

NAACCR ACCOMPLISHMENTS RELATED TO MISSION, GOALS, AND OBJECTIVES

BETWEEN MAY 2004 - JUNE 2005:

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

The following four items had codes and code definitions modified for use with cases diagnosed January 1, 2006 and later:

Primary Payer (Item #630)
Type of reporting source (Item #500)
Census Tr Cert 1970/80/90 (Item #364)
Census TR Certainty 2000 (Item #365)

A number of new items were added :

Five data items introduced to support the rules revisions for coding histology and multiple primaries proposed by SEER:

Ambiguous Terminology as Basis for Diagnosis (Item #442)
Date of Conclusive Diagnosis (Item #443)
Multiplicity Counter (Item #446),
Multiple Tumors Reported as Single Primary (Item #444)
Date of Multiple Tumors (Item #445)

Three data items were introduced by the CoC to supplement information currently documented in its FORDS manual:

Systemic/Surgery Sequence (Item #1639)
Comorbidities and Complications #7-#10 (Item #3161 – 3164)
Comorbidities and Complications Coding System (Item #3165)

Five data items were introduced from a variety of sources:

Number of Tumors/Histologies (Item #447) - This data item was developed by the Record Consolidation workgroup using the current multiple primary rules. This new item is complimentary to the newly approved multiple primary data items requested by SEER, with the benefit of being able to identify single tumors with multiple histologies.

Indian Health Service Linkage (Item #192) - NPCR requires this item in their Call for Data and sought formal placement of the item in the NAACCR transmission record.

Patient System ID Hosp (Item #21) – Provides a unique, non-repeating number automatically assigned to patients by the hospital tumor registry software system. It is anticipated that this item will be used by software vendors to link back to all reported tumors for a patient.

Follow-up source – central (Item #1791) - Indicates the source from which consolidated information was obtained on a patient's vital status and date of last contact.

GIS coordinate quality (Item #366) – Allows registries to indicate the bases of the assignment of the longitude and latitude information reported in the record.

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

Proposed a new data item called GIS Coordinate Quality that was approved by the UDS Committee in September 2004. This data item describes the basis of the assignment of latitude and longitude for a case.

Added a new code for the two Census Tract Certainty data items for the special situation where the city or ZIP code has only one census tract.

Standards Volume III was updated and released to the membership in January 2005.

Two NAACCR metafiles were released, 10D in the fall and the 10E metafile in the spring to coincide with the updates and release of v 01.01.02 of the Collaborative Staging System algorithm.

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

Moved three educational on-line GIS presentations from the old NAACCR GIS Workgroup web page, hosted by the North Carolina Cancer Registry, to the GIS Committee web page on the NAACCR web site.

Assembled a 20-page document listing GIS-related educational web sites and their descriptions, which will be posted on the committee's web page.

Finalized a GIS survey to assess the GIS capabilities, geocoding practices, and training needs of the NAACCR membership registries.

Held three 4.5 day Institutes on basic registry operations as part of the CDC contract.

Developed two CD-ROM educational tools Race and Ethnicity and Descriptive Epidemiology as part of the CDC contract.

Conducted the Toolkit Workshop in the fall 2004 supported in part by the NCI contract and the CDC cooperative agreement.

Committee Leadership training was provided to all committee chairs and board members at the biennial Leadership Retreat in November 2004.

Held a third Cancer Surveillance Institute I: Principles and Public Health Applications (CSI I) in January 2005 as part of the CDC contract.

NAACCR will hold an advanced course in conjunction with the 2005 annual meeting on Leadership Training.

4. Provide technical assistance to NAACCR member organizations.

Developed a SAS routine that calculates distances between the latitude/longitude coordinates of a patient's residence address and the coordinates of a treatment facility and posted it on the NAACCR website.

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

Published a report (available on the NAACCR website) on several free software packages that can be used for the spatial analysis of cancer clusters.

The chair meetings were convened by the President and included quarterly teleconferences and two in-person meetings to increase awareness, cooperation, and collaboration on all projects.

A web alert system was created so that members could subscribe and receive email alerts when new content on web pages is added.

CINA+ Online was updated to reflect the look and feel of the rest of the web site.

An electronic voting/survey software is now available to facilitate NAACCR elections and electronic surveys.

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

7. Maximize the dissemination, interpretation, and use of registry data.

The research program publication listing and annotated bibliography booklets were updated listing all research publications prepared under the auspices of NAACCR and using the aggregated data sets from member submissions.

NAACCR IRB received and reviewed 14 applications in the last year.

Two RFAs for CINA Deluxe were released for support of NAACCR-member researcher-initiated projects. Seven awards were made.

CINA+ Online was enhanced to enable inclusion of cancer incidence information for Latino populations.

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

NAACCR continued to send representatives and to take an active role in the National Coordinating Council for Cancer Surveillance.

The Sponsoring Member Organizations met in person twice annually with the NAACCR board. In addition, the board held two teleconference calls with the SMOs.

The Implementation Oversight Board met monthly during the last year.

The approved board minutes were posted on the Web site.

All members of the Board and all Committee Chairs attended the NAACCR Leadership Retreat held in November 2004. Representatives of sponsoring member organizations were invited to attend.

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

A total of 22 articles were published in 2003-2004 by NAACCR members using NAACCR data resources and 2 are in press.

Two collaborative manuscripts were published in 2003 and 2 in 2004.

Four reports were printed in either CINA or posted to the NAACCR website.

One 4-volume statistical monograph was published.

A Washington Update was developed for and distributed to NAACCR members.

The NAACCR exhibit was displayed at the IARC Conference in Honolulu (June), the ICC Conference in

Washington D.C (March), the NCRA Conference in Portland, Oregon (April), and arrangements have been to have it displayed at the SER Conference in Salt Lake City, Utah in June.

10. Maintain financial and economic stability for NAACCR

Received a new contract from NCI for technical assistance in cancer surveillance activities.

NAACCR maintained current grants and contracts by submitting continuation applications and renewing existing agreements, whenever possible.

In fiscal year 2005, make 1% on investment portfolio. **EXCEEDED.** *The 2005 Morgan Stanley Jumbo CD rate is 3.00%; the 2006 Morgan Stanley Jumbo CD rate is 3.51%; the Washington Mutual fund rate of return for FY05 is 6.67%; all exceeding the goal of 2%. The bank money market, which contains only sufficient dollars to pay operational expenses in conjunction with the checking account, pays an interest rate of 1.7%. Overall, we made 3.42% on all investments.*

The Board developed a five-year plan to enhance the financial diversity and independence of the organization.

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

BETWEEN MAY 2003 - JUNE 2004:

1. **Provide consensus standards for coding, editing, and data exchange and promote best practices for the collection and use of cancer and patient information**
2. **Coordinate the implementation of standards to promote continuity in data collection and exchange, and analysis.**
 - Revised and updated NAACCR vol II, v10.2 (including recommended standard usage of abbreviations in the text fields).
 - Produced two v10 EDITS metafiles (10B and 10C).
 - Participated in the preparation of Implementation Guidelines for 2004 Data Standards, specifically Collaborative Stage and reporting rules for non-malignant brain/CNS tumors.
 - Surveyed the NAACCR membership and subsequently made recommendations for the future utilization of "orphaned" items in the NAACCR record layout.
 - Surveyed the NAACCR membership and evaluated current patterns of utilization of the data item "reporting source."
 - Adopted recommendations from the UDSC "subsequent therapy" work group to retain previously "orphaned" subsequent therapy items for use by hospital registries.
 - Started work on the next set of "major" changes to NAACCR data standards, for implementation 01/01/06.
3. **Provide educational resources related to registry operations and data utilization.**
 - Developed a training module for benign brain tumor data collection by July 31, 2003. **MET**
 - Conducted a Toolkit Workshop in the fall 2003 **MET**
 - Developed two CD-ROM educational tools on registry operations (Audits: Casefinding and Reabstracting and Followup). The CD ROMS are part of the "Central Cancer Registry Operations" Training Series. Released 4 additional CDs in the series: case ascertainment; EDITS, visual editing, and principles of abstracting. **MET**
 - Held two 3-5 day Institutes on cancer registry operations, one in the Central US and one in the Western US. **MET**
 - In January 2004, held a second Cancer Surveillance Institute I: Principles and Public Health Applications (CSI I). **MET**
 - In Spring 2004, held a first Cancer Surveillance Institute II: Statistics and Methods (CSI II). **MET**
 - NAACCR held an advanced course in conjunction with the 2004 annual meeting. **MET**
4. **Provide technical assistance to NAACCR member organizations.**

Three Mentor Fellowships were awarded. **MET**

Two best practices work groups were held, each coordinated by professional staff with a facilitator. **MET**

Initiated and released the Process Improvement Program (PIP) for conference support for a state-based or local workshop. Three awards were made. **NEW!**

The report, "Creation of a Record Consolidation Test File" was completed and distributed to the membership.

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

Chair meetings were convened by the President and will include quarterly teleconferences and two in-person meetings to increase awareness, cooperation, and collaboration on all projects. **MET**

Implemented electronic balloting through NAACCR web site **MET**

Using GIS in the collection, Analysis and Presentation of Cancer Registry Data: A Handbook of Basic Practices was completed and released by the GIS Taskforce. **MET**

NAACCR website was re-designed, now meeting ADA requirements, in addition to enhancing navigation and content to better meet needs of education and networking. **MET**

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

Maintained at 100% the proportion of registries that execute the EDITS program on their annual NAACCR file submission. **MET**

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

Initiated a Call for Data for a Hispanic Statistical Monograph in May 2003, with release of the report by the end of 2003. **MET**

Assessed the completeness and utility of Beale codes on NAACCR call for data submissions by March 2003. Evaluated cancer incidence by these codes and produce a report by January 2004. **MET.**

Finalized all projects in the Breast Cancer Research Group and submit them to Cancer Causes and Control for review for publication by July 2003. **MET**

Continued the activities of the Summary Stage Comparability Project to evaluate the impact of code changes from 1977 and 2000. **MET**

Initiated an assessment of registry procedures for numerator and denominator identification of Asian Pacific Islanders. **MET**

A report was prepared listing all research publications prepared under the auspices of NAACCR and using the aggregated data sets from member submissions. **MET**

NAACCR IRB received and reviewed 16 applications.

In May 2004, NAACCR released a software program, Record Uniqueness, which evaluates data files for the extent of unique records and supplies information to guide decisions to reduce uniqueness, when needed.

Publications:

Weir HK, Thun MJ, Hankey BF, Ries LAG, **Howe HL**, Wingo PA, Jemal A, Ward E, Anderson RN, Edwards BK. Annual report to the nation on the status of cancer, 1975-2000, featuring the uses of surveillance data for cancer prevention and control. *J Natl Ca Inst*, 2003; 95 (17):1276-99.

Wu X-C, Chen VW, Steele B, Roffers S, Klotz JB, Correa CN, Carozza SE. **Cancer Incidence in Adolescents and Young Adults in the United States, 1992–1997.** *J Adol Health* 2003;32:4-5-15.

Howe HL. **The North American Association of Central Cancer Registries.** In Fritz A and Roffers SD (eds). *Cancer Registry Management*. Lenexa (KS): National Cancer Registrars Association. 2004.

Hall I, Jamison P, Fulton JP, Clutter G, Roffers S, Parrish P. **Reporting cutaneous melanoma to cancer registries in the United States.** *J Am Acad Dermatology* 2003;49(4):624-30H.

Howe HL, Edwards BK, Young JL, Shen T, West DW, Hutton M, Correa CN. **A vision for cancer surveillance in the United States.** *Cancer Causes and Control*. 2003;14:63-72.

Hotes JL, Ellison LF, Howe HL, Friesen I, Kohler B. A Comparison of Breast Cancer Case Attributes by Multiple Primary Rules. *Ca Causes and Control*. 2004; 15:185-91.

Howe HL, Weinstein R, Schult T, Kohler B, Hotes J. Registering multiple primary tumors in central cancer registries. *J Reg Management* 2003; 30(4): 113-6.

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

NAACCR continued to send representatives and to take an active role in the National Coordinating Council for Cancer Surveillance. **MET**

The Sponsoring Member Organizations met in person twice annually with the NAACCR board. In addition, the board held two teleconference calls with the SMOs and initiated an Implementation Oversight Board that met quarterly during the last year. **MET**

The approved board minutes were posted on the Web site. **MET**

NAACCR Education Committee developed central registry questions for the CTR exam of NCRA.

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

A Washington Update was developed for and distributed to NAACCR members. **MET**

The NAACCR exhibit was displayed at the IARC Conference in Honolulu (June), the ICC Conference in Washington D.C (March), the NCRA Conference in Portland, Oregon (April), and arrangements have been to have it displayed at the SER Conference in Salt Lake City, Utah in June.

Awareness of NAACCR has been raised among the Latino community, Intercultural Cancer Council, C-Change through its release of Cancer Incidence in US Hispanics/Latinos, 1995-2000 with requests for participation in meetings of these groups. Also NAACCR was broadly represented in the Cancer Surveillance Summit sponsored by the Access Team of C-Change.

10. **Maintain financial and economic stability for NAACCR**

NAACCR maintained current grants and contracts by submitting continuation applications and renewing existing agreements, whenever possible. **MET.**

Initiated 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. **MET.**

By January, evaluated the existing investment plan for its returns on assets in comparison to economic indicators. **MET**

In fiscal year 2004, make 1% on investment portfolio. **EXCEEDED.** *One CD included step increases from 4.35% to 5.35% before maturing April 2004. Currently, the National City money market rate is 1.34%. Due to a less than 1% rate on the Morgan Stanley money market, in November 2003 those funds were transferred to a 2-yr CD earning 2.74% and a 3-yr CD earning 3.35%.*

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

BETWEEN MAY 2002 - JUNE 2003:

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.

By March 2003, evaluate the multiple primary rules and how they apply with regard to their appropriateness for public health purposes. **MET.** A review was held in December 2002 and report with recommendations was in press in May 2003.

By January 2003, under the leadership of the Registry Operations Committee, a systematic evaluation of the current process for standards implementation will be undertaken. **MET.** An implementations guidelines document, with time lines was released in January 2003.

Release a handbook on GIS standards and recommendations for cancer registries by February 2003. Obtain acceptance of report recommendations by NAACCR Board by December 2002. Prepare a plan for follow-up actions on recommendations accepted by the NAACCR Board by April 2003. **MET.** The report is in press in May 2003.

Release report of death clearance best practices work group by February 2003. Develop action plan to implement best practices in all NAACCR member registries including monitoring and assessment tool to determine registries in compliance to validate assessment of DCO indicator in registry certification and CINA products. **MET.** A guideline was released in spring 2003.

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

The current process and timeline for implementing new and revised standards will be reviewed by June 2001 with recommendations completed by December 2002 in response to the 2000-2002 Overarching Goal on this issue. Any new recommendations will be distributed to the membership with special efforts to encourage compliance by all standard setters in the six month period following release of the recommendations. **MET.** The new guideline recommends a three-year cycle for major changes and a one-year cycle for minor changes.

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

Complete a best practice guideline for Hispanic identification by April 1, 2003. **MET.**

Complete the revision of the Ovarian cancer monograph and receive an acceptance for this publication in Cancer by Spring 2003. **MET.** Supplement to CANCER published May 15, 2003. A copy of the supplement was distributed to all NAACCR members.

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

On an ongoing basis NAACCR will continue to send representatives and to take an active role in the National Coordinating Council for Cancer Surveillance. **MET.**

The Sponsoring Member Organizations will meet in person twice annually with the NAACCR board. **MET.**

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. **MET.**

The approved board minutes will be posted on the Web site. **MET.**

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

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. **MET.** Article published on adolescent cancer [Wu]; Vision for Cancer incidence surveillance [in press, Cancer Causes and Control, Howe et al]; Annual report to the nation [in press JNCI, Weir et al]; updated chapter on NAACCR for NCRA textbook [in press, Howe]; Ovarian cancer in the US, 1992-97 [Cancer supplement, Goodman and Howe (eds)].

GOAL 10: Attain financial and economic stability for NAACCR.

Save \$50,000 to bridge potential gap in renewal and recompetition of contracts in the future. **MET.**

BETWEEN MAY 2001 - JUNE 2002:

GOAL 4: Provide technical assistance to NAACCR member organizations.

By June 2001, the Registry Operations Committee will produce two procedural documents for use by cancer registries.

MET 2002: Series III and IV of Procedure Guidelines released

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

By January 2002, increase to 100% the proportion of registries that execute the EDITS program on their submission to the *Call for Data*.

STATUS: 1997 CINA 60% of registries submitting data ran EDITS
1998 CINA 90% of registries submitting data ran EDITS
1999 CINA 85% (46 of 54) registries submitting data ran EDITS
2000 CINA 94% (58 of 62) registries submitting data ran EDITS

MET: 2001 CINA 100% (61 of 61) registries submitting data ran EDITS
2002 CINA 100%

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

The following articles were published about cancer surveillance from NAACCR research groups, committees, or other NAACCR representatives that pertain to cancer registration or used the NAACCR aggregated data set.

Wu XC, Chen VW, Steele B, Ruiz B, Fulton J, Liu L, Carozza SE, Greenlee R. Subsite-specific incidence rate and stage of disease in colorectal cancer by race, gender, and age group in the United States, 1993-1997. *Cancer* 2001;92:2547-10.

Hall, I, Jamison, P, Fulton, JP, Clutter G, Roffers SD, Parrish, P. The Reporting of Cutaneous Melanoma to Cancer Registries in the United States. [On-line]. Available May 2002 <http://www.naacr.org/Stats/EpiReports.html> : North American Association of Central Cancer Registries, April 2002, pages 1-19.

Fulton, J, Chiaverini, L, Roffers, S, Curran, D, Parrish, P, Clutter, G, Hall, I, Jamison, M, Newton, C. The Collection and Use of Occupational and Industry Data by NAACCR Member Registries. In Wu et al (eds), *Cancer in North America, 1995-1999. Volume Three: NAACCR Incidence Combined Rates*. Springfield, IL: North American Association of Central Cancer Registries, April 2002.

Howe HL, Wingo PA, Thun MJ, Ries LAG, Rosenberg H, Edwards BK. Annual report to the nation on the status of cancer, 1973-1998, featuring cancers with recent increasing trends. *J Natl Cancer Inst* May 2001;93:824-42.

Edwards BK, Howe HL, Ries LAG, Thun MJ, Rosenberg H, Yancik R, et al. Annual report to the nation on the status of cancer, 1973-1999, featuring implications of age and aging on US cancer burden. *Cancer* 2002;94:2766-92.

NAACCR ACCOMPLISHMENTS RELATED TO MISSION, GOALS, AND OBJECTIVES

BETWEEN MAY 2000 - JUNE 2001:

4. Provide technical assistance to NAACCR member organizations

The Registry Operations Committee will review and revise Volume III of the Standards volumes by April 2000.

MET: The document was released in December 2000.

By April 2000, the Registry Operations committee will release two series in the procedure guidelines for registry operations.

MET: Series I: Interstate data exchange printed in December 1999

Series II: Calculating the Death Certificate Only Rate printed in June 2000.

By June 2001, develop a template of examples on data presentation and display to be included in the registry report to all members by making it available on the NAACCR Web site.

MET: CINA+ Online meets this objective and was launched on the NAACCR web site on July 1, 2000

By April 2000, participate in the development of workshop on the technical aspects of *Call for Data*, designed specifically for the data processing staff at the registries.

MET: Your Call-for-Data Toolkit Workshop was presented in September 1999 and September 2000.

By April 2000, the DEPC will provide the template of 4-4M to all members by making it available on NAACCR website.

MET: *CINA+ Online* released July 2000.

5. Provide mechanisms for networking among NAACCR members.

For next NAACCR Annual Meeting in Chicago April 1999, develop a method to educate member organizations on the uses of the website (e.g., poster session, presentation, technical workshop).

MET: Demonstration provided at NAACCR exhibit. Handout available for all registrants.

By January 1999, develop a detailed index on Web for data and data reports and have a Web Coordinator for this index.

MET: Site index developed by NAACCR staff. Will be used for re-design of site and loaded to existing site.

NAACCR staff will ensure that an interactive mentor database is developed and launched on the NAACCR Web site by June 2001.

MET: June 2001

7. Enhance the completeness of case finding and data collection.

Members of the NAACCR board will identify a method to facilitate exchange of death certificate data among or with all state registries.

MET: The final document was approved by the Board in November 1999 and will be finalized and distributed to all members.

8. Maximize the dissemination, interpretation, and use of data.

By April 2000, decrease the time lag from 3 to 2 years in the *Call for Data* for CINA monograph by improving availability of accurate and more timely cancer statistics. DEPC, in conjunction with Registry Certification, will request 1993-97 data submission in December 1999.

MET: In 2000, lag time decreased from 3 to 2 years with publication of 1997 data.

By April 2000, increase the number of U.S. registries participating in the *Call for Data* by 10% (to 46 from 42 in 1999).

STATUS: 1996 *CINA* 39 US registries submitted data
1997 *CINA* 32 US registries (59% of eligible US registries) submitted data
1998 *CINA* 40 US registries (70% of eligible US registries) submitted data
1999 *CINA* 42 US registries (74% of the 57 eligible U.S. registries)
MET: 2000 *CINA* 50 US registries (88% of the 58 eligible U.S. registries)

By December 2001, release *CINA Plus* for public use.

MET: *CINA + Online* was developed went online in July 2000.

By January 2002, increase to 100% the proportion of registries that execute the EDITS program on their submission to the *Call for Data*.

STATUS: 1997 *CINA* 60% of registries submitting data ran EDITS
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2000 *CINA* 94% (58 of 62) registries submitting data ran EDITS
MET: 2001 *CINA* 100% (61 of 61) registries submitting data ran EDITS

10. Develop and maintain collaborative relationships with national and international organizations to further mutual goals, maximize resource utilization, and promote complementary efforts.

By January 1999, improve relations among sponsors to enhance progress in consensus in data collection and surveillance.

MET: Consensus is that mechanisms are in place to enhance this progress and they are working effectively

By January 2001, the NAACCR Executive Office will maximize electronic filing, archiving, form development and all electronic means to perform all office procedures to maximize efficiency, use current technology, and minimize use of paper and other natural resources.

11. Provide advocacy for registries and the utilization of registry expertise.

NAACCR will inform all of its members on a regular basis of any legislative issues that affect resources for cancer registration or that affect the operational procedures of cancer registries.

MET: Beginning 4/00, bi-weekly NAACCR Washington Update was initiated.

NAACCR will inform all of its members on a regular basis of any legislative issues that affect resources for cancer registration or that affect the operational procedures of cancer registries.

MET: Beginning 4/00, bi-weekly NAACCR Washington Update will be initiated

NAACCR members will contact state and local organizations such as Divisions of the ACS, advocacy groups, insurance providers, etc.

MET: Division meeting of ACS attended in Fall 1998; membership letters sent to 17 divisions in January 1999, several responded. Letters sent to Canadian Cancer Society divisions in Fall 1999; no new members generated.

By April 1999, the Public Relations committee will prepare appropriate narrative for pamphlets and letters for these marketing activities. The board will identify resources to professionally prepare and reproduce these materials.

MET: Staff prepared a brochure for the organization, completed and approved by the board in November 1999 for this purpose.

By June 2001, compile a resource list of experts, publicize and communicate the availability of technical expertise on data analyses and interpretation, data utilization, and report preparation and writing.

12. Attain financial independence and economic stability for NAACCR.

By January 1999, put 25% of annual dues in a CD or other investment.

MET: October 1999

13. Provide objective criteria for certification of cancer registries and collaborate with registries to obtain certification.

By April 2001, 40 registries will be certified.

MET: In 2000, 51 registries were.

NAACCR ACCOMPLISHMENTS RELATED TO MISSION, GOALS, AND OBJECTIVES

BETWEEN MAY 1999 - APRIL 2000:

1. Provide standards and models for the collection, coding, editing, and exchange of cancer and patient information.

Encourage membership to submit to the Uniform Data Standards Committee recommended changes for existing data element definitions as they determine that such changes may be warranted.

MET: Form for suggested revisions/ additions is on the NAACCR Web site for anyone to access.

As an ongoing activity, the Registry Operations Committee will develop Procedure Guidelines for Cancer Registries. At a minimum, the committee will produce one each year.

MET: 1999-2000, Series I released.

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

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), NPCR audits (audit co-PI), SEER Quality assurance activities (NCI QA program), NPCR site visits (CDC Contract program officer), 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.

MET: Met in 1999. In 2000, *CINA* DQI sent to committee in for 1991-95 data

On an ongoing basis the Education Committee will work with the other committee chairs to assess and meet the educational needs evident from the activities of these committees.

MET: Collaboration with DEPC, PUDF, 1999-2000 and UDS/ IT for planning basic regional. Also coordinated with short course organizers and CSCP staff.

By April 1999, the Data Use and Confidentiality Subcommittee will publish a report of guidelines on the release of registry data and confidentiality issues.

MET: Report released in March 2000.

By January 1999, develop a list of mentors to distribute to membership.

MET: Completed Access database in August 1999. Loaded on Web March 2000.

4. Provide technical assistance to NAACCR member organizations

The Registry Operations Committee will review and revise Volume III of the Standards volumes by April 2000.

MET: The document was released in December 2000.

By April 2000, the Registry Operations committee will release two series in the procedure

guidelines for registry operations.

MET: Series I: Interstate data exchange printed in December 1999

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By June 2001, develop a template of examples on data presentation and display to be included in the registry report to all members by making it available on the NAACCR Web site.

MET: CINA+ Online meets this objective and was launched on the NAACCR web site on July 1, 2000

By April 2000, participate in the development of workshop on the technical aspects of *Call for Data*, designed specifically for the data processing staff at the registries.

MET: Your Call-for-Data Toolkit Workshop was presented in September 1999 and September 2000.

5. Provide mechanisms for networking among NAACCR members.

For next NAACCR Annual Meeting in Chicago April 1999, develop a method to educate member organizations on the uses of the website (e.g., poster session, presentation, technical workshop).

MET: Demonstration provided at NAACCR exhibit. Handout available for all registrants.

By January 1999, develop a detailed index on Web for data and data reports and have a Web Coordinator for this index.

MET: Site index developed by NAACCR staff. Will be used for re-design of site and loaded to existing site.

7. Enhance the completeness of case finding and data collection.

Members of the NAACCR board will identify a method to facilitate exchange of death certificate data among or with all state registries.

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By January 1999, improve relations among sponsors to enhance progress in consensus in data collection and surveillance.

MET: Consensus is that mechanisms are in place to enhance this progress and they are working effectively

By January 2001, the NAACCR Executive Office will maximize electronic filing, archiving, form development and all electronic means to perform all office procedures to maximize efficiency, use current technology, and minimize use of paper and other natural resources.

11. Provide advocacy for registries and the utilization of registry expertise.

NAACCR will inform all of its members on a regular basis of any legislative issues that affect resources for cancer registration or that affect the operational procedures of cancer registries.

MET: Beginning 4/00, bi-weekly NAACCR Washington Update will be initiated

NAACCR members will contact state and local organizations such as Divisions of the ACS, advocacy groups, insurance providers, etc.

MET: Division meeting of ACS attended in Fall 1998; membership letters sent to 17 divisions in January 1999, several responded. Letters sent to Canadian Cancer Society divisions in Fall 1999; no new members generated.

By April 1999, the Public Relations committee will prepare appropriate narrative for pamphlets and letters for these marketing activities. The board will identify resources to professionally prepare and reproduce these materials.

MET: Staff prepared a brochure for the organization, completed and approved by the board in November 1999 for this purpose.

By June 2001, compile a resource list of experts, publicize and communicate the availability of technical expertise on data analyses and interpretation, data utilization, and report preparation and writing.

12. Attain financial independence and economic stability for NAACCR.

By January 1999, put 25% of annual dues in a CD or other investment.

MET: October 1999

14. Provide objective criteria for certification of cancer registries and collaborate with registries to obtain certification.

By April 2001, 40 registries will be certified.

MET: In 2000, 51 registries were.

NAACCR ACCOMPLISHMENTS RELATED TO MISSION, GOALS, AND OBJECTIVES

Through APRIL 1999:

1. Provide standards and models for the collection, coding, editing, and exchange of cancer and patient information.
2. Coordinate changes and assure continuity in data to be collected and exchanged.
3. Provide educational resources related to registry operations and data utilization.

The Education Committee will maintain and update at least annually a resource directory for the NAACCR membership for distribution on the NAACCR web site.

MET: Completed in December 1998.

4. Provide technical assistance to NAACCR member organizations.

The DEPC will conduct a breakout session each year at the NAACCR annual meeting on the process of data submission and technical aspects of participating in the *Call for Data*, in conjunction with Certification Committee.

MET - An breakout session was conducted at the 1998 NAACCR annual meeting. A similar session is planned for 1999. The session will continue to be held annually as a breakout session at the annual meeting as long as technical assistance is needed for these activities.

5. Provide mechanisms for networking among NAACCR members.

The following will be updated routinely, and at least annually, on NAACCR's web page:

MET: Data from the Education Committee regarding training resources; Lists of upcoming training opportunities planned by NAACCR and other organizations; NAACCR newsletters; NAACCR membership directory; Notice of the annual meeting and the preliminary conference program.

Newsletters will be published quarterly each year.

MET.

Before the NAACCR Annual Meeting in Vancouver April 1998, contact chairs of NAACCR standing committees and ask that they discuss how the NAACCR website can best meet their committee's needs for dissemination of information.

MET - 4/18/98

By July 1998, complete redesign of the NAACCR website to enhance continuity, simplify maneuverability, decrease load time where possible and revise page headings to facilitate correct indexing of the site by search engines and directories.

MET - New design of website debuted 6/2/98

By August 1998, register the website with popular search engines to increase visitation and encourage link popularity.

MET - 100 search engines through RegisterIt 6/12/98

By September 1998, develop policies (with the approval of the Public Relations Committee) and procedures concerning content, eligibility for posting, and maintenance of the site.

MET - 8/4/98

By November 1998, contact all sponsoring organizations to request a list of their major events (annual meetings, workshops, training sessions) to be included on the web site calendar and request, if they maintain a website, to include a link to the NAACCR website.

MET - All sponsoring organizations were contacted in June 1998

By April 1999, develop a multimedia section for the website which may include, slide shows, audio spots, and/or pictures of events pertaining to NAACCR.

MET - Slide show about NAACCR on website with narration, 7/1/98. Audio spot from the President on the home page 6/12/98. Photo album of Vancouver meeting, 7/28/98. Confidentiality presentations added 10/98

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

By April 1997, release a NAACCR standard to assess the completeness of reporting.

MET - standard released in the fall 1996 NAACCR newsletter

By April 1999, increase to 100% the proportion of registries that use the NAACCR layout and meet all standards for variable (field) definitions and codes in their submission for the *Call for Data* and all records are converted to the same ICD-0 version./standard.

MET: For 1997 *Call for Data*, 57% of registries submitted in NAACCR layout, 55% - met all standards, NAACCR std codes, and of variable definitions and codes, 71% used ICD-0 2 codes.

For 1998 *Call for Data*, 100% of the registries submitted in NAACCR record layout and used ICD-02 codes

For 1999 *Call for Data*, 100% of the registries submitted in NAACCR record layout and used standard definitions and codes

By October 1996, obtain permission for 100% of the audit results to be shared with the DEPC for use in defining standards of quality for the *Call for Data* submissions.

MET - May 1996

7. Enhance the completeness of case finding and data collection.

8. Maximize the dissemination, interpretation, and use of registry data.

For each annual release, include mortality data and rates for member states and provinces in the CINA monograph.

MET - 1997

For each annual release, include pediatric cancer information in the annual CINA monograph for the U.S., Canada, and North America.

MET - 1997

By April of each year, place a copy of the electronic data set, a duplicate of the prepared diskette, on the NAACCR Internet home page.

MET - 1996, 1997, 1998, 1999

By April 1999, include U.S. regional mortality data.

MET -1999

By April 1998, obtain funding for beta testing the production of the public data set of individual records.

MET - funding was obtained in April 1998.

9. Identify key organizations, individuals, and groups with whom constructive relationships can be developed for cancer control and establish communications for strategic positioning.

By January 1999, increase membership by 5%.

MET: 4/97 base was 120 members

April 1998: 123 members, a 2.5% increase.

March 1999: 127 members, a 5.8% increase.

By January 1999, all 12 Canadian provinces and territories will be members.

MET - All members by December 1998.

10. Develop and maintain collaborative relationships with national and international organizations to further mutual goals, maximize resource utilization, and promote complementary efforts.
11. Provide advocacy for registries and the utilization of registry expertise.

By January 1999, and if feasible, have NAACCR become a member of CSTE and continue to distribute CSTE Washington Update to all Registry Directors, Committee Chairs and Board members.

Not feasible. CSTE does not have organizational members. CSTE looking for other means to formalize relationship

For the each annual meeting, the Public Relations, Data Evaluation and Publication, and Program committees will organize a news conference highlighting the release of the *CINA* publication and to showcase the annual meeting. The Public Relations Committee, will assume the lead responsibility for arranging such news conferences.

MET - April 1997: Press release of highlights from *CINA* was done in Boston with multiple media interviews.

In April 1998, a press conference, in addition to press release, was held at the NAACCR annual meeting in Vancouver.

April 1999: press release and press conference were held.

By December 1998, compile a resource list of experts, publicize and communicate the availability of technical expertise on data analyses and interpretation, data utilization, and report preparation and writing.

MET - Mentor Form completed to post on Web for self-identification of experts.

By December 1998, DEPC will compile a resource list of experts, publicize and communicate the availability of technical expertise on data analyses and interpretation, data utilization, and report preparation and writing.

MET - merged with 11-8.

By January 2001, monitor and inform members of relevant legislative actions.

MET - Beginning May 1998, circulating CSTE Washington Update to Board, Chairs and Registry Directors

12. Attain financial independence and economic stability for NAACCR.

By April 1997, assure long term support for the activities of the Data Evaluation and Publication Committee either through contracts or the addition of permanent NAACCR staff.

MET - May 1997, NCI agreed to pay for the computer programming and preparation of WP tables for CINA.

July 1997, CDC awarded grant money to support the development of a Public Data Set.

August 1997, CDC agreed to pay for printing of CINA using a Purchase Order.

October 1998, CDC approved support of Editors and printing and distribution as part of contract CSCP.

By January 1999, obtain some financial compensation for the Editorial team working on the CINA publication.

MET - October 1998

By January 1999, define duties for an Executive Director and define the duties.

MET - Completed at January 1999 meeting with Business consultant

By January 1999, hire a bookkeeping service to assist the Treasurer.

MET - Service was hired in April 1998.

By January 1999, investigate how NAACCR could become self-supporting.

By January 2003, implement plans for NAACCR to be self-supporting.

By January 2003, attain financial independence and economic stability for the organization.

By January 2003, secure support for NAACCR staff to provide professional support to all NAACCR standing committees.

MET ALL - In October 1998, awarded a cooperative agreement for infrastructure support of NAACCR.

By January 1999, investigate an alliance with other scientific organization to share administrative resources.

Not Necessary. Cooperative agreement meets administrative needs.

By January 1999, institute a long term plan to cover the printing and distribution of CINA.

MET - CDC incorporated these costs into the CSCP contract with NAACCR.

By January 2003, have financial resources to support 20% of an Executive Director position.

MET - As of January 1999, we have 100% support for an Executive Director.

13. Provide objective criteria for certification of cancer registries and collaborate with registries to obtain certification.

By December 1999, 40 of 62 registries will submit data for certification.

MET - In December 1997, 29 registries submitted data.

In December 1998, 50 registries submitted data.

By April 2000, 30 registries will be certified.

MET: In April 1998, 23 registries were certified.

As of 4/99, 31 registries were certified.