last five years of data.
- 6-5 By January 2009, increase to 100% the proportion of registries that perform death clearance and achieve less than 5% DCO cases.
- 6-6 By January 2010, increase to 100% the proportion of registries that perform death clearance and achieve less than 3% DCO cases.

6-7 By December 2007, all registries will submit their data for the annual CINA call for data.

GOAL 7: Maximize the dissemination, interpretation, and use of data.

7-1 By May 2006, create and release a research data set of individual records from registries that participate in the *Call for Data*.

7-2 By January 2006, increase the number of US registries participating in the *Call for Data* by 2 registries (from 65 in 2005 to 67).

7-3 Finalize all projects using CIUSHL, 1995-2000 regarding cancer among US Latinos and submit them for publication by May 2006.

7-4 Annually a report will be prepared listing all research publications prepared under the auspices of NAACCR and using the aggregated data sets from member submissions.

7-5 Release two RFAs annually for CINA Deluxe NAACCR-member researcher-initiated projects.

GOAL 8: Develop and maintain collaborative relationships with other national organizations or groups to enhance collection and use of cancer registry data.

8-1 On an ongoing basis, NAACCR will continue to send representatives and to take an active role in the National Coordinating Council for Cancer Surveillance.

8-2 On an annual basis, the President and Executive Director will attend the annual in-person meeting of the Canadian Council of Cancer Registries.

8-3 The Sponsoring Member Organizations will meet in person twice annually with the NAACCR board.

8-4 All members of the Board and all Committee Chairs will attend the NAACCR Leadership Retreat to be held biannually at a time designated by the President. Representatives of sponsoring member organizations will be invited to attend.

8-5 The approved board minutes will be posted on the Web site.

8-6 NAACCR shall organize and run workshops or retreats to foster leadership, team building, and work products to address the goals and objectives of the cancer surveillance community.

GOAL 9: Provide advocacy for registries and for the utilization of registry expertise.

9-1 To bring NAACCR registration expertise to the attention of others, NAACCR will continue to contact, as appropriate, other organizations that are registering health events to explore sharing our expertise or expanding our surveillance roles. NAACCR will exhibit at appropriate cancer conferences or public health meetings.

9-2 The NAACCR board, staff, and members will contact other health organizations to market the existence of and the roles of NAACCR. The NAACCR Board and Committee Chairs will explore liaisons to other groups.

9-3 The NAACCR board and members will look for opportunities to write articles about cancer registration and NAACCR for professional journals, lay publications, and the news media.

9-4 Washington Update will be developed and distributed for NAACCR members.

Goal 10: Maintain financial and economic stability for NAACCR.

- 10-1 Annually, NAACCR will maintain current grants and contracts by submitting continuation applications and renewing existing agreements, whenever possible.
- 10-2 By January of each year, evaluate the existing investment plan for its returns on assets in comparison to economic indicators.
- 10-3 In fiscal year 2006, make 3% on investment portfolio.

GOAL 11. Provide objective criteria for NAACCR certification of cancer registries and collaborate with registries to achieve excellence in cancer surveillance.

- 11-1 By December 2007, 79 of 79 registries will submit data for certification.
Status: In December of 2004, 70 of 79 (89%) registries submitted data for certification.
- 11-2 By December 2007, all 12 Canadian registries will be certified
Status: In February of 2005, 8 of the 13 (62%) Canadian registries were certified. Quebec did not submit 2002 data.
- 11-3 Certification committee will work with registries to support training to help them move toward certification at the highest standard.
- 11-4 The Registry Certification committee will develop a self-assessment tool for registries to use in evaluation of registry operations efficiency, application of best practice processes that could be used in a data quality profile of the registry.

INFRASTRUCTURE GOAL: Plan, develop, establish, and maintain all components for an infrastructure for NAACCR, including staffing, physical resources, and other aspects related to conducting business in the United States and Illinois.

- G-1.** The Executive Director will manage the NAACCR Executive office.
- G-2.** The Executive Director will manage and oversee all operations, including a structure, set of policies and procedures of all required and necessary fiscal operations, of the Executive office.
- G-3.** The Executive Director will recruit and supervise staff for the executive office.
- G-4.** The Executive Director will perform all duties and responsibilities of the principal investigator of grants and contracts, when appropriate.
- G-5.** Staff will provide support and services to the Board of Directors and to NAACCR committees and selected subcommittees.
- G-6.** NAACCR will maintain the operation of an electronic office to the extent feasible.
- G-7.** NAACCR will maintain an Institutional Review Board for review of all NAACCR research.
- G-8.** NAACCR will develop a training program with various offerings that will be supported through partial sponsorships and registration fees.
- G-9.** NAACCR will develop a Research Program to facilitate knowledge of research opportunities, processes, and registry information between researchers and central cancer registries