

**NORTH AMERICAN ASSOCIATION OF  
CENTRAL CANCER REGISTRIES  
(NAACCR)**

**MISSION AND OBJECTIVES RELATED TO GOALS  
2001 – 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 Web site and NAACCR List Serv, using established dissemination protocol, with posting by June of each year.

**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 Contract Objective Ed-1: Hold two 3-5 day Institutes on basic registry operations, one in the Central US and one in the Western US.
- 3-5 Contract Objective Ed-2: Develop two CD-ROM educational tools on specific basic registry operations. The CD ROMS would become a "Fundamentals of Registry Operations" Training Series.
- 3-6 Contract Objective Ed-3: Develop a training module for benign brain tumor data collection by July 31, 2003.
- 3-7 Contract Objective CS-2: Conduct a the Toolkit Workshop in the fall 2003.

**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.
- 4-2 Contract Objective CS-18: Develop a best practices operations approach to record consolidation. The committee will also act as an advisory group to support and consult with NCI-SEER on revision of multiple primary data collection rules as documented in the report of the NAACCR Multiple Primary Review that would require approval and review by the SEER Program and analysis of implementation issues related to the record consolidation tool.
- 4-3 Contract Objective CS-17: Evaluate of comparability of methods for consolidation of records from different sources on the same cancer, including supporting implementation of a record consolidation test project.

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

- 5-1 By January 2004, 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 2004, increase to 100% the proportion of registries that complete the NAACCR protocol

to evaluate duplicates on submission for the *Call for Data*.  
**Status:** Not met: 60/64; 93.8% (Maryland, South Dakota, Nunavut, Quebec)

6-2 By January 2004, increase to 100% the proportion of registries that achieve the NAACCR standard duplicate rate of 1 duplicate per 1,000 records (0.1%)

**Status:** 56/64; 87.5% (Arkansas, Delaware, Maine, Ohio, South Dakota, Maryland, Nunavut, Quebec)

6-3 By January 2004, increase to 100% the proportion of registries that execute the EDITS program and submit a file that is 97% error free.

**Status:** Goal met: 100% ran edits on their file.

6-4 By January 2004, increase the proportion of registries to 100% that perform death clearance

**Status:** 51/64; 79.7%

6-5 By January 2003, 100% of the registries performing death clearance will achieve less than 5% DCO cases.

**Status:** 50/64; 78.1%

6-6 By January 2008, 100% of registries performing death clearance will achieve less than 3% DCO cases

**Status:** 50/64; 78.1%

6-7 By December 2004, all registries will submit their data for the annual CINA call for data.

**Status:** 64 Registries submitted for the 2004 Call for Data: Kansas, Mississippi, Vermont, Puerto Rico, Pennsylvania, and Tennessee did not submit.

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

7-1 By June 2004, create and release a research data set of individual records from registries that participate in the *Call for Data*.

7-2 By January 2003[4], increase the number of US registries participating in the *Call for Data* by 6 percent (from 50 in 2002 to 53).

7-3 Initiate a Call for Data for a Hispanic Statistical Monograph in May 2003, with release of the report by the end of 2003.

7-4 Assess the completeness and utility of Beale codes on NAACCR call for data submissions by March 2003. Evaluate cancer incidence by these codes and produce a report by January 2004.

7-5 Finalize all projects in the Breast Cancer Research Group and submit them to Cancer Causes and Control for review for publication by July 2003.

7-6 Cooperative Agreement Objective SS-2: Continue the activities of the Summary Stage Comparability Project to evaluate the impact of code changes from 1977 and 2000.

7-7 Contract Objective CS-4: Initiate an assessment of registry procedures for numerator and denominator identification of Asian Pacific Islanders.

**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 The Sponsoring Member Organizations will meet in person twice annually with the NAACCR board.
- 8-3 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.
- 8-4 The approved board minutes will be posted on the Web site.

**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.
- 9-2 The NAACCR board, staff, and members will contact other health organizations to market the existence of and the roles of NAACCR.
- 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 **[outdated]** By January 2001, educate policy makers about the need for funding support for full members that meet performance criteria and educate when necessary and appropriate on legislative actions, and NAACCR will send representatives to important legislative hearings or briefings that include matters related to cancer registration or use of registry data
- 9-5 The Executive Director and Board of Directors will prepare an article on NAACCR for peer-reviewed publication with an international audience.
- 9-6 The President-elect, who is also an IARC Board member, will present information about NAACCR to the IARC Board, using recently developed manuscripts and other materials about NAACCR and its activities.

**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 Initiate dialogue at provincial level/ through organizations of Canadian cancer centers to develop comparable fiscal strategies for Canada that have worked in the US at the national level.
- 10-3 By January of each year, evaluate the existing investment plan for its returns on assets in comparison to economic indicators.
- 10-4 In fiscal year 2004, make 1% on investment portfolio.
- 10-5 In fiscal year 2004, if necessary, use up to \$200,000 to bridge potential lapses in the CDC cooperative agreement funding..

**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 2003, 79 of 79 registries will submit data for certification.

**Status:** 70 of 79 registries submitted data for the Call for Data 2004, certification

11-2 By December 2003[4], all 12 Canadian registries will be certified

**Status:** 12 of 13 submitted; of these, 7 were certified.

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.

11-5 By June 2004, initiate a second Cancer Surveillance Institute to provide training in statistics and methods for cancer surveillance.

11-6 Engage a consultant to evaluate the NAACCR method for estimating completeness

**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 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, when appropriate.

**G-5.** Staff will provide support and services to the Board of Directors and to NAACCR

**G-6.** Continue to develop structure, policies and procedures for NAACCR as a fiscal agent and as a business entity in the state of Illinois.

**G-7.** NAACCR will maintain the operation of an electronic office to the extent feasible.