

NAACCR ANNUAL BUSINESS MEETING AGENDA
Detroit, Michigan
June 6, 2007

- | | |
|---|--------------------------------------|
| 1. <i>Call to Order</i> | Betsy Kohler |
| 2. <i>Approval of Minutes from 2006 Meeting</i> (pgs.) | Betsy Kohler |
| 3. <i>President's Report</i> | Betsy Kohler |
| 4. <i>Treasurer's Report</i> (pgs.) | Lilia O'Connor |
| a. Balance Sheet as of 4/30/07 | |
| b. Investment / Revenue and Expense History | |
| c. NAACCR Gifts, Donations, and Bequest Program (pg.) | |
| d. List of Sponsors' Support of All Kinds (pg.) | Lilia O'Connor |
| 5. <i>Executive Director's Report</i> (pg.) | Holly L. Howe |
| 6. <i>Membership Report from the Board</i> (pg.) | Susan Bolich-Aldrich |
| 7. <i>Standing Committee Reports</i> | |
| a. Bylaws | Maureen MacIntyre |
| b. Communications (pg.) | Dan Curran |
| c. Data Evaluation and Certification (pgs.) | Thomas Tucker |
| d. Data Use and Research (pgs.) | Maria Schymura |
| e. Education (pg.) | Mignon Dryden |
| f. Information & Technology (pgs) | Ken Gerlach |
| g. Nominating (Vote on Action) (pgs.) | Vivien Chen |
| h. Program (pg.) | John Graff |
| i. Registry Operations (pgs. 22-24) | Susan Gershman/ Susan Bolick-Aldrich |
| j. Uniform Data Standards (pgs. 25-26) | Andrew Stewart |
| 8. <i>Other Committee Reports</i> | |
| a. Cancer Registration Steering Committee | Liz Ward |
| b. GIS (pgs.) | Francis Boscoe/ Kevin Henry |
| c. Interoperability Ad Hoc Committee | Ken Gerlach |
| d. NAACCR IRB (pgs.) | Holly L Howe |
| e. Scientific Editorial Board (pg.) | Myles Cockburn |
| 9. <i>Liaison Reports</i> | |
| a. Commission on Cancer (pgs. 33-35) | Susan Van Loon |
| b. AJCC | Colleen Sherman |
| 10. <i>Announcement of Future Meetings</i> | Betsy Kohler |
| a. 2008 – Denver, Colorado | |
| b. 2009 – San Diego, California | |
| c. 2010 – Quebec City, Quebec | |
| 11. <i>New Business</i> | |
| a. Election: 2007-08 Nominating Committee | Betsy Kohler |
| b. Appoint Chair: Nominating Committee | Betsy Kohler |
| c. Other Business from the Floor | Betsy Kohler |
| 12. Vision Statement for 2007-2009 from President-Elect | Susan Gershman |
| 13. <i>Adjournment</i> | |

Appendix of Documents for Delegates at the Business Meeting

1. NAACCR Organization Charts (pgs.)
 - a. NAACCR Organization Chart (pg.)
 - b. NAACCR Executive Office Organization Chart (pg.)
2. 2006-2010 Goals & Objectives including Overarching Objectives (pgs.)
3. 2006-2007 Accomplishments (pgs.)
4. NAACCR Policies (pgs.)
5. Bylaws (pgs.)
6. Standing Rules (pgs.)

NAACCR ANNUAL BUSINESS MEETING AGENDA
Regina, Saskatchewan
June 14, 2006

1. Call to Order

Betsy Kohler

Written materials were distributed to all attendees prior to the meeting. President Betsy Kohler called the meeting to order at 12:10 pm. Voting delegates were polled and it was determined that a quorum was present.

2. Approval of Minutes from 2005 Meeting

Betsy Kohler

Minutes of the 2005 NAACCR Annual Business Meeting.

Approved

3. President's Report

Betsy Kohler

One action item on NAACCR's agenda that came out of the NAACCR Board's self evaluation was the recruitment of Board members and NAACCR Committee Chairs. The Board will continue to encourage members to be involved in NAACCR committees and NAACCR leadership positions. The Board will be taking a more active role in recruiting new individuals as NAACCR leaders. Lilia O'Connor's term as Treasurer will end next year. Betsy encouraged individuals to nominate themselves or another person for this role. They should speak with Lilia to obtain information. Betsy said that NAACCR will re-consider Annual Conference fees. She asked for input from members. She asked members to speak with herself or other Board members after the meeting to provide input.

4. Treasurer's Report

Lilia O'Connor

a. NAACCR Gifts, Donations, and Bequest Program

The NAACCR Gifts, Donations, and Bequest Program report was presented for review.

b. List of Sponsors' Support of All Kinds

Lilia O'Connor

NAACCR's list of Sponsors' Support of All Kinds was presented for review.

c. NAACCR Balance Sheet

Lilia O'Connor

Lilia reviewed the NAACCR Balance Sheet as of April 30, 2006.

NAACCR's Balance Sheet is in a positive situation. Total assets equal \$872,138.29.

5. Membership Report from the Board

Susan Bolick-Aldrich

None submitted

6. Standing Committee Reports

a. Bylaws **Maureen MacIntyre**

No requests for bylaws changes were made and Maureen referred to written report for the remainder of information.

b. Communications **Catherine Tapp**

Referred to written report.

c. Data Evaluation and Certification **Thomas Tucker**

Referred to written report.

d. Data Use and Research **Maria Schymura**

i. Overarching Goal – Assessing Surveillance Data Needs:

The group streamlined the application process to gain access to the CINA Deluxe files. Applications can be submitted four times a year now. The abstract review sub-committee reviewed all 2006 Annual Conference abstracts. The APII has developed an algorithm and a presentation will be given tomorrow at the meeting.

e. Education **Mignon Dryden**

i. Overarching Goal –Retention and Recruitment:

The workgroup will be re-convened this year. Please inform Shannon Vann, Mignon Dryden or anyone from the Education Committee if you are interested in joining this group.

The educational matrix is almost complete and will be available on the NAACCR web site. The annotated bibliography project is being headed up by Herman Menck. Two advanced workshops will be offered at the 2006 NAACCR Annual Conference.

f. Information & Technology **Ken Gerlach**

i. Overarching Goal -- Real-time Electronic Reporting

Real-Time Reporting task force recommendation has been posted on the NAACCR web site. However the report does not sufficiently include Canadian information for informatics. The E-Path Transmission Workgroup has been busy with implementation guidelines. This group is being led by Eric Durbin. They are looking at synoptic reports and are working with CAP on this. The E-Path subcommittee is being led by Carol Kosary. They are developing a companion document to go with the HL7 format implementation guide. The Cancer Abstract Transmission Workgroup is looking for alternatives of the cancer abstract transmission. The group will move forward with implementation.

g. Nominating **Vivien Chen**

There were five Board positions available for election this year. They were President-Elect, SMO Representative, and three At-Large

Representatives. 78.4% of the membership voted in the general election. 90% of the SMOs voted for the SMO Representative. The results were:

- S President-Elect: Susan Gershman
- S SMO Representative: Elizabeth Ward
- S Representative-At-Large: Mignon Dryden, Maureen MacIntyre, and Karen Knight.

Vivien moved that the ballots for 2006 be destroyed.

ACTION: The membership voted to destroy the 2006 voting ballots.

She encouraged members to nominate and desire to be nominated for future elections.

h. Program **Jon Tonita**

Jon Tonita reviewed the actions and activities for the 2006 Annual Conference. He thanked his Committee and all those involved with the Annual Meeting.

i. Registry Operations **Susan Gershman/ Susan Bolick-Aldrich**

Susan Gershman thanked Susan Bolick-Aldrich for her hard work this past year. The Death Clearance Workgroup plans to complete their work this year. An update will be provided at the NAACCR Showcase later in the Conference. Record Consolidation information is on the NAACCR web site. If individuals are aware of any issues with the coded changes, please contact the group.

j. Uniform Data Standards **Andrew Stewart**

Future issues for the committee will be the 2007 implementation guidelines. Two areas of concern will be addressed. First, the National Provider ID number introduction. Second, the introduction of the multiple primary and histology coding rules set for January 1, 2007. Anyone interested in speaking with Andrew about this should see him at the meeting. He also thanked Lori Havener for her leadership and assistance over the last year.

7. Other Committee Reports

a. GIS **David O'Brien**

A GIS survey was distributed this past year. The analysis of the survey data was completed this year. A report will be available next year and will be posted on the NAACCR web site. The survey results showed that members wanted to know how to better geocode their work. This feedback resulted in the group's creation of a best practices document that will be developed. A meeting will take place at the Annual Conference to begin work on this. Last year a SAS routine was created. This Great

Circle Distance Calculator can be obtained on the NAACCR web site.

- b. Scientific Editorial Board** **Myles Cockburn**
Referred to written report.
- c. NAACCR IRB** **Holly L Howe**
Referred to written report.
- d. The Cancer Registration Steering Committee** **Liz Ward**
Holly Howe provided input regarding this group's work. This committee was previously known as the IOB. This committee is filling the need it was intended to do by the NAACCR Overarching Objectives.
- e. Retention and Recruitment** **Mignon Dryden**
Addressed in Education Committee report.

8. Liaison Reports

- a. Commission on Cancer** **Susan Van Loon**
Referred to written report.
- b. AJCC** **Colleen Sherman**
No report.

9. Executive Director's Report

Holly L. Howe

- a. Overarching Goal – Data Standardization Across Disciplines**
Holly provided background about this effort. It was originally created out of efforts from C-Change. Since then, C-Change has stalled any plans to conduct this meeting. Tom Kean was hired as the C-Change Executive Director recently. He has been an advocate of the cancer surveillance field.

NAACCR has sustained a 25% cut this past year due to changes in federal awards. This past year involved the Board prioritizing all activities and spending line-items. The Board was able to approve a balanced budget through additional revenue streams and cost cuts. Dues and fees were not raised. NAACCR has also been very active in applying for corporate donations. Over 60 organizations have been contacted. Many applications are still pending and NAACCR is hopeful that we will secure some additional dollars. The Gifts, Donations, and Bequest Program secured \$2,792.25 during the 2005-2006 fiscal year. The goal was \$10,000. NAACCR is now focusing on the NAACCR Training Program. Members are encouraged to take advantage of this program. Two webinar series will be offered this year. A Central Registry and Hospital Reporting series will be offered. Membership dues were sent out June 2, 2006. In-

person workshops will also be offered next year. These will include CTR Prep workshops, Registry Operations, and specialty workshops. Holly also called their attention to the Support From All Sources report. She thanked all organizations for their support.

10. Announcement of Future Meetings

a. 2007 – Detroit, Michigan **Betsy Kohler**

b. 2008 – Denver, Colorado **Betsy Kohler**

Betsy reminded members that Detroit will host the 2007 Annual Conference. Due to venue restrictions and other various issues, Denver will host the 2008 conference.

11. New Business

a. Election: 2006-07 Nominating Committee **Betsy Kohler**

Betsy opened the floor for nominations. Nominees were:

- S Viven Chen
- S Donna Turner
- S Laura Stephenson-Vine
- S Jeannette Jackson-Thompson.

Betsy called for a vote for each.

ACTION: Nominees Vivien Chen, Laura Stephenson-Vine, and Donna Turner we approved as the 2006-2007 Nominating Committee.

b. Appoint Chair: Nominating Committee **Betsy Kohler**

ACTION: Betsy appointed Vivien Chen as the Chair of the 2006-2007 Nominating Committee.

c. Other Business from the Floor **Betsy Kohler**

Viven Chen thanked the entire NAACCR membership and those that donated to the Louisiana Tumor Registry fund. They are greatly appreciative of everyone's donations.

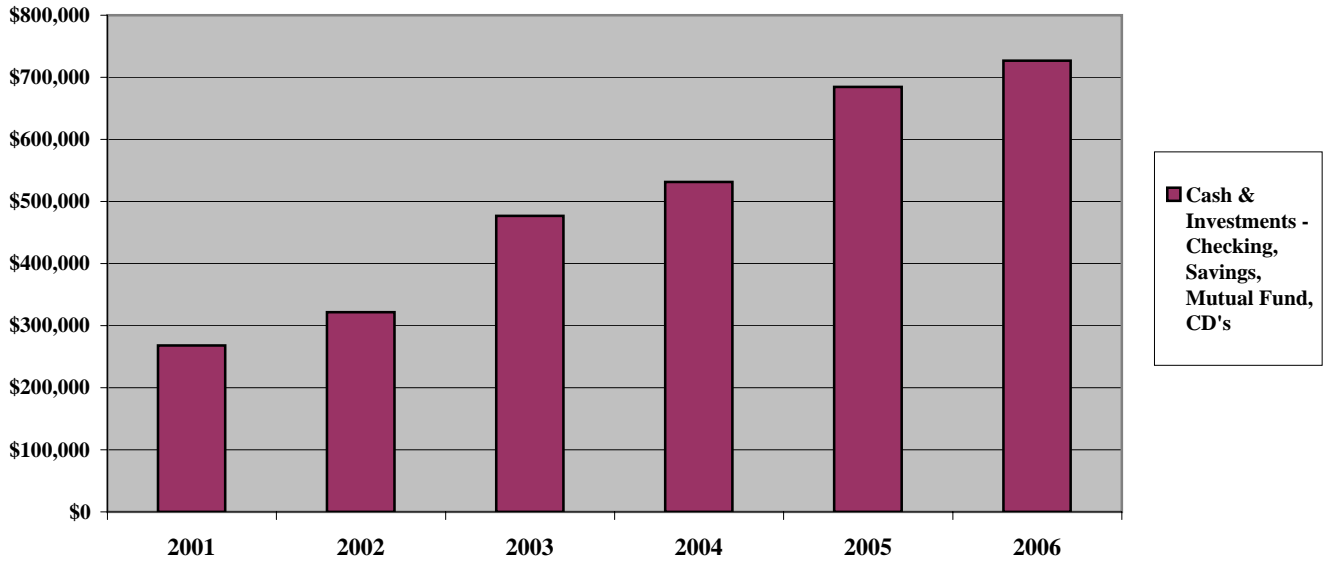
12. Adjournment

The meeting adjourned at 1:10 pm.

NAACCR, Inc.
 Balance Sheet
All Funds
 As of April 30, 2007

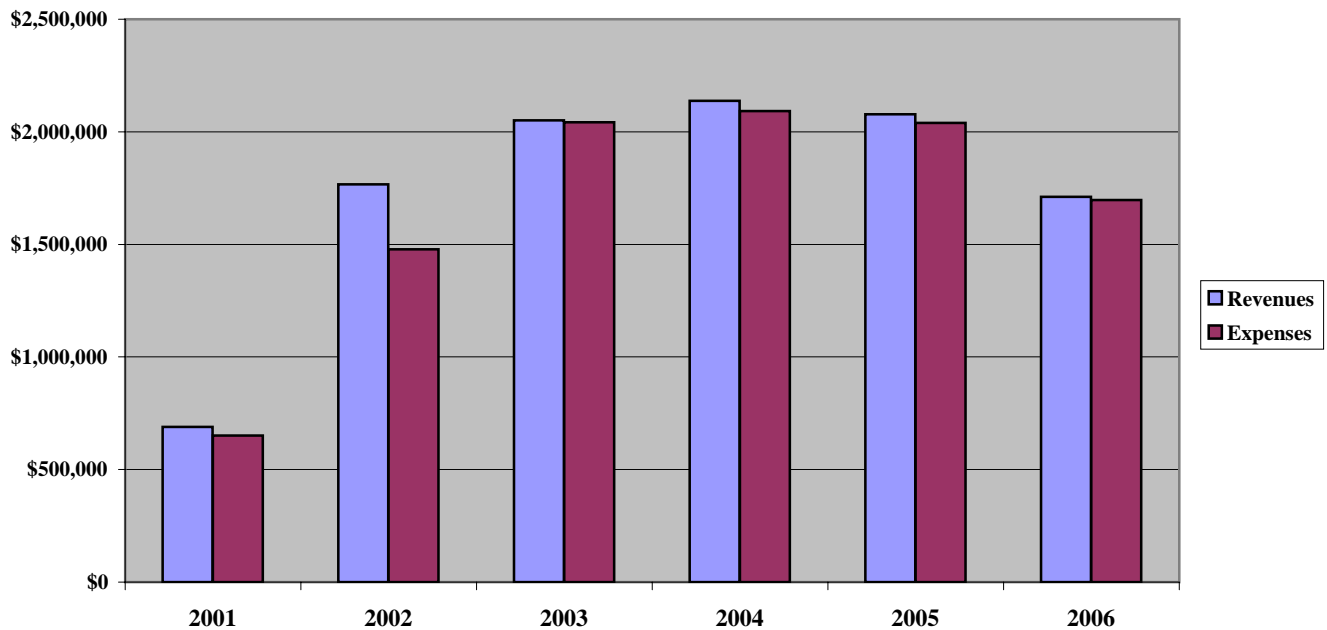
Assets	Previous Month	Current Month
<i>Cash</i>		
Checking	8,734.64	69,657.15
Flex Spending Account	5,111.89	3,689.04
Business Money Market Checking	265,409.37	266,226.66
<i>Investments</i>		
Morgan Stanley Trust	12,179.14	12,230.75
Certificates of Deposit	250,000.00	250,000.00
Washington Mutual Fund	319,978.41	333,882.51
<i>Subtotal Cash & Investments</i>	<u>861,413.45</u>	<u>935,686.11</u>
<i>Receivables</i>		
Indirect Funds Receivable	13,391.48	16,416.74
Grants Receivable Fund 29	0.00	0.00
Grants Receivable Fund 81	70,419.25	72,779.48
<i>Subtotal Receivables</i>	<u>83,810.73</u>	<u>89,196.22</u>
<i>Prepays</i>		
Prepaid Health Insurance	4,915.04	4,915.04
Prepaid Dental Insurance	299.92	272.73
<i>Other</i>		
Total Equipment	192,283.37	192,283.37
Accumulated Depreciation	<u>(156,950.42)</u>	<u>(158,819.24)</u>
Total Assets	<u><u>985,772.09</u></u>	<u><u>1,063,534.23</u></u>
Liabilities		
<i>Current</i>		
Accounts Payable	0.00	0.00
Wages Payable	0.00	0.00
FICA	0.00	0.00
IL Unemployment Tax	4,628.44	300.02
IL State W/H Tax	0.00	0.00
NY State Tax	494.01	290.98
SIMPLE IRA	0.00	0.00
Flex Spending	(2,247.18)	(2,196.67)
Washington DC Member Deposit	108.20	108.20
Total Liabilities	<u>2,983.47</u>	<u>(1,497.47)</u>
Net Assets		
Unrestricted Net Assets	865,005.02	865,005.02
Board Designated Net Assets	2,000.00	2,000.00
Temporarily Restricted Net Assets	4,110.00	4,110.00
Change in Net Assets	<u>111,673.60</u>	<u>193,916.68</u>
Total Net Assets	<u>982,788.62</u>	<u>1,065,031.70</u>
Total Liabilities and Net Assets	<u><u>985,772.09</u></u>	<u><u>1,063,534.23</u></u>

Cash & Investments



Source: NAACCR Audited Financial Statements

Revenue and Expenses



Source: NAACCR Audited Financial Statements

NAACCR Gifts, Donations, and Bequest Program Donors

Fiscal Year June 1, 2006 thorough May 31, 2007

Activity through May 15, 2007

NAACCR Members

General Fund

Date	First Name	Last Name	Amount
9 /8 /2006	Ann	Rimicci	\$100.00
9 /8 /2006	Frances	Ross	\$100.00
9 /8 /2006	Baozhen	Qiao	\$100.00
9 /8 /2006	Herman	Menck	\$50.00
9 /8 /2006	Aaron	Adade	\$50.00
9 /11/2006	Xiaocheng	Wu	\$500.00
9 /14/2006	David	Lyalin	\$100.00
9 /26/2006	John	Graff	\$50.00
10/30/2006	Glenn	Copeland	\$50.00
11/21/2006	Susan	VanLoon	\$50.00
11/21/2006	Melinda	Lehnherr	\$100.00
12/7 /2006	Mei-Chin	Hsieh	\$50.00
12/20/2006	Vivien	Chen	\$500.00
12/27/2006	Marc	Goodman	\$250.00
2 /8 /2007	Melanie	Williams	\$50.00

Corporate and Others

General Fund

9 /8 /2006	Frye Williamson Press, Inc.		\$150.00
12/29/2006	Jane	Braun	\$25.00

TOTAL: \$2,275.00

Support-of-all-kinds from Sponsoring Organizations for 2006-2007

American Cancer Society - ACS

- \$5,000 grant to support Cancer Surveillance Institute I: Principles and Public Health Application
- Sponsor with Distinction (\$20,000)
 - \$5,000 Training
 - \$5,000 Research
 - \$5,000 Data Standards
 - \$5,000 Cancer Surveillance

American College of Surgeons - ACoS

- Silver sponsor of Annual Conference
- Sponsor with Distinction (\$20,000)
 - \$20,000 Data Standards

American Joint Committee on Cancer - AJCC

- Silver sponsor of Annual Conference
- Sponsor with Distinction (\$20,000)
 - \$20,000 Data Standards

Canadian Association of Provincial Cancer Agencies - CAPCA

- Dues

Centers for Disease Control & Prevention - CDC

- Year four of a five-year cooperative agreement to support NAACCR infrastructure (\$600,000 annually since 2000; including support for the Annual Conference)
- Use of a CDC phone bridge for conference calls. Assignment of three CDC teleconference bridge lines.
- Support for Clinical Data Workgroup in-person meeting (\$12,300)
- Dues

College of American Pathologists

- Bronze sponsor of Annual Conference
- Dues

National Cancer Institute - NCI

- Year two of a five-year grant in support of Annual Conference (\$30,000 in 2007)
- Year three of a five-year contract to NAACCR for Technical Assistance for Cancer Surveillance (5-year \$2.2 million)
- Additional \$64,000 in year 3 for special projects
- Provides the infrastructure for the NAACCR ListServ
- Phone bridge for teleconference calls of the BOD and Program Committee
- Distribution costs of quarterly newsletter and other major mailings to membership
- Silver sponsor of Annual Conference
- Dues

National Cancer Registrars Association - NCRA

- Phone bridge for teleconference calls of the CRSC
- Administrative support of the CRSC meetings through a transcription service
- Exhibitor at the 2007 Annual Conference
- Complimentary NCRA membership for the NAACCR Executive Director.
- Dues

Public Health Agency of Canada

- Gold sponsor of Annual Conference
- Dues

Statistics Canada

- Dues

as of May 15, 2007

Executive Director Report 2007

Detroit, Michigan, June 6, 2007

NAACCR INFRASTRUCTURE

Continued in second year of five-year grant support for the annual meeting (NCI).
Continued in third year of five-year award received for various cancer surveillance activities (NCI).
Continued in fourth year of 5-year cooperative agreement for infrastructure support (CDC).
Managed dues collection and all fiscal operations of the organization.
Obtained grant from ACS to partially support CSI I in 2007.
Obtained grant from Susan G Komen Foundation for 3 years to “Quantifying Transportation Barriers in Accessing Health Facilities for Breast Cancer Diagnosis and Treatment”
Obtained a five-year conference support grant from CDC.
Expanded NAACCR Gifts, Donations, and Bequests Program.
Initiated a pilot study with a consultant to ascertain feasibility of a NAACCR corporate fund-raising campaign.

STAFFING

Used consultants for an additional 0.4 FTE.
Maintained total 9 FTE; 4 vacancies occurred; 3 refilled; 4th hiring is in progress.
Added and filled a Trainer position, which will increase total NAACCR FTE to 10.

ACTIVITIES

General

Provided professional and administrative support to committees: Board, DURC, DECC, GIS, Program, Communications, Education, IT, Nominating, Registry Operations, UDS, and Interoperability.
Served as a clearinghouse for all NAACCR training materials, standard volumes, and other publications.
Planned and held a NAACCR Leadership Retreat in January 2007.
Continued NAACCR participation in C-Change with Mignon Dryden on Cancer Workforce activities and Dr Howe acting as Chair of the Access Team.

Data Standards

Maintained current data standards volumes, including timely releases, and support of the NAACCR EDITS metafiles.
Expanded staff activities in electronic health record developments by other organizations.
Coordinating consensus development of Canadian standards with integration into Standards Volume II.

Data Use

Collaborators in the 2007 Annual Report to the Nation with a feature on AIAN populations.
Updated the NAACCR Bibliography (both the list and the annotated version) of Research publications
Released the four-volume CINA 2000-2004 monograph in April
Moved *CINA+ Online* to a new platform with better and more efficient performance; updated it in April with 2000-2004 data.
Created two new research tools: CINA in SAS and CINA Plus in SEER*Stat for use by the membership.
Administered and led the NAACCR IRB, with 10 applications reviewed and CINA Deluxe released for member research projects
Continued on data analytic projects on methods for trend analysis with holey data; utility of stage data in health services research (access); evaluation of selected treatment variables; and defining rare tumors from CINA Deluxe (three have presentations included in 2007 annual meeting).
Initiated a data analysis project on evaluating area-based approach to generating incidence rates for specific Latino groups.

Data Evaluation

Completed Registry Certification of 2004 data
Conducted personalized feedback on data quality of CINA submissions and review of CINA Deluxe file.

Training

Held a *Toolkit* Workshop
Held 5th Cancer Surveillance Institute I: Principles and Public Health Applications
Supported 4 Mentor Fellowships through the NCI contract.
Supported 2 Process Improvement Program work shops through the NCI contract.
Held 2 NAACCR institutes for CTR Exam Preparation
Held 4 Regional Training Programs (Massachusetts and 3 in Texas)
Launched two new webinar series: one for central registry staff and one for hospital registry staff.

NAACCR Membership Report 2006-2007

Member Type	Number of Members
Full	79
Sponsoring	9
Sustaining	24
Individual	<u>22</u>
Total Members	134

New NAACCR Members 2006-2007

Member Type	Member Name
Sustaining	Holy Cross Hospital Registry Partners, Inc.
Individual	Jill Barnholtz-Sloan, PhD April Fritz, RHIT, CTR David Steward

DATE: May 15, 2007
TO: NAACCR Board of Directors and Committee Chairs
NAACCR Membership
FROM: Dan Curran, MS, CTR, Chair, Communications Committee
RE: Annual Report to Board

The Communications Committee oversees and directs NAACCR's web site, is responsible for public relations, and produces the *NAACCR Narrative*. The volunteers and staff listed at the end of this report are to be commended for their efforts this year. Their service to the NAACCR membership is part of the reason why NAACCR is a strong and viable organization!

These are our achievements over the past year:

- Finalized committee goals and gained board approval
- Published four editions of the *NAACCR Narrative*
- Reviewed web site postings, web statistics, and tested new pages
- Interviewed committee chairs to solicit ideas for the web site
- Researched press release format, content, and distribution methods
- Created a NAACCR press release format approved by the board
- Wrote a press release production procedure
- Identified and assigned additional procedures needed by the committee
- Developed a document describing how committees can develop content for press releases
- Wrote press releases for annual meeting events and a grant award
- Worked with Josh Whitley to create a media web page for the distribution of press releases
- Worked with Herman Menck, NCRA, and the publisher to market the central registry textbook
- Identified new technologies and software that would improve the effectiveness of the web site and public relations activities

Communications Committee Members

Toshi Abe, MSW, CTR – New Jersey State Cancer Registry
Connie Bura – American College of Surgeons
Dan Curran, MS, CTR, Chair – Public Health Institute, C/NET Solutions
Lynda L. Douglas, CTR, Massachusetts Cancer Registry
Alyssa J. Elting, Oregon State Cancer Registry
Annette A. Hurlbut, RHIT, CTR - IMPAC Medical Systems
Karen Knight, MS - North Carolina Central Cancer Registry
Maureen MacIntyre, MHSA - Cancer Care Nova Scotia
Herman R. Menck, MBA
Jennifer L. Murray - Tennessee Department of Health
Antoinette Percy-Laurry, MSPH – SEER/NCI
Kurt Weiss - Nebraska Health and Human Services System

NAACCR Staff Support

Joshua F. Whitley - Computer Support Specialist

NAACCR Narrative Editorial Review Board

Mignon Dryden, CTR - Cancer Registry of Northern California
Holly L. Howe, PhD – NAACCR
Robin Otto, RIHA, CTR – Pennsylvania Cancer Registry

NAACCR Narrative Production Editor

Royale Anne Hinds - Assistant to the Executive Director

NAACCR Narrative Managing Editor

Dan Curran, MS, CTR - Public Health Institute, C/NET Solutions

Data Use and Research Committee (DURC)
Annual Report
June 2006 – May 2007

Members: Greer Gay, Robert Greenlee, Holly Howe, Ahmedin Jemal, Betsy Kohler, Carol Kosary, Andrew Lake, Carol Lowenstein, Maureen MacIntyre (board Liaison), Jim Martin, Colleen McLaughlin, David Roney, Maria Schymura (chair), Ghislaine Villeneuve, Dee West, Jennifer Wike, Brad Wohler, Xiao Cheng Wu

Accomplishments for this year include:

- Reviewed, provided suggestions for modification, and approved the Operating Procedure Manual of the Research Proposal Review Subcommittee.
- Reviewed and made recommendations regarding the 2007 Call for Data materials, including data items and edits.
- Considered a request for making a subset of the CINA Deluxe file available in a SEER*Stat format to facilitate registry data comparisons with other regions and national rates. Committee members volunteered to explore other alternatives (e.g., CDC Wonder) but found that confidence intervals and standard error statistics were not available in these. Two alternatives were proposed: 1) A SAS dataset version of the published CINA volumes; 2) an electronic file of the data variables in CINA+ Online to be accessed through SEER*Stat. The committee readily agreed to the SAS dataset and recommended that the CINA+ Online SEER*Stat concept be brought up at a town hall meeting in order to receive input from registries and to gauge their comfort with having data available in this format. The committee also recommended that the Confidentiality Subcommittee review the implications of the SEER*Stat format. Ultimately, the committee recommended that the evaluation of the Confidentiality Subcommittee be shared with registries and that registries be asked to consent to the inclusion of their data in CINA+ Online in SEER*Stat format. The committee reviewed and approved all materials related to gaining access to the CINA+ Online SEER*Stat file.
- Discussions were held regarding a SAS program that NAACCR is developing to match registry geocoded census tract data with the percent census tract poverty estimate from census data. Registries will be able to download the program from the NAACCR website and run it on their data. The program report will provide the census tract by poverty level information and also group this information into four groups used in the literature for indicating poverty. The groups are <5%, 5-9%, 10-19%, and 20+%. NAACCR would like to request case data with poverty indicated by these four groups in a future NAACCR Call for Data for inclusion on the CINA Deluxe research file. The literature states that area-based poverty indicators at a census tract level are preferred over county indicators. Committee members were supportive of this concept but raised the following issues: (1) the impact of incomplete geocoded data (registries stated that 100% of ZIP code data are captured as opposed to maybe only 80% of census tract); (2) whether the aggregate output might identify specific census tracts, which would then pose confidentiality issues. IMS created a report of the distribution of census tracts by the 4 poverty level groups, stratified by registry which DURC members reviewed. The DURC recommended further evaluation. Two members

volunteered to test the SAS file on their registry data and suggested improvements to the SAS program that have been incorporated.

- The committee reviewed a request from NCI that NAACCR archive files so that delay-adjusted completeness estimates could be calculated. The committee was supportive of this idea but pointed out that this would require a change to the data use agreement. DURC member also thought that in order to justify this change, further potential research use of archived files should be identified.
- The committee will form a workgroup to examine the distribution of derived summary stage.

Accomplishments of the various DURC subcommittees are detailed below.

Abstract Review Subcommittee

Members: Darlene Dale, Mignon Dryden, John Graff, Robert Greenlee, Holly Howe, Annette Hurlbut, Jeannette Jackson-Thompson, Missy Jamison, Jim Martin, Herman Menck, Paul Mills, Serban Negoita, David O'Brien, Karen Pawlish, Bruce Riddle, Frances Ross, Maria Schymura (chair), Recinda Sherman, Andrew Stewart, Donna Turner, Xiao Cheng Wu

The committee reviewed 145 abstracts submitted for the 2007 NAACCR Annual Meeting.

Asian/Pacific Islander Identification Panel

Members: Peg Balcius, Frank Boscoe (chair), Cheryll Cardinez, Vivien Chen, Catherine Grafel-Anderson, Scarlett Gomez, Michael Green, Holly Howe, Mei-Chen Hseih, Betsy Kohler, Sandy Kwong, Andrew Lake, Lihua liu, Barry Miller, Arti Schwartz, Maria Schymura, Melanie Williams

The past year has really been two steps forward, two steps back. At last year's NAACCR meeting the NAPIIA algorithm was featured in a plenary session, with a promise to make the algorithm available for testing and evaluation imminently. This version of the algorithm recoded cases coded as Asian NOS (code 96). Instead, the committee elected to postpone this so as to incorporate Pacific Islander NOS (code 97) into the algorithm. After nearly a year of effort, no substantive Pacific Islander name lists were created or identified, and so the work group decided to revert back to the previous algorithm (albeit with some minor enhancements and logical improvements and a more clearly written narrative). The group finalized the SAS code. DURC has approved the narrative document. The algorithm and narrative will next be reviewed by the NAACCR board and UDS.

The work group will be suspending operations until such time as a Pacific Islander name list becomes available. Myles Cockburn, as part of an independent research project not connected to this workgroup, is working on such a list that is expected to be available in 2008. In the meantime, Frank Boscoe will be searching the literature for any Thai, Kampuchean or Laotian name lists.

CINA Editorial Subcommittee - Formerly the CINA Production Subcommittee

Members: Cheryll Cardinez, Michel Cormier, Rick Firth, Holly Howe (chair), Carol Kosary, Andy Lake, Suzanne Leonfeller, Colleen McLaughlin, Dave Roney, Xiao Cheng Wu

- Implemented an Internet-based submission process of all forms for the NAACCR Call for Data.
- Produced and released the four-volume monograph for Cancer in North America, 2000-2004, meeting all deadlines in the production cycle.
- Evaluated data submitted from 65 member registries for inclusion in all CINA products, including the monograph, the 2000-2004 CINA+ Online, CINA Plus in SEER*Stat, and CINA Deluxe.
- Created CINA Plus in SEER*Stat.
- Created and released a SAS dataset of the statistics released in CINA 1999-2003.
- Revised roles of committee members to editorial with greater participation by all members.

Confidentiality Subcommittee

Members: Toshi Abe, Glenn Copeland, Dennis Deapan, Eric Holowaty, Georgette Haydu, Melissa Hudson, Missy Jamison, Lori Koch, Colleen McLaughlin (chair), Xiaoling Niu, David Stinchcomb, Kurt Weiss

The confidentiality subcommittee has been working on an annotated bibliography of confidentiality materials. The bibliography is divided in sections for reports, articles, software and tools, and books. For each bibliography entry, the subcommittee has noted the level of the material (basic, intermediate, advanced); the orientation of the material (principles, practical applications, theory, and tools); and the potential target audience (registry operations management, data stewards, researchers, as well as a few other categories). Each entry is also accompanied by a brief summary and links to the material on the web, if available.

The subcommittee also reviewed the CINA Online for SEER*Stat database and prepared a short report for NAACCR members concerning the confidentiality issues related to this database.

Rapid Case Ascertainment

Members: Carol Lowenstein (chair)

This subcommittee has not yet been convened. Results from the survey conducted in the Spring of 2006 were tabulated; presented to the DURC during its in-person June meeting; and, submitted to the NAACCR board.

Research Proposal Review Subcommittee

Members: Sally Bushhouse, Patricia Colsher, Glenn Copeland, Ron Dewar, Brenda Edwards, Holly Howe (chair), Jeannette Jackson-Thompson, Ahmedin Jemal, Carol Kosary, Andy Lake, Charles Lynch, Jim Martin, Serban Negoita, David Roney, Hannah Weir, Xiao Cheng Wu

Highlights include:

- Review panels were convened for each quarter and all reviews were conducted in a timely basis, following the guidelines of the subcommittee procedures.
- During the 2006-2007 year, 10 proposals were submitted and 7 were approved.

Research Subcommittee

Members: Vivien Chen (chair), Patricia Colsher, Dennis Deapen, Theresa Dolecek, Sally Glaser, Holly Howe, Richard Knowlton, Carin Perkins, Baozhen Qiao, Maria Schymura

The Research subcommittee is charged to facilitate and enhance research activities in NAACCR and among its members.

The Research Subcommittee identified and recruited its “initial” members in winter 2006. The representation of members includes SEER and NPCR registries, those that have an established track record of conducting research and those that are relatively new as well as an individual member. Once the specific goals are finalized, the subcommittee will open its membership to all NAACCR members.

The Research Subcommittee began its monthly conference calls in January 2007. During the initial calls, the discussion was focused primarily on identifying specific goals and/or research ideas for the subcommittee. Numerous topics and research areas were suggested and discussed.

The subcommittee identified survival analyses to be one of its research areas. While active follow-up is limited to SEER registries, all NPCR registries perform linkages with state mortality files and other secondary data files. Nearly all central registries in North America have now cumulated sufficient cases (data since 1995) and adequate post-diagnosis time to examine survival and prognosis. Methodology on survival analyses will be an area of emergent need for NAACCR members.

After lengthy discussion, the subcommittee felt that a survey of NAACCR members would be an efficient way to identify the research needs of cancer registries. A small group was formed to develop a survey questionnaire.

The subcommittee will consider reviewing the NAACCR Registry Research Matrix to identify gaps in the matrix that outside researchers need.

DATE: April 30, 2007

TO: NAACCR Board of Directors
NAACCR Committee Chairs

FROM: Mignon Dryden, CTR
Chair, Education

RE: Report to Board

The Education Committee has worked on the following projects this year:

- Educational Matrix - This has been updated and is posted on the Web. Jim Hofferkamp has agreed to update this matrix provided committee members and others alert him to new information.
- Annotated Bibliography – This project has been assigned a sub-committee headed by Herman Menck and hopes to have an updated version available in the Spring/Summer 2007.
- Advanced Workshops - Topics for current and future workshops are solicited from registry members, the Board and other Committees as well as proposed by the Education committee members and then discussed and voted on at the Education teleconferences. For the 2007 Annual Meeting, workshops on Recruitment and Retention and Multiple Primaries/Histologies will be offered. Workgroups have been convened to work on the details of these two workshops.
- Additional Topics for Trainings and Workshops – Ideas for future trainings and workshops, including the Webinar Series are solicited from committee members, NAACCR staff and registry members and discussed by the Education Committee. Suggestions from committee members were incorporated into the second webinar series to begin in October 2007.
- Recruitment and Training – This workgroup was convened this past summer and has representatives from NPCR, ACOS, NAACCR, member registries as well as a former SEER staff member and a hospital-based registry that participates in the CDC MERP project. An electronic survey was developed and completed by members. It is currently being analyzed. The workgroup planned the agenda for a workshop on recruitment and retention to be presented the day after the NAACCR annual conference.
- Webinar Series Update - Five hospital and seven central registry webinars have been conducted to date and have all been very positively received. A total of 98 hospital and 57 central registry subscriptions have been purchased. Subscribers to the current series were asked to complete a survey about the webinars. Overall, the feedback was positive. Through the survey, we solicited topic ideas for future webinars. These suggestions were incorporated into the schedule for the next series. The next series will begin October 2007. A schedule and registration form were distributed at the NCRA annual education conference April 2007.
- Trainer Program – A representative from one of NAACCR's sponsoring organizations brought to the attention of the NAACCR board the need for good trainers in the cancer surveillance profession. The education committee has formed a workgroup to develop a program to address the need for well-trained trainers. A draft outline and project concept was presented to the Board at their April teleconference and the concept was approved. The workgroup will now take the concept and develop the program.

North American Association of Central Cancer Registries
Information and Technology Committee Annual Report
June 2006 to May 2007

E-Path Transmission Work Group

The E-Path Transmission Work Group (WG), chaired by Eric Durbin, continues to work on the Standards for Cancer Registries, Volume V, *Pathology Laboratory Electronic Reporting*. This Volume has been in deployment and implementers are submitting recommendations for changes, corrections, and enhancements.

The E-Path Transmission Work Group has scheduled a face-to-face meeting on May 21 – 22, 2007 to update Volume V, to develop strategies to expand the scope of Volume V to include guidance on synoptic cancer pathology reports, to discuss the steps to upgrade to HL7 Version 2.5 or higher, and to explore the suitability of conformance software i.e. Messaging Workbench (MWB).

Interoperability Work Group

This Work Group is a collaboration of the Uniform Data Standards Committee and the IT Committee and is chaired by Gary Levin and Ken Hill. The mission of this WG is to explore the possible conversion of NAACCR data items to be more consistent with other national data standards. The WG continues to monitor the deployment of the National Provider Identifiers (NPI), part of the HIPAA requirements, and is awaiting the policy statement about the distribution of NPI related information to public health entities. In addition, the WG continues efforts to change the date data items from a text-type format to a date-type format.

Cancer Abstract Transmission Work Group

The task of this Work Group is to explore alternative mechanisms or formats to transmit the cancer abstract. The present format is the column-delimited format as described in Standards Volume II. As a first step in this process, the Cancer Abstract Transmission Work Group, co-chaired by Jim Martin and Ken Gerlach, developed a matrix to review the core criteria and software criteria of selected data transmission tools which determined the most suitable national format is the HL7 CDA (Clinical Document Architecture) Release 2. The WG is working towards a pilot implementation of this format in two states --- from a hospital cancer registry to a central cancer registry.

Path Lab Sub-committee

The sub-committee, chaired by Carol Kosary, continues working on many projects to help registries develop electronic path (e-path) lab reporting as well as providing a forum for sharing e-path reporting experiences. This sub-committee has developed and the Board has approved a guidance document titled, “Electronic Pathology (E-Path) Reporting Guidelines”. This document is geared towards registry and laboratory managers and has been posted on the NAACCR web-site.

Security Work Group

This new Work Group is a collaboration of the Registry Operations Committee and the IT Committee and is chaired by Herman Menck. The charge of this WG is to update existing

and develop, as needed, NAACCR cancer registry operations and information technology security standards, policies, and procedures. The WG is in the early stage of developing an outline or table of contents of areas to be covered e.g disaster recovery. The next step will be to find volunteers to compile and write, as necessary, a description for each of the identified sections or chapters. Volunteers are needed.

Volume I Subcommittee

Standards Volume I has been updated to be compatible with revisions in the Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary, Version 11.2.

Submitted April 2007

Ken Gerlach, Chair

NAACCR Information and Technology Committee

NAACCR 2006-2007 NOMINATING COMMITTEE

Annual Report

Committee Members: Vivien W. Chen, Louisiana Tumor Registry
Laura Stephenson, Wisconsin Cancer Reporting System
Donna Turner, Manitoba Cancer Registry

Board Liaison: Karen Knight

NAACCR Staff: Joshua Whitley

Positions for Election: Treasurer and 3 Positions of Representative-at-Large

Overview

The committee was charged with securing nominations for NAACCR officers and preparing a slate of candidates for election through electronic voting. Beginning in the Fall of 2006, the committee held meetings on a regular basis by teleconference and email. Committee members were all very actively involved and NAACCR staff provided excellent support. The tasks charged to the committee have been successfully completed.

Work Chart and Timeline

The initial meetings were focused on: defining functions/activities, establishing a timeline, assigning responsibilities, and assigning time allotments and due dates for each activity. The work chart and timeline were very helpful in ensuring all tasks were completed on time and the election results could be provided to the NAACCR Executive Office prior to the printing of the NAACCR Directory.

Electronic System

This was the fourth year that the electronic system was used for both nomination and voting procedures. The system functioned well without major problems, despite a change in the NAACCR support staff. The call for nominations was circulated using the NAACCR List Serv but nominations and responses were faxed to the NAACCR office. As a result, NAACCR staff had to retype candidate information.

Balloting was organized by circulating the candidate and call for voting materials via email to voting delegates with link to a URL that directed the voter to an electronic ballot. This database was accessed through a NAACCR-assigned password and voting ID. The database was 'activated/de-activated' by NAACCR staff in accordance with a predefined voting timeline.

Voting Delegate Verification

Based on last year's committee recommendation, the Board endorsed the voting delegate verification process prior to voting. An email was sent from the NAACCR office to the designated voting delegates using their email addresses, as listed in the most current NAACCR Directory. Delegates were asked to verify whether they were indeed the voting delegates; if not, to inform NAACCR of the new delegates. The non-respondents were divided up among the committee members for further contact and follow-up. All but three registries, mostly U.S. Territories, responded to the verification.

Promotion and Nomination

An article on the Call for Nomination that described the nominating process and eligibility of nominees was submitted by the Nominating Committee for the Fall 2006 issue of the *Narrative*. In addition, two promotional notices were emailed to NAACCR members via List Serv. The first notice used the holiday season theme and was sent prior to the Call for Nomination. The second notice, *Nom-i-nate* (sung to the tune of "Let it Snow"), was sent during the nomination period. Call for nominations were circulated on January 2, 2007 with a second notice sent on January 22, 2007. The nomination period closed on February 6, 2007. We received a total of 9 candidates with diverse representation. Two candidates were nominated for Treasurer and seven candidates for three positions of Representative-at-Large.

Voting and Results

A slate of candidates and ballots were prepared by NAACCR staff. Voting opened on February 19, 2007 and closed on March 19, 2007. An article on "Let us Vote" (again to the tune of "Let it Snow") was published in the Winter 2007 issue of *Narrative* during the voting period. The response rate for the NAACCR general election was 84.4%. The electronic ballots for all positions were tabulated, validated and reported to the NAACCR President. This year there was a tie in the third Representative-at-Large position. Following NAACCR Policies, the Board cast lots to break the tie.

Remaining Tasks

The committee will present the report at the NAACCR annual business meeting in Detroit.

Challenges, Lessons Learned and Recommendations

- Personal contact to solicit nominees has proven to be the most effective way to conduct the Call for Nomination and is highly recommended. This process should begin shortly after the committee is formed (late summer/early fall).
- Verification of voting delegate information is a key step for improving voting response rate. Personal contact, in addition to email communication, is extremely

effective.

- Candidates often spend much time preparing their information. The committee felt this information should be shared with all NAACCR members, allowing them to have input in the voting process by discussing with their voting delegates.
- The committee recommends a fully electronic nomination process which allows candidates to type their information online and to submit it electronically (instead of faxing). The information is then ready for posting on the web.
- The overlap of the NPCR competitive grant application and NAACCR voting period may have resulted in the less than desirable response rate (84.4%).
- The phone and email reminder for voting by NAACCR staff and committee members was effective. It should continue to be used in the future.
- The limited space and capability of the NAACCR web server during the voting period did not allow for a reminder email to be properly sent. The server has been updated and this should no longer be an issue for next year.
- The committee highly recommends that a Canadian representative be included in next year's committee and, if possible, a member from the previous year as well for continuity and more effective and efficient process of nomination and voting.

Acknowledgements

Karen Knight was the NAACCR Board Liaison to the committee. We appreciated her participation and input. Joshua Whitley was the NAACCR staff member assigned to this committee. He managed the List Serv circulation on nomination and voting and maintained electronic balloting system. We appreciate his assistance and active participation.

Respectfully submitted,

Vivien W. Chen, Ph.D.
Chair, Nominating Committee
May 1, 2007

NAACCR Program Committee 2007 Year End Report

May 17, 2007

John J. Graff, PhD – Chair, Program Committee

As stated in the NAACCR Operating Manual, “The Program Committee is responsible for the program for the Annual Conference and works with the conference planner to set guidelines for meeting logistics and locations.”

The 2007 Program Committee consists of the following members:

Name	Affiliation
John Graff, Chair	MDCSS – Detroit
Nancy Lozon	MDCSS – Detroit
Joanne Harris	MDCSS – Detroit
Patrick Nicolin	MDCSS – Detroit
Fawn Vigneau	MDCSS – Detroit
Gloria Kwiatkowski	MDCSS – Detroit
Holly Howe	NAACCR, Executive Director
Betsy Kohler	NAACCR President / New Jersey State Registry
Charlie Blackburn	NAACCR
Shannon Vann	NAACCR
Jan Conway	NAACCR
Brenda Edwards	NCI
Marsha Reichman	NCI
Andrew Stewart	American College of Surgeons
Randi Rycroft	Colorado Cancer Registry
Mignon Dryden	California Health Collaborative
Dee West	Northern California
Fran Michaud	CDC
Jon Tonita	Saskatchewan Tumor Registry
Eric Holowaty	Cancer Care Ontario
Won Silva	Michigan Cancer Surveillance Program
Patricia Lim	Venue West
Jeannette Jackson-Thompson	Missouri Cancer Registry

We have held monthly teleconference meetings since August, 2006 (with the exception of December 2006 and March 2007) to plan the program and activities of the 2007 Annual Conference. Each teleconference begins with a roll call of Committee members and a review of the minutes from the previous call.

A conference theme was decided on the first Committee call, “Cancer Knows No Borders,” and was subsequently approved by the NAACCR Board of Directors. This program theme highlights the international scope of NAACCR and its members as well as the integration of the numerous specialties and disciplines that are involved in cancer registration, treatment and research. The Committee discussed and chose Plenary Session topics and reached a final decision on:

- GIS – Cartographies of Cancer
- Determining Quality of Cancer Care Using Cancer Registry Data
- Interoperability of Cancer Registration Standards

The invited plenary speakers are all well-published and recognized leaders in their areas of specialty.

The Call for Abstracts was distributed to the NAACCR List Serve on October 16, with a submission deadline of December 8. We received a record response to the Call for Abstracts, with 145 oral and poster submissions. The Abstract Review Sub-Committee, led by Maria Schymura (Chair of the Data Use and Research Committee), reviewed the submitted abstracts, accepting all but 3 presentations. When the abstract review process was completed, Maria forwarded the results to me. I, with the assistance of Fawn Vigneau, positioned the approved oral presentations into the Program Outline, by presentation theme.

The Final Program consists of 11 Plenary Speakers, 91 Concurrent Session (oral) speakers and 50 poster presentations. Acceptance and assignment were sent out to authors.

This year's Conference Program will be unique in a number of respects:

- Poster viewing will have assigned times both during the Tuesday evening Opening Reception AND during a specified 1-hour "Break Period" on Wednesday morning. The quality of our poster presentations has been increasing greatly from year to year, and the Program Committee wanted substantial dedicated time for Conference attendees to focus on poster viewing and interaction with poster authors.
- This year marks NAACCR's 20th Anniversary. We will have a special presentation given by Betsy Kohler at the Opening of the Conference. We will also have a celebration of NAACCR's 20 years during the Tuesday evening Opening Reception.

As the NAACCR membership continues to grow and the Annual Conference evolves with our ever-changing world of cancer registration and research, many lessons are learned from the planning of each year's Conference. Some special lessons that were standouts during this year's preparation process include:

- Include language in the Call for Abstracts that states that the abstract submitter should hear confirmation of receipt from Venue West of his/her submission within 2 weeks of the abstract deadline. We cannot be held responsible for email filters or other electronic failure inhibiting the submission process.
- A cross reference should be made to the complete program list and abstract spreadsheet when mailing registration materials. In the past, this cross reference has not been made and new authors/presenters do not receive Conference registration materials.
- When mailing response (acceptance/rejection) letters to abstract submitters, pay close attention to how the address has been entered into the Excel spreadsheet database. With some addresses (especially foreign addresses), the fields do not work well with a mail merge and the letters may not make it to the intended recipient.

The NAACCR Annual Conference is the only opportunity for the entire NAACCR membership to come together and interact with regard to past, present and future organization, industry and scientific activities. The Annual Conference is an important showcase of the work being done by NAACCR and its membership. Involvement in the Program Committee is important for providing input on Annual Conference planning, including topics covered, speakers invited for presentation and other planned activities. Necessary members for the Program Committee include:

- Chair, from the host institution
- Chairs/Hosts from previous and following years' Annual Conference
- A member from the Education and Communications Committees
- A member of the NAACCR Board of Directors
- Representatives of NCI and CDC
- Representative from a Canadian registry

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES

Registry Operations Committee (ROC)

Annual Report

May 2007

Members: Susan Bolick-Aldrich (Co-chair), Susan T. Gershman (Co-chair), Jael Anaya, Maria Celaya, Gayle Clutter, Jan Conway, Rose Garner, Carol Hahn-Johnson, Joanne Harris, Mary Jane King, Gary Levin, Mary Lewis, Seban Negoita, Robin Otto, Lisa Pareti, Lina Patel-Parekh, Reita Pardee, Cathy Rimmer, Randi Rycroft, Wendy Scharber, Nancy Schlag, Betty Smith, Shannon Vann, Kim Vriends, Brad Wholer

Goals and Objectives:

1. Promote best practices for the collection and use of cancer and patient information.
2. Coordinate the implementation of changes that promote continuity in data to be collected.
3. Provide educational resources related to registry operations.
4. Provide technical assistance and facilitate the exchange of technical information among NAACCR members.

Canadian Territorial Registries (Mary Jane King): Canada is represented on the Registry Operations Committee by a member of the Canadian Council of Cancer Registries (CCCR) Data and Quality Management Committee (DQMC). The objective of the DQMC is to provide recommendations and advice to CCCR on matters relating to the quality and standardization of cancer registry data. Working through its various subcommittees [Staging Implementation Working Group, Education Committee, Resolution Issues Group, Canadian Cancer Registry (CCR) Professional Workshop, and Multiple Primary and Histology Working Group], the DQMC accomplishments during the 06-07 fiscal year include: initiation of review and revision of the CCR data quality (DQ) indicators with Statistics Canada; collaborative staging training; 2007 Multiple Primaries and Histology Coding (MP/H) rules training; continued resolution of coding issues; inclusion of CCCR standards in the NAACCR Standards Comparison, including submission of the CCCR Reportable Diagnosis List to NAACCR Vol. II; the addition of CCCR requirements to the NAACCR Required Status Table; and collaboration on major/minor changes for June 2008.

The DQMC goals for next year include: revise the DQ indicator reports and adjust the recommended guidelines; conduct analysis of reported staging data (TNM and CS) and recommend DQ indicators for stage data; continue implementation of the 2007 MP/H rules, including support for the provincial and territorial registries and training on additional schemes; address additional issues such as record layout and benign brain coding; and continue ongoing work with NAACCR, including furthering the integration of CCR with NAACCR standards.

Death Clearance Workgroup (Robin Otto and Susan Bolick-Aldrich, Co-Chairs): The Death Clearance Workgroup was formed in 2005 to address unresolved issues with the death clearance process and to create a single document that includes all available resources on death clearance within one source. The Workgroup met monthly this past year and has made tremendous progress toward the finalized Death Clearance Document. Issues that have arisen that will require consensus are being prepared for discussion by the CRSC and the NAACCR Board of Directors in upcoming months. The timeline for completion of the document is October 2007.

Issues Impacting Registry Operations: An issue still under discussion is the review of Category 5 of the Breast Imaging Reporting and Data System (BI-RADS), developed by the American College of Radiology.

Multiple Primary and Histology Coding Rules (Carol Hahn-Johnson, Chair): The Multiple Primary and Histology (MP/H) Coding Rules have been completed. The Train the Trainers program reached over 5000 registrars by the end of the Fall 2006 trainings. Tumor registrars are also receiving training via the National Cancer Institute's Surveillance, Epidemiology, and End Results Program (NCI/SEER) Breeze Sessions web-based training. These sessions are available on the NCI/SEER web site for viewing as well as downloading. No modifications to the MP/H Coding Rules are expected until at least January 2008.

Benign Brain Tumors / Multiple Primary Rules Work Group: The benign and borderline intracranial and CNS tumors multiple primary rules have been completed. They will be reviewed at the ROC's in-person meeting at the 2007 NAACCR Annual Conference, on Monday, June 4.

Hematopoietic Work Group: This group is on hiatus until after the July 2007 CDC hematopoietic meeting.

Process Improvement Program (Shannon Vann, Chair): Process Improvement Workshops were/will be presented in conjunction with the annual statewide meetings of the following groups:

- 2006: Alabama Cancer Registrars Association, 9/26/06
Washington State Tumor Registrars Association, 9/29/06
New York State Cancer Registrars Association, 10/19/06
- 2007: The Tumor Registrars Association of Tennessee, to be held 9/20/07

Record Consolidation Subcommittee Report (Jennifer Seiffert, Chair): By consensus, the subcommittee has met on a quarterly basis again this year, since most activity has occurred in the work groups (see Work Group Reports, below). Two articles on subcommittee activities were submitted to the NAACCR newsletter during the year, as required.

Tumor Linkage Best Practices Work Group (Jerri Linn Phillips and Colleen Sherman, Co-chairs). The work group's preliminary analysis of the new multiple primary rules indicates that the approach of a histology-pairs table will not be adequate for an automated system. The logic is more complex than can be accommodated in a single table. The group wants to postpone further work on developing a template until after some experience is gained with 2007 data and after working through issues that may turn up with the new rules. They have concluded, however, that a first step will be to prepare a rule set for determining which MP/H rule set to apply to a case, by date, site, histology, and other characteristics.

Work continues on the paper analyzing the site-pairs table (created for use with the former multiple primary rules) against multiple primary data in actual registries. Deborah Bringman is performing the analysis. The group is discussing whether the emphasis of the analysis should be on validating the site pairs table, or validating the registry data.

Data Item Consolidation Work Group (Peggy Adamo and Jael Anaya, Co-chairs). Work continues on the report on the survey of consolidation of demographic items conducted in 2005. They have had very poor attendance at their scheduled teleconferences and have not held all scheduled calls. Peggy Adamo will be rescheduling a meeting when she has a report prepared for distribution. She will be inviting all Subcommittee members to the call in hopes of recruiting some more members to the work group.

Record Consolidation Test Work Group (Frances Ross, Chair): The Expert Panel has completed review of melanoma and head and neck test cases, comparing tumor counts using the old and new multiple primary rules. The group has drafted their analysis plan, which is near completion. It will include descriptive analyses of the differences in counts from the old to the new rules. The Expert Panel has reviewed half of the breast test cases and found them to be problematic. They have held a meeting with SEER to discuss issues and questions identified in the review. SEER responded with directions on how the Tables in the breast MP rules were used, and the experts will finalize their answers on these cases during May.

Security Workgroup (Herman Menck, Chair): The Security Work Group is a group with representation from both the Information Technology Committee and the ROC. Its objective is to explore the feasibility of defining information technology security needs (e.g., hardware, software, firewalls, Internet transmissions of data, web-based applications, data encryption on laptops, security policies, and disaster recovery) for cancer registration, with the intent of compiling and enhancing associated standards and guidance. The group will provide a chapter on security that will be incorporated into the new version of Volume III. This draft is expected to be completed around December 2007.

Volume III Workgroup: This work group is currently being organized to update Volume III: Standards for Completeness, Quality, Analysis, and Management of Data.

UDSC Activity: 2006-2007

**Prepared by: Andrew K. Stewart
Chair, UDSC
May 15, 2007**

1) Publication of 2007 NAACCR Implementation Guidelines

Clarified the six items by SEER/NCI to support the Histology and Multiple Primary abstracting rule changes.

- Ambiguous Terminology DX [442]
- Date of Conclusive DX [443]
- Mult Tum Rpt as One Prim [444]
- Date of Multiple Tumors [445]
- Multiplicity Counter [446]
- Number of Tumors/Hist [447]

Provided further documentation for the 10 National Provider Identifiers (NPI) for facility and individual health care providers in the United States. NPI is a unique identification number for health care providers, had been scheduled for 2007 implementation by the Centers for Medicare & Medicaid Services (CMS) as part of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Providers are currently obtaining NPI codes and then May 2007 implementation date set by CMS has been rolled back due to software and vendor technical concerns regarding access to validation lists for released NPIs.

Clarified reporting requirements of SEER/NCI, CoC, and NPCR for cases diagnosed starting January 1, 2007.

2) Publication of NAACCR vol. II, v11.2

Updates to vol. II included all issues addressed in the 2007 NAACCR Implementation Guidelines. In addition, corrections were made to incorrect documentation of the urban-rural continuum codes for 2003.

Provided further documentation for the 10 National Provider Identifiers (NPI) for facility and individual health care providers in the United States, and clarified the relationship between the NPI – Reporting Facility [#545] and Registry ID [#45] item.

3) Interoperability Work Group

Joint Workgroup of UDSC and IT - co-chaired: Gary Levin & Ken Hill

A broad review of the NAACCR data dictionary (vol. II) has been started to identify items within the NAACCR data standards that warrant review in order to be consistent with nationally recognized data standards used in other health IT systems. As a starting point, legacy data and how date fields changed through time have been reviewed. The work of this group is being absorbed into the Symantic Interoperability Workgroup of the Ad Hoc Interoperability Committee.

4) Edits Work Group – S. Capron

Posted the following NAACCR Edit sets to the web:

- V11CAL07 for NAACCR (September, 2006)
- NACR110C - version 11.0C (September 18, 2006)
 - Included corrections and addition of inter-item edits
- NACR111 - version 11.1 (January 12, 2007)
 - Included modifications required by the 2007 Implementation Guidelines
- NAACCR v11.1 (anticipated release: end of May, 2007)

5) Canadian data item comparison with NAACCR data items – L. Havener & E Hamlyn

Monthly meetings to review/compare Canadian data items with NAACCR standards are being held and observed differences are being documented. Dependent on the results of the review Canada may be submitting requests to change existing items and/or requests for new data items to UDS. Subsequent steps will include a review of NAACCR items that are not currently collected by Canada. Finally, Canada will provide Collect and Transmit information to include in the Standards Volume II Required Status table.

6) Future issues:

Future assessment and evaluation of data items appearing in vol. II will require close coordination with the Ad Hoc Interoperability Committee and its workgroups as a transition period should be anticipated between the existing flat-file data transmission standards to those developed to be semantically and syntactically “intraoperable” with other health information informatics and technology standards.

NAACCR GIS Ad-Hoc Committee
Year End Report
April 30, 2007

The GIS committee was busy and productive throughout 2006-07. Here are the main items we worked on:

1. NAACCR grant award from the Susan E. Komen Foundation: “Quantifying Transportation Barriers in Accessing Health Facilities for Breast Cancer Diagnosis and Treatment”

The committee contributed substantially to a large grant proposal to the Susan E. Komen Foundation to examine issues of whether travel differences create disparities and inequalities in the quality of care received. The project includes the development of a sophisticated GIS tool to measure actual road-network travel distances between residences and hospitals. The proposal has been funded, and members of the committee will actively provide technical and logistical oversight. This is the first grant funding received by NAACCR from a non-governmental source.

2. GIS-themed plenary session and GIS-related presentations at the 2007 annual meeting

Once again, GIS will have a prominent position at the annual meeting, as reflected in the conference theme, “Cancer Knows No Borders”. A GIS-themed plenary session will be moderated by David Stinchcomb. Presenters in this session were nominated by GIS committee members.

3. Review article summarizing past GIS-related NAACCR presentations

The last several years have witnessed great breadth and depth of GIS-related presentations at the NAACCR annual meeting. Much of this work is not known beyond the registry community itself. In order to publicize this work, the GIS committee is preparing a review article, led by Kevin Henry and David Stinchcomb. This is underway and will be completed in the year ahead.

4. SAS Distance Calculator Utility

Committee members oversaw minor enhancements to this tool, and it was actively promoted at the 2006 annual meeting, led by the efforts of Chris Johnson. Distance to hospital was included in the most recent call for data, though few registries participated. This tool will be incorporated into the 2007 Toolkit Workshop. The experience of the Komen grant (see above) should inform the long-term utility of this tool.

5. Geocoding best practices handbook

In 2006, the GIS committee, working with Dan Goldberg of the University of the Southern California, developed an outline for a geocoding best practices handbook. The handbook reflects a need for guidance about geocoding techniques that emerged from the committee’s recent survey of NAACCR registries. Mr. Goldberg received a contract for this work in December 2006 and wrote a full draft. He is currently revising the draft with the editorial oversight of the GIS committee.

Once the handbook is published (originally expected to be published in electronic format only, but recently nominated for hardcopy publication by NAACCR management), the handbook will be publicized through conference presentations and potentially an abridged summary that can be published in a rapid-turnaround

electronic journal. This would effectively make the handbook accessible through PubMed, Web of Science, and other medical/scientific databases.

6. GIS-related NAACCR data items

Committee members authored a standard for block group and made several enhancements to the GIS Coordinate Quality data item. All of these were approved by the UDS Committee in early 2007.

7. Education

Frank Boscoe taught a section on GIS at the NAACCR Toolkit Workshop in Nashville. He and Chris Johnson are on the faculty for the Toolkit Workshop in 2007.

8. Member map

David Stinchcomb designed a map showing the NAACCR membership that can be used on publications (e.g., the NAACCR Membership Directory) and for various promotional purposes. The committee is also exploring map-themed graphics that can be used as a backdrop for this year's conference, given the conference theme.

9. GIS Survey

In the past year, committee members followed up with registries who had not submitted their GIS surveys, interpreted the results, and presented these results to the NAACCR Board. The NAACCR Board requested that the findings of the survey be summarized in a white paper format, rather than a Powerpoint presentation. This is still in progress and is expected to be completed very soon, led by Recinda Sherman and David O'Brien. The survey findings will also be shared in a presentation at the annual meeting.

Additionally, there were several items on our agenda that we decided not to pursue. One was the publication of the GIS Handbook and/or Luc Anselin's commissioned report on cluster software in the *International Journal of Health Geographics*. Despite an official policy that authors from participating institutions (e.g., NCI, CDC) can publish in this journal for free, we were quoted an exorbitant price by the journal.

We also debated whether to apply for permanent (as opposed to *ad hoc*) committee status, but elected to remain as an *ad hoc* committee for now. We note, however, that our committee clearly does not function as a true *ad hoc* committee, in that there is no fixed goal that would result in the termination of the committee upon its completion.

Other members and guests not mentioned above who contributed substantially and actively to the committee (by doing more than simply attending conference calls: by contributing agenda items, reviewing drafts of documents, etc.) were Bob Borchers, Myles Cockburn, Stephanie Foster, Holly Hodges, Eric Holowaty (board rep.), Jennifer Kachajian, Christian Klaus, Mary Mroszczyk, Kim Porter, Tom Richards, and Josh Whitley (minute taker).

Blank Space for IRB

Blank Space for IRB

DATE: May 15, 2007
TO: NAACCR Board of Directors & NAACCR Committee Chairs
FROM: Susan Van Loon, ACoS Liaison
RE: Report to Board

As the NAACCR liaison to Commission on Cancer (COC) I attended the COC annual meeting in October 2006 in Chicago. Highlights of the meeting are as follows: Leadership changes were announced, Frederick Greene, MD, FACS was reappointed to a second term as COC chair. During this meeting the COC announced the launch of Electronic Quality Improvement Packets (e-Quip) for breast cancer. This is a web-based application, which provides individualized case summary reports for breast cancers as submitted to the NCDB by participating hospital-based cancer programs. The State Chair outstanding Achievement awards were also presented.

The NAACCR Cancer Care Initiatives 2007 annual report was submitted to COC in May 2007. This report summarizes NAACCR's key projects/initiatives; recently released publications; future conferences and educational programs and emerging issues within the organization.

The 2007 annual meetings of the committees of the Commission along with the annual meeting of the State Chairs is scheduled to take place in Chicago May 17-18, 2007. I am planning to attend.

AJCC Liaison Annual Report

As NAACCR's liaison to the AJCC, I am a member of the Collaborative Staging Task Force and I attend the AJCC's annual meetings.

Last September, the AJCC convened a Collaborative Stage needs assessment meeting comprised of individuals with expertise in the areas of staging, informatics, research and programming. During this meeting, the group identified several topic areas to be addressed for the next major Collaborative Stage release and beyond. The topic areas include: training, documentation, relationships with outside groups and interoperability issues. Collaborative Stage Version 2 will be implemented in 2010 coinciding with the publication of AJCC's *Cancer Staging Manual*, 7th ed and implementation of NAACCR Version 12. AJCC's changes are expected to require additional site-specific factors to be added to the CS schemas, for collection of additional tumor markers and perhaps genetic information.

The group has continued to meet via a series of conference calls to further work through these issues. After all of the issues are reviewed, a plan will be developed to assign specific tasks to smaller groups. One of the areas to be addressed is related to the coding structure, so Lori Havener will be invited to work with some of the groups so that appropriate information will be provided to NAACCR.

I also attended the AJCC's Annual Meeting in Chicago last September, where many of these same issues were also discussed.

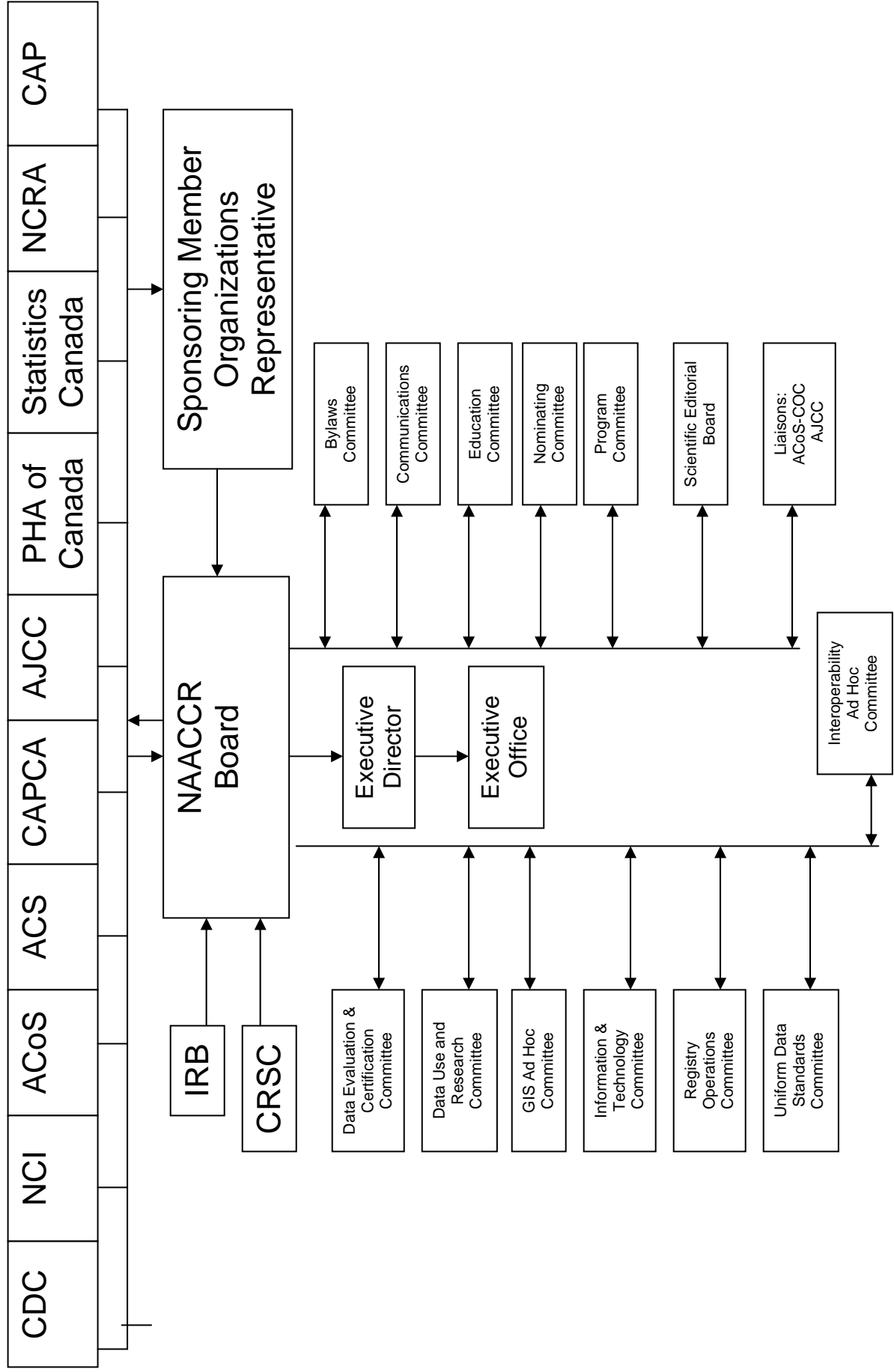
I will continue to routinely submit updates to the NAACCR Narrative.

--Colleen G. Sherman, RHIA, CTR
AJCC Liaison

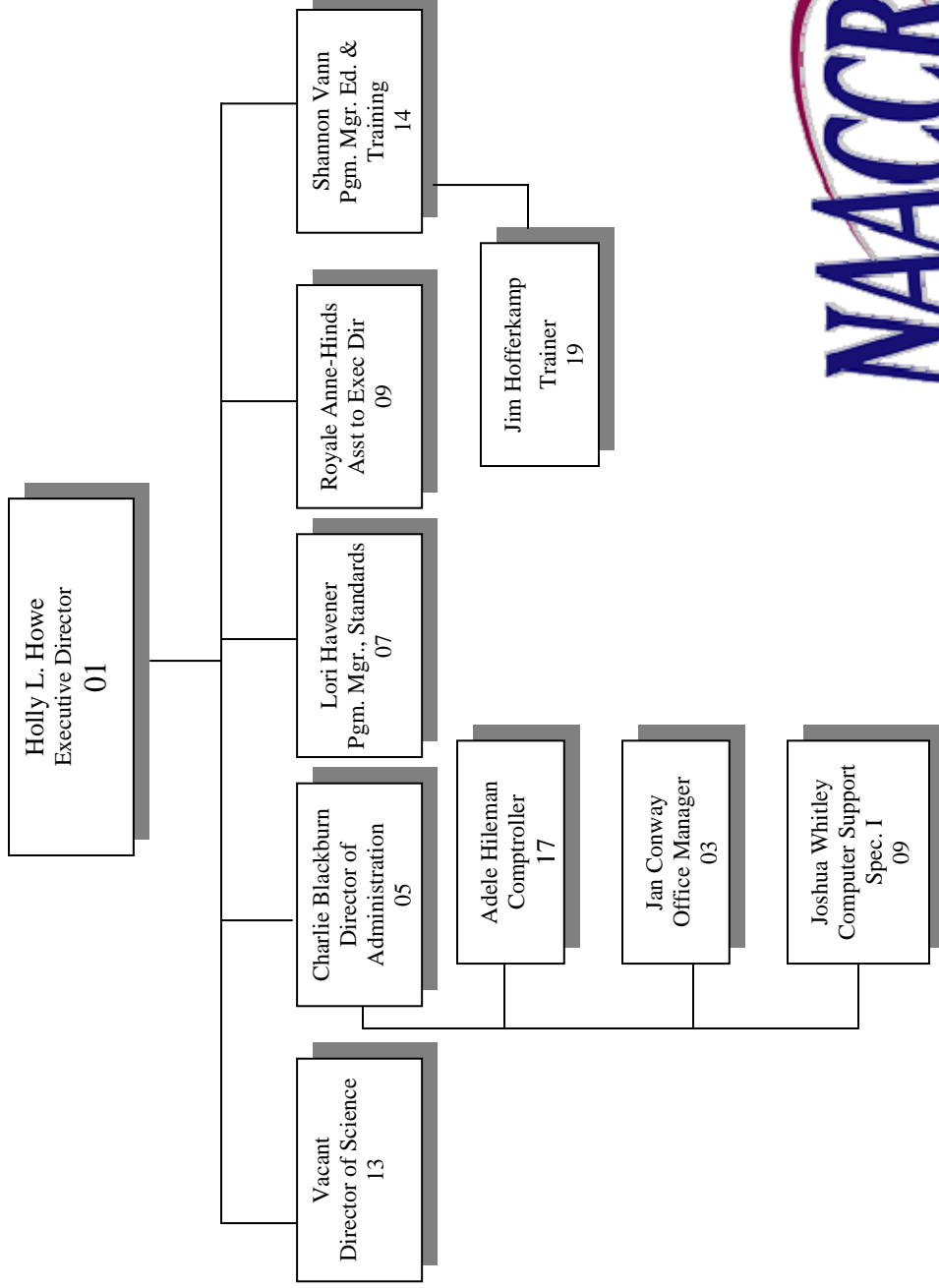


Appendix of Documents for Delegates at the Business Meeting

North American Association of Central Cancer Registries (NAACCR, Inc.) Organization Relationship 2007-2008



NAACCR Executive Office



**NORTH AMERICAN ASSOCIATION OF
CENTRAL CANCER REGISTRIES
(NAACCR)
MISSION AND OBJECTIVES RELATED TO GOALS
2006 – 2010
*As of June 6, 2007***

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.

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 The Education Committee will review using their established protocol all education/training materials for use by NAACCR.
- 3-2 In January 2008, plan and hold a Cancer Surveillance Institute I: Principles and Public Health Applications (CSI I).
- 3-3 Plan and hold a second Cancer Surveillance Institute II: Statistics and Methods (CSI II) in NAACCR FY 2008.

- 3-3 Conduct a Toolkit Workshop in the fall 2007.
- 3-4 NAACCR will hold an advanced course in conjunction with the annual meeting.
- 3-5 Hold up to 3 additional in-person trainings using NAACCR training staff, usually at the request of NAACCR members.
- 3-6 Provide a 12-session Webinar series for central cancer registries
- 3-7 Provide a 8-session Webinar series for hospital cancer reporters.

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 Administer the Process Improvement Program (PIP) for conference support for a state-based or local workshop to the extent resources are available from the NCI contract

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 Conduct data analyses to assess quality of CINA submissions.
- 6-2 Assess a case fatality approach to the NAACCR Method to assess case ascertainment completeness.
- 6-3 NAACCR will conduct special studies to evaluate and standardize socio-demographic data.
- 6-4 By September 2007, repeat of the work of the first Record Consolidation task force, using the same test cases and the same procedures to determine the number of primary malignancies, but apply the new Multiple Primary and Histology coding rules.

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

- 7-1 Produce the CINA monograph, all CINA Plus products, and the research files for CINA Deluxe from the 2008 NAACCR *Call for Data* in a timely and accurate manner.
- 7-2 Annually a report will be prepared listing of all research publications prepared under the auspices of NAACCR and using the aggregated data sets from member submissions.
- 7-3 Release four RFAs annually for CINA Deluxe NAACCR-member researcher-initiated projects.
- 7-4 Establish and maintain a peer review process for proposals submitted for using the CINA Deluxe research data file.

- 7-5 NAACCR will participate in the annual report to the nation.
- 7-6 Ensure that statistical analytic support is provided for the NAACCR Research Program that is timely and accurate.
- 7-7 By July 1, 2008, develop a shortest path finder using a roadmap network to process registry listings of breast cancer patients and calculate actual travel distance and travel time between the residence of all patients and all facilities visited for diagnosis and treatment.

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 quarterly 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.

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 2008, make 4% 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 Certification committee will work with registries to support training to help them move toward certification at the highest standard.

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.

NAACCR ACCOMPLISHMENTS RELATED TO MISSION, GOALS, AND OBJECTIVES

BETWEEN June 2006 - May 2007:

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

Publication of 2007 NAACCR Implementation Guidelines

Clarified the six items by SEER/NCI to support the Histology and Multiple Primary abstracting rule changes.

Ambiguous Terminology DX [442]

Date of Conclusive DX [443]

Mult Tum Rpt as One Prim [444]

Date of Multiple Tumors [445]

Multiplicity Counter [446]

Number of Tumors/Hist [447]

Clarified reporting requirements of SEER/NCI, CoC, and NPCR for cases diagnosed starting January 1, 2007.

Provided further documentation for the 10 National Provider Identifiers (NPI) for facility and individual health care providers in the United States, and clarified the relationship between the NPI – Reporting Facility [#545] and Registry ID [#45] item.

A broad review of the NAACCR data dictionary (vol. II) has been started to identify items within the NAACCR data standards that warrant review in order to be consistent with nationally recognized data standards used in other health IT systems. As a starting point, legacy data and how date fields changed through time have been reviewed.

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

The UDS Committee completed review and revision of Volumes I and II of the NAACCR standards documents. Updates to volume II included all issues addressed in the 2007 NAACCR Implementation Guidelines. In addition, corrections were made to incorrect documentation of the urban-rural continuum codes for 2003.

The Board of Directors reviewed and approved all revised standards documents.

The NAACCR membership was provided copies of all revised standard documents.

Canadian data item comparison with NAACCR data items. Monthly meetings to review/compare Canadian data items with NAACCR standards are being held and observed differences are being documented. Dependent on the results of the review Canada may be submitting requests to change existing items and/or requests for new data items to UDS. Subsequent steps will include a review of NAACCR items that are not currently collected by Canada. Finally, Canada will provide Collect and Transmit information to include in the Standards Volume II Required Status table.

Posted the following NAACCR Edit sets to the web:

- V11CAL07 for NAACCR (September, 2006)
- NACR110C - version 11.0C (September 18, 2006)

- Included corrections and addition of inter-item edits
- NACR111 - version 11.1 (January 12, 2007)
 - Included modifications required by the 2007 Implementation Guidelines
- NAACCR v11.1 (anticipated release: end of May, 2007)

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

Developed and held a 12 part series of webinar training for central cancer registry staff.

Developed and held a 8-part series of webinar training for hospital cancer registry staff.

Developed and held six in-person training courses on registry operations throughout the year.

Developed and held a 4-part weekly webinar course for CTR Exam Preparation.

Conducted the Data Toolkit Workshop in the fall 2006 supported in part by the NCI contract.

Held a 5th NAACCR Cancer Surveillance Institute (CSI) I: Principles and Public Health Applications (CSI I) in February 2007.

Planned and held 7 courses in conjunction with the NAACCR annual conference.

4. Provide technical assistance to NAACCR member organizations

Developed the NAACCR Asian Pacific Islander Identification Algorithm (NAPIIA).

Held three process improvement programs and approved a fourth to be held next year.

Gave five Mentor Fellowships.

Gave one Scholarship to a person from a developing registry (non-North American) to attend the 2007 NAACCR annual conference.

An annual conference was held, on the theme, "Cancer Knows No Borders," The Final Program consisted of 11 Plenary Speakers, 91 Concurrent Session (oral) speakers and 50 poster presentations. Acceptance and assignment were sent out to authors.

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

The President convened chair meetings, including two quarterly teleconferences and two in-person meetings.

Committee Chairs, the President, and the Executive Director routinely informed the membership on key issues in the newsletter (each quarter), listserv, and a town meetings (as appropriate).

Published four editions of the *NAACCR Narrative*

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

Evaluated data submitted from 65 member registries for inclusion in all CINA products, including the monograph, the 2000-2004 CINA+ Online, CINA PPlus in SEER*Stat, and CINA Deluxe.

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

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

Created and released a research data set of individual records from registries that participated in the *Call for Data*.

Created and released two new research and surveillance tools: *CINA in SAS* and *CINA Plus in SEER*Stat*.

Released *CINA+ Online* in a new and improved software and hardware system to sustain responsiveness at current levels of usage on the Website.

Reviewed 11 and approved 9 applications for CINA Deluxe in the last year (IRB and Research Proposal Review Subcommittee).

The committee reviewed 145 abstracts submitted for the 2007 NAACCR Annual Meeting.

Implemented an Internet-based submission process of all forms for the NAACCR Call for Data.

Produced and released the four-volume monograph for Cancer in North America, 2000-2004, meeting all deadlines in the production cycle.

NAACCR developed a SAS program to match registry geocoded census tract data with the percent census tract poverty estimate from census data. The program is available on the NAACCR website. The program report provides the actual census tract by poverty level information and also groups this information into four categories.

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 Executive Director and President attended the annual in-person meeting of the Canadian Council of Cancer Registries.

The Sponsoring Member Organizations met four times with the NAACCR board: twice in-person and twice by teleconference.

The Cancer Registration Steering Committee has met bi-monthly during the last year.

Posted approved monthly board minutes on the Web site.

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

NAACCR members using NAACCR data resources published a total of six articles in 2006 and two are in press.

One collaborative manuscript was published in 2006.

One surveillance report was posted to the NAACCR website.

The NAACCR exhibit was displayed at the NCRA Conference in Las Vegas (April).

10. Maintain financial and economic stability for NAACCR

NAACCR maintained the NCI conference support grant, the ACS CSI I support grant, the NCI contract, and the CDC cooperative Agreement during the past year.

NAACCR received a new 3-year grant from the Susan G Komen Race for the Cure for \$298K for three years to support activities of the GIS Committee.

NAACCR received a new 5-year grant from CDC to support the annual conference.

NAACCR received donations in the amount of \$2125 from members; \$150 from private donors, \$20K from corporations.

NAACCR realized 8.46% return on the entire investment portfolio. (EXCEEDED goal of 4%).

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

Conducted review of data for 70 registries for registry certification.

NAACCR Policy Decisions

Policy Issue	Date	Year	Org Unit	Decision
<u>Active</u>				
Annual Awards				
	3/9	1992	Board	No annual awards categories will be established, but will continue on an ad hoc basis [revised 7/13/95]
Annual Awards - Board Voting				
	04/18	2001	Board	Each voting member of the board will have one vote each for the Calum S. Muir Memorial Award and the Constance L. Percy Award for Distinguished Service. [Updated 03/16/05]
Annual Awards - Calum S. Muir Memorial				
	7/13	1995	Board	A Calum S. Muir Memorial Award will be established for outstanding contributions in cancer registration. The award will be bestowed each year at the annual conference.
Annual Awards - Clarification Calum S. Muir Award				
	2/18	1998	Board	The purpose of the award is to honor someone who has made long term contributions in cancer registration and that the contributions are substantive. Preference is for recipient to be an active member of NAACCR with long term commitment to the organization. The intent is that it not be a post-humous award.
Annual Awards - Clarification Connie Percy Award				
	03/17	2004	Board	Policy provides a clarification in award criteria. The revised definition is: a distinguished service award has been established to recognize an individual who contributed exceptional volunteer service to NAACCR during the past 12 months, or sustained, current, and long-term contributions to the organization. The award may be bestowed once each year usually at the annual meeting. More than one award may be given in any year. No limit is placed on the number of times an individual may be recognized by the Constance L. Percy Award for Distinguished Service. [Updated 3/16/05]

Policy Issue	Date	Year	Org Unit
Annual Awards - Recognition of Chairs & Others	10/24	2000	President

Decision

At the end of a his/her term, the President will send a letter of recognition with a NAACCR pin to all NAACCR Chairs. A copy of the letter will be sent to the Chairs' supervisor. In addition, the President may at his or her discretion recognize others who have made substantive or a significant contribution to the organization during their tenure with a NAACCR pin. [Updated 03/21/01]

Annual Awards - Rename Distinguished Service Award

04/05	2004	Board
-------	------	-------

The name of the Distinguished Service Award will hereafter be called the "Constance L. Percy Award for Distinguished Service."

Annual Business Mtg - Proxy Delegates for Voting

07/18	2001	All
-------	------	-----

If the voting delegate will not be able to attend the annual business meeting of NAACCR a proxy delegate can be designated to vote on behalf of the member organization. The proxy delegate must:

- Be an employee or member of the NAACCR member organization;
- Be physically present at the NAACCR business meeting; and
- Submit the following statement on letterhead of the member organization to NAACCR staff at the registration desk for the annual meeting:

_____ is a member of the _____ (name registry or sponsor organization) and will serve as my proxy for voting at the annual meeting of NAACCR on June __, 200__.

Signed: _____ (signature of voting delegate)

Date: _____ [Updated 3/16/05]

Annual Meeting - Abstract Review

3/15	2006	DUR
------	------	-----

Abstracts for the annual NAACCR meeting will not be accepted beyond the due date specified in the "call for abstracts" instructions. Exceptions may be made for e-mail delivery failure or natural disasters (e.g., Hurricane Katrina). The decision as to whether a late abstract will be considered for review in such a case will be made jointly by the chair of the Abstract Review Subcommittee, the chair of the Data Use and Research Committee, and the NAACCR President.

Policy Issue	Date	Year	Org Unit	Decision
Annual Meeting - Approval of final program	8/3	1993	Program	The Board must approve the final program, including theme and major sessions and topics
Annual Meeting - Cancellation - Any NAACCR Meeting	10/22	2003	Board	A decision to cancel the NAACCR annual meeting or any in-person meeting of the organization due to disaster or other emergency can only be made by a vote of the Board of Directors. The Board will consult with the Executive Director who will have both input and vote on the cancellation decision. As soon as the President or Executive Director is aware of a disaster or emergency situation that may impact severely the ability to hold the meeting or to travel to the meeting, an emergency conference of the board will be convened as soon as possible without regard to normal business hours. Every effort will be made to convene a quorum. If a quorum cannot be achieved, the vote will be taken with all available Board members. No proxy votes will be accepted. All Board members will ensure that the NAACCR executive office has current business and personal contact information, including office contacts, cell phone, pager, home phone number, home email address, or any other communication device that could be used to contact them in an emergency situation regardless of time of day.

Policy Issue	Date	Year	Org Unit	Decision
Annual Meeting - Cancellation Policy	5/17	2000	All	<p>The following will be included on all meeting registration materials: Registrants providing written notice of cancellation received by the NAACCR Executive Office on or before <insert a date 30 days prior to the conference> will be refunded the registration fee minus a <insert dollar amount> processing fee. All refunds will be processed after the annual conference. No refunds will be issued after <insert a date 30 days prior to the conference>. Substitutions of registrants are allowed at any time. The following will NOT be printed on any registration materials, but will serve as a guideline in handling special family crisis situations: Refunds minus a <insert dollar amount> processing fee may be given to registrants who must cancel within the 30 day period prior to the annual conference due to a family emergency. Refund requests must be submitted in writing and addressed to the NAACCR Executive Office. A family emergency is defined as the hospitalization or death of the registrant or a family member of the registrant. In the case of hospitalization, a family member is defined as a spouse, domestic partner, child, grandchild, or parent (including step and in-laws) of the registrant. For refund purposes, the death of a family member will include a spouse, domestic partner, child, grandchild, parent, grandparent or sibling (including step and in-law). This policy will serve as a guideline for all NAACCR workshops, courses, and meetings.</p>
Annual Meeting - Cancellations and Refunds	4/26	1994	Treasurer	<p>A cut-off date will be established for refunds and cancellations, with possible penalty for late cancellations. [Revised 5/17/2000, Annual Meeting - Cancellation Policy].</p>
Annual Meeting - Free hotel rooms	5/17	2000	Program	<p>The following guidelines should be followed in using the free hotel rooms given by the hotel in association with the NAACCR annual meeting. A suite should be provided to the NAACCR President for the days of the annual meeting (including the board meeting); then the host registry should use rooms as needed; then invited plenary speakers should be given free rooms to reduce NAACCR meeting expenses; and finally remaining rooms should be given to NAACCR staff, again to reduce meeting expenses.</p>

Policy Issue	Date	Year	Org Unit	Decision
Annual Meeting -- Host and Non-Hosted Invitations	11/21	2006	Board	Beginning with the 2010 annual conference, NAACCR will entertain venues as either hosted or non-hosted selections. A HOSTED venue will result from a member extending a written invitation to the NAACCR Board to hold the conference within their geographic jurisdiction. Before accepting the invitation of a proposed HOST, the NAACCR Board will ascertain that there are appropriate cities and hotels (in size, cost, and location). The HOST will convene and chair a Program Committee to plan the content of the conference and work with NAACCR staff in organizing the concomitant workshops. The HOST will work closely with the Executive Office staff and the conference planner on all administrative and logistical aspects of the conference.

A NON-HOSTED venue will result from any of the following situations: the Board chooses a venue without an invitation by a local member; a member offers to chair the Program Committee only; or a member offers to assist with local logistics or on-site support only. In a NON-HOSTED venue, the Board will approach local members to inquire about interest in participating in the planning or implementation of the annual conference before the meeting location is made public. In a NON-HOSTED venue, the Board will identify a Program Chair and Committee.

The purpose of this policy is to open up options for meeting venues to include all places in the United States and Canada. It is becoming increasingly difficult to identify venues, even when HOST invitations are received, that are sufficiently large, have relatively easy and reasonable air travel access, and are also cost-affordable to our membership. Non-hosted venues also extends the opportunity for more members to participate, in part, in the conduct of the annual conference without total responsibility for all aspects of the meeting. Finally, expanding the options can result in the removal of the label, "host," which has precluded some registries from extending an invitation to hold the annual conference.

Annual Meeting - Host Registry Appreciation	Date	Year	Org Unit
	04/18	2001	All
Two free registrations for the annual meeting will be provided to the host registry in appreciation of all their efforts in hosting the meeting.			

Policy Issue **Date** **Year** **Org Unit** **Decision**

Annual Meeting - Not Scheduling Concurrent Mtgs

11/21	2001	Program	The NAACCR Annual meeting is the one time during the year that members meet as an organization. The meeting includes the annual meeting program, social activities, workshops, committee meetings, and meetings of the Board of Directors. Other organizations or groups are permitted to hold related meetings in conjunction with the NAACCR annual meeting, provided that these meetings do not conflict with any scheduled NAACCR activities (including all those noted above). In order to coordinate room needs and timing of events, all requests must be submitted to the Executive Director (or designee) for approval. Any special needs for the meeting (e.g., food, audio-visual supplies, or other support) must be billed directly to the organization. Meeting organizers must coordinate their room requests and other special meeting needs with the official NAACCR conference planner.
-------	------	---------	---

Annual Meeting -- Professional Taping

02/16/1	2005	Board	Taping and selling of tapes of the annual meeting will not be undertaken due to expected financial commitments and anticipation of a small market for sales.
---------	------	-------	--

Annual Meeting - Promotional Items

03/20	2002	Program	No promotional materials by commercial entities will be placed in the conference bags, unless they are materials pertaining to NAACCR or the conference
-------	------	---------	---

Annual Meeting - site selection

1/23	1993	Board	The site of the annual meeting will be selected at least two years in advance. [Updated 06/06/05]
------	------	-------	---

Policy Issue Date Year Org Unit Decision

Annual Meeting -- Workshop Policies (2)

Policy Issue	Date	Year	Org Unit	Decision
	2/15	2006	Education	<p>Policies:</p> <ul style="list-style-type: none"> ·All workshops will be planned and budgeted to break even at low enrollment. ·Workshops will not be cancelled due to low enrollment. The hardships and costs on NAACCR members and workshop presenters caused by canceling an announced workshop due to low enrollment are substantial. ·All instructors shall be offered an honorarium. ·All participants shall expect continental breakfast and light refreshments during breaks. ·Workshops shall be offered at a frequency that maximizes attendance. <p>Procedures:</p> <p>A. Planning/Logistics</p> <ul style="list-style-type: none"> ·The NAACCR Program Manager for Education and Training (PMET) will coordinate the planning for all workshops, in conjunction with the Education Committee and the Program Committee ·All proposed training opportunities must be submitted using the "Proposed Workshop Submission Forms" to the PMET for approval by the Education Committee at least 9 months in advance of the annual conference. ·The agenda and speaker list must be reviewed and approved by the Education Committee 180 days prior to the annual meeting. ·Scheduling of workshops at the annual meeting is at the discretion of the Program Committee. ·The Education Committee is responsible for deciding the topic of the Advanced Course(s). A workgroup, assigned by the Education Committee, will develop the course agenda(s). ·SEER is responsible for the content, speakers, and printed or electronic materials for the SEER*Stat and SEER*Prep workshops; NAACCR is responsible for registration and arranging equipment, electrical connections, and food. <p>B. Financial</p> <ul style="list-style-type: none"> ·The PMET will work with the lead instructor, Program Committee, and NAACCR Director of Administration to develop a course budget and fee structure based on expected attendance such that the course will break even at the minimum expected enrollment. The budget will include provisions for travel, honoraria, food, A-V, and room rentals. This budget must be included as part of the submissions materials for the proposed workshop since expected attendance, faculty fees, and other course materials affect the feasibility of offering courses at or below the maximum guideline for

Policy Issue	Date	Year	Org Unit	Decision
				workshop registration fees.
				-Based on the enrollment history for ongoing courses and the timeliness of topics for Advanced Courses, the PMET, or designated NAACCR staff, will develop attendance estimates for each course.
				-If the expected attendance is too low to allow offering a course at a reasonable fee, the PMET or the Education Committee chair will provide the Board with a recommendation that the course not be offered that year. The Board will make a final determination prior to announcement of the course.
				-Each speaker will designate on the speaker agreement form whether an honorarium will be accepted, with the amount offered following current NAACCR guidelines. The honorarium shall be assured from the workshop revenues, or when revenues unexpectedly fall short, other revenue will be used.
Board - Agenda and meeting materials				
	8/30	1994	Board	All materials will be sent at least 24 hours in advance of Board conference calls and meetings.
Board - Insurance (2)				
	06/06	2005	Board	Insurance to bond the Board will be purchased.
Board - Letters of support for grant applications				
	9/23	1997	Board	All requests must describe a study that falls within the mission of NAACCR. Materials must be submitted to the Board that describe the study, including specific aims and the use of registry data; a list of all co-investigators; and demonstrate that when the project involves human subjects the project has been submitted to an IRB for
Board Operations				
	10/20	2004	President	The President will annually remind the membership that issues, concerns, or other topics may be addressed to any board member for placing on the Board's meeting agenda.

Policy Issue	Date	Year	Org Unit	Decision
Call for Data - Extension Requests				
	11/23	2004	DUR	The NAACCR standard for timeliness for central registry data is that data are available within 23 months after the end of the calendar year. The submission deadline for the NAACCR Call for Data reflects this standard. Individual registries, however, may occasionally encounter extraordinary events that may delay the submission of data. In these circumstances, an extension to the deadline for the Call for Data may be requested. Consideration will be given to extraordinary events at the registry on a case-by-case basis. Requests for extensions beyond the submission date, stated in the NAACCR Call for Data letter, must be made in writing to the NAACCR office and will be reviewed by the CINA Production Subcommittee. Each request must detail the reasons for the late submission and include an anticipated date that the data will be submitted. [Updated 06/06/05]
Committees - Chairs				
	4/16	1996	Board	Each request will be considered relative to the timelines for the processing of the CINA data and production of the CINA publication. Consideration will be given to extraordinary events that affect the registry and are beyond the control of the registry. Requests for extensions more than 2 weeks beyond the published submission date may affect the inclusion of the registry's data in CINA as well as their registry certification status.
Committees - Budgets (1)				
	8/3	1993	All	NAACCR staff may not Chair Standing Committees
Committees - Budgets (2)				
	06/06	2005	All	All committees will submit a budget to the Treasurer to maximize predictability in cash flow. [Revised 06/06/05]
				All committees will submit a budget to the designated Executive Office staff person to maximize predictability in cash flow.

Policy Issue	Date	Year	Org Unit	Decision
Conference/Meeting Locations - Smoke Free Cities	08/17	2005	All	<p>The NAACCR Board of Directors reviewed the Action item from C-Change regarding support of Smoke-Free Cities by committing to hold organization meetings in only those cities that are smoke-free. We find that the list is too limiting to fully make this commitment at this time and the definition is unclear since some cities on the list do not meet all three criteria: smoke-free workplace, smoke-free restaurants, and smoke-free bars.</p> <p>However, at the time meeting locations are being negotiated with local venues, NAACCR will always inquire about the smoke-free status of the city. We will not hold a meeting in a facility that does not have an adequate number of smoke-free rooms in the hotel to fill our room block. Further, if more than one venue is being considered, the venue with smoke-free policies in restaurants and bars will be given preference.</p>
Confidentiality 99-01	11/17	1999	All	<p>NAACCR 99-01 position statement on confidentiality approved by the Board. This document may be used as an official position of the organization. Available as a separate document with detailed</p>
Education - Video Conferences And Training	4/23	1998	All	<p>All NAACCR sponsored video (land and satellite) conferences must be reviewed and approved by the Education Committee</p>
Elections - Canadian representation (1)	1/4	1995	Nominating	<p>The Chair of the Nominating committee will ensure that at least one Canadian be placed on the ballot for each election. [Revised 06/06/05]</p>
Elections - Canadian representation (2)	06/06	2005	Nominating	<p>The Chair of the Nominating committee will attempt to secure at least one Canadian be placed on the ballot for each election.</p>
Elections - Nominations	10/20	2004	Board	<p>The Board will provide the Nominating Committee with perceived underrepresentation of groups of members in the Board composition.</p>

Policy Issue	Date	Year	Org Unit	Decision
Elections - Nominations: Position Statements	1/13	1992	Nominating	The Election Ballots will include a position statement from each of the candidates.
Elections - Nominations: Soliciting a ballot (1)	1/13	1992	Nominating	The Nominating Committee will issue a call to the membership for nominees before determining a slate of candidates. [Updated
Elections - Nominations: Soliciting a ballot (2)	10/20	2004	Nominating	The Chair of the Nominating Committee will prepare annually for the Fall Newsletter or other communication media an announcement of the responsibilities of being a Board member and the importance of the content in the candidate profile or information summary that is provided to voting delegates.
Elections - Nominations: Uncontested	1/23	1993	Nominating	Once the call for nominees has been completed, positions may be placed on the ballot as uncontested
Elections - Results of election balloting	3/15	2000	Nominating	The number (counts) of valid votes for each person running for office will be recorded in the Executive Office. These counts will not be released publicly, but will be available to any member, or representative of a member organization, upon request to the Executive Director.
Elections - Voting	07/18	2001	All	For election of organizations officers or representatives to the board and for election of candidates for the nominating committee (done at the annual business meeting), or Board votes for recipients of awards, the following rules must be followed (in addition to other operations or policies with regard to timing or other factors that are defined by the committees). <ol style="list-style-type: none"> 1. Each voting delegate cannot cast more than one vote for any candidate on the ballot. 2. This rule must be clearly stated on all ballots.

Policy Issue	Date	Year	Org Unit	Decision
External funding - authority to make application	3/24	1993	Board	The Board will have the authority to write and submit applications for external funding of any type. Such actions do not require a vote of the full membership. [Updated 06/06/05]
Finance - Authority Fund 15 Line Item Transfers	01/23	2003	Executive	The Executive Director has the authority to transfer up to 25% of a budget category to a different budget category within Fund 15 during any one board meeting interval, and shall notify the Board of the action at its next regular meeting.
Finance - Donation to Calum Muir Memorial Fund (1)	1/24	1997	Board	NAACCR budget will be reviewed at annual Board meeting to determine the amount that can be sent to this fund.
Finance - Donation to Calum Muir Memorial Fund (2)	06/10	2002	Board	A \$500 contribution will be sent annually as long as there are sufficient funds for this purpose.
Finance – General and Administrative Overhead Rate	8/23	2006	Exec Office	NAACCR will follow the usual and customary practice of charging the current calculated general and administrative overhead rate for all dollars received as a general donation, Sponsor of Distinction, or other monetary gift. (24% G&A as of 6/1/06)
Finance - Investment Policy	1/19	2000	Board	NAACCR 00-01 position statement on NAACCR Investment Policy was approved by the Board. This document will guide the BOD in the philosophy for making investment. At this time, it was decided that the Board would not engage a Portfolio Manager
Finance - Tax Year	9/10	1998	Board	The tax year for filing taxes will be the same as the NAACCR fiscal year [Jun 1 B May 31]
General - Founding Date	2/28	1996	All	1987 was the official year that NAACCR was founded.

Policy Issue	Date	Year	Org Unit	Decision
General - Holding joint meetings - NCRA and NAACCR	1/23	1993	Board	Agendas and memberships are not sufficiently overlapping to warrant joint annual conferences. [Updated 06/06/05]
General - Leadership Development	10/20	2004	Board	Beginning in January 2005, the Board will discuss the leadership needs and leadership development program of the organization at least every three years.
General - NAACCR official address	9/23	1997	All	For all official correspondence, such as responses to grants to the organization, the official applicant and address of the NAACCR headquarters must be used (as of 05/01/1999, it is 2121 West White Oaks Drive, Springfield, Illinois 62704-6495.)
General - Use of NAACCR Logo (1)	4/23	1998	All	The logo may be used for all officially sanctioned activities of the organization. Print, electronic, and video copies are available through the home office. If there is uncertainty, refer query to the President. [Revised 10/20/04 and 06/06/05]
General - Use of NAACCR Logo (2)	10/20	2004	All	The policy of April 23, 1998 is expanded to include among appropriate uses of the NAACCR logo, requests from member organizations to use the logo to show affiliation with the organization or to show a link with NAACCR activities.
General - Use of NAACCR Logo (3)	06/06	2005	All	The logo may be used for all officially sanctioned activities of the organization. Print, electronic, and video copies are available through the Executive Office. If there is uncertainty, refer query to the Executive Director..
General - Use of organization letterhead	4/26	1994	All	Use of letterhead is restricted to official business of the organization.

Policy Issue	Date	Year	Org Unit	Decision
Investment Policy & Guidelines 00-01	11/19	2000	Board	Available as a separate document with detailed language.
Lobbying, Advocacy, and Education	6/25	1997	All	No NAACCR materials or resources may be used in lobbying (i.e., activity to influence legislation or a legislative effort) at any governmental level. Any requests for advocacy efforts should be referred to the Board for approval before engaging in any such activity. Any requests for information or materials that are publicly available in NAACCR materials or publications may be shared with
Membership - Mailing Labels	8/18	1999	Executive	As long as NCI maintains the NAACCR mailing list as a public service, NAACCR will provide a hard copy of the labels when the Executive Director determines that the mailing will be of a benefit to the membership and does not involve a survey. If the Executive Director cannot determine benefit, the President will be consulted.
Membership - Changing Categories	9/10	1998	Board	All members that change or want to change their membership category must complete a new membership application and submit it for review. Once approved and dues are paid, the member will be recognized in the new category and the directory will be updated.
Membership - Use of Listserv	1/19	2000	Staff	As long as NCI maintains the NAACCR listserv as a membership service, NAACCR will approve submissions when the Executive Director determines that the information will be of a benefit to the membership and does not involve a survey. If the Executive Director cannot determine benefit, the President will be consulted.
Membership Dues	3/15	2000	Board	Dues are for a complete fiscal year, regardless when in the year they are paid. Dues will not be pro-rated when a member is not a member for the full year.

Policy Issue	Date	Year	Org Unit
Membership Dues -- Consequences of Outstanding	01/17	2001	Board

Decision

If a NAACCR member has not paid membership dues by the dates listed below, the following consequences will apply:

- A. December 31st
 - .Their data will not be published in CINA.
 - .They will not be allowed to vote for NAACCR officers.
 - .They will not be allowed to vote at the annual business meeting.
 - .Their staff cannot run for election.
 - B. Membership Directory Finalization Date
 - .The entity will not be published in NAACCR lists such as the Membership Directory, on the website, and on letterhead.
 - .Their staff will not receive reduced rates to attend the annual meeting.
 - C. End of the NAACCR Fiscal Year (May 31st)
 - .The entity will be required to reapply for membership and pay all dues in arrears in order to receive membership reinstatement.
 - .The member's staff representation on NAACCR committees will be dropped.
- The Membership Committee (Board of Directors) still must vote to delete members from membership status. The list of past due members as of the end of each fiscal year will be reviewed during the in-person board meeting at the annual conference to vote on deletions from membership status.

Membership Dues - Due date

10/25	1995	Treasurer
-------	------	-----------

Cut-off date for payment of membership dues will be December 31 of each year, beginning in 1996. Dues must be current for voting privilege at the annual meeting and publication of data in the annual CINA monograph. [Revised 2001, Membership dues, consequences of outstanding dues]

Organization Business - Legal Filings Notification

10/20	2004	Board
-------	------	-------

Beginning in August 2004, a biannual report of the status of all legal filings for NAACCR, Inc. will be prepared by the Executive Office for the Board of Directors.

Organization Business - Review of Policies

10/20	2004	Board
-------	------	-------

Beginning in January 2005, all policies of the organization will be reviewed every three years by the Board of Directors to ensure that they are still appropriate and relevant.

Policy Issue	Date	Year	Org Unit	Decision
Personnel Policies and Procedures				
Registry Certification - Annual Release - Outcomes				
	05/21	2003	Board	Registry certification certificates will be prepared and mailed immediately at the conclusion of the annual review process. They will not be held for distribution at the Awards Luncheon of the Annual Meeting. However, all recipients will be congratulated individually by the President at the Awards Luncheon: first time recipients will be acknowledged first; then who advanced from silver to gold; and finally all other recipients. A group photo of all recipients will follow.
			Registry	
Specialty Registries				
	9/20	2000	All	NAACCR encourages the integration of special cancer surveillance needs when- ever possible into the ongoing activities of existing central cancer registries. As a matter of policy, NAACCR does not support the development of specialty registries that largely duplicate the ongoing activities of existing central cancer registries. NAACCR can serve as resource for information regarding special cancer surveillance needs.
Staff - Attendance at IACR meeting				
	3/15	2000	Board	The Executive Director will attend the IACR annual meeting as an official representative of NAACCR. Expenses will be covered by NAACCR.

Policy Issue	Date	Year	Org Unit	Decision
Staff - Background Checks on New Hires	12/20	2006	Staff	NAACCR will conduct background and credit checks for all new hires. The checks will be conducted on the top candidate who is a finalist for a NAACCR position as a last step in the hiring process. A negotiated offer will be contingent upon the outcome of the checks. Should a check reveal any issues, the decision about proceeding with a hire will be at the discretion of the NAACCR Executive Director, with consultation, if necessary, with the auditing firm, attorney, Board of Directors, or other advisors. Action required for the Executive Director will be handled by the NAACCR Board of Directors. This screening process and authorization will be included in the NAACCR Personnel Policy Handbook and implemented in the interview process. With considerations of individual privacy, results of the checks may be destroyed as long as a notarized document is substituted in the employee file defining the checks that were conducted and an explanation of why hiring proceeded despite the findings in the checks.
Staff - ExecDir Spending Authority on contracts	8/16	2000	Board	The Executive Director, as principal investigator of cooperative agreements, contracts, or grants, must consult with the President before spending unobligated funds in excess of \$5,000. The President may approve, disapprove, or refer the request to the Board.
Staff - ExecDir Spending Authority on Fund 10 (3)	4/18	2007	Executive	The Executive Director is authorized to spend Fund 10 up to a total of \$25,000 per fiscal year without pre-approval by the Board of Directors. This authorization is dependent on a favorable total variance in Fund 10 revenues over expenses of at least 10% at the time an expenditure is made or obligated. The Executive Director shall notify the Board of an expenditure or obligation at the next
Staff - ExecDir Spending Authority on Fund 15	02/16	2005	Board	The Executive Director must have Board approval for any unbudgeted expense from semi-restricted funds (Fund 15) of more than \$15,000 in one fiscal year. The Board will be notified simultaneously of an unbudgeted expense.

Policy Issue	Date	Year	Org Unit	Decision
Staff - Registration for the Annual meeting				
	5/17	2000	Staff	Staff will pay registration fees for the annual meeting as long as it is not paid from unrestricted NAACCR monies (Fund 10).
Staff - Signature Authority				
	9/20	2000	Executive	<p>The Executive Director shall have the authority to sign the following documents:</p> <ul style="list-style-type: none"> • All consultant agreements that are paid from grants and contracts awarded to NAACCR; • All contracts and sub-contracts that are paid from grants and contracts awarded to NAACCR unless the agreement will bind the organization beyond the scope of a grant or contract (e.g., annual meeting contracts, conference management contract); • All contracts, grants, purchase orders, or other types of agreement, less than \$5,000 that will be paid from Fund 10 (unrestricted funds) if it is directly related to a budgeted item that has been pre-approved by the Board. • All unbudgeted contracts, grants, purchase orders, or other types of agreements that will be paid from Fund 10 that are less than \$1000 after receiving a written or e-mail approval by the President.
Standards - Timing for Revisions (1)				
	10/15	1997	All	All suggested revisions that are completed by the annual meeting will be released in the standards volume and the data exchange layout to be effective in January of the subsequent year. Revisions will occur no more frequently than once a year. [Revised 06/06/05]
Standards - Timing for Revisions (2)				
	06/06	2005	All	All suggested revisions will be released in the standards volume and the data exchange layout in a timeframe that is consistent with the current version of the NAACCR Implementation Guidelines. Revisions will occur no more frequently than once a year.

Policy Issue	Date	Year	Org Unit	Decision
Surveys of Membership				
	07/18	2001	All	<p>General Procedures</p> <p>All surveys of the NAACCR membership must be approved by the NAACCR Board of Directors prior to sending them to the membership.</p> <p>Specific Requirements</p> <p>In addition to the survey instrument, the following questions must be addressed and submitted to the NAACCR Board.</p> <ol style="list-style-type: none"> 1) What is the purpose of the survey? (What questions will the survey answer?) 2) How will the survey help the NAACCR membership? 3) What is the scope of the survey? (How many questions, format, time needed to complete, etc.) 4) Who should respond to the survey? (Registry Director, Director of Operations, IT director, person most knowledgeable about a certain issue, etc.) 5) Who will analyze the survey? 6) When will the results of the survey be made available? 7) How will the results of the survey be shared with the NAACCR membership? 8) Are resources currently available to meet the needs for distribution and analysis in the time line proposed.
Travel -- Liaisons				
	4/26	1994	Board	<p>Organization funds may be used to support travel of liaisons to participate in meetings in order to promote and strengthen our connection to other organizations.</p>
Travel - NAACCR Travel Per Diem (1)				
	3/17	1999	All	<p>When a meal is provided as a working breakfast, working lunch, or a dinner is extended without cost to the traveler, the per diem for that day should be reduced as follows: 15% for breakfast; 25% for lunch; and 40% for dinner. [Revised 06/06/05]</p>
Travel - NAACCR Travel Per Diem (2)				
	06/06	2005	All	<p>When a meal is provided as a working breakfast, working lunch, or a dinner is extended without cost to the traveler, the per diem for that day should be reduced according to the current per diem reimbursement guidelines.</p>

Policy Issue Date Year Org Unit Decision

Travel - NAACCR Travel Per Diem Reimbursement (1)

9/23	1997	All	Per diem reimbursements will be based on federal guidelines and allocated in quarter day increments, before 6 am, 6 to noon, noon to 6 pm and after 6 pm. Revised 3/17/99.
------	------	-----	---

Policy Issue Date Year Org Unit Decision

Rescinded

Annual Meeting -- Workshop Policies

Policy Issue	Date	Year	Org Unit	Decision
	11/14	2005	Education	<ul style="list-style-type: none"> ·All workshops will be planned and budgeted to break even at low enrollment. ·Workshops will not be cancelled due to low enrollment. The hardships and costs on NAACCR members and workshop presenters caused by canceling an announced workshop due to low enrollment are substantial. ·All instructors should be offered an honorarium. ·All participants should expect continental breakfast and light refreshments during breaks. ·Workshops should be offered at a frequency that maximizes attendance.Procedures: <ul style="list-style-type: none"> A. Planning/Logistics ·The NAACCR Program Manager for Education and Training (PMET) will coordinate the planning for all workshops, in conjunction with the Education Committee and the Program Committee ·The agenda and speaker list must be reviewed and approved by the Education Committee 180 days prior to the annual meeting. This applies to the Short Course as well as the Advanced Courses. ·Scheduling of workshops at the annual meeting is at the discretion of the Program Committee. ·The Education Committee is responsible for deciding the topic of the Advanced Course(s). A workgroup, assigned by the Education Committee, will develop the course agenda(s). ·SEER is responsible for the content, speakers, and printed or electronic materials for the SEER*Stat and SEER*Prep workshops; NAACCR is responsible for registration and arranging equipment, electrical connections, and food. B. Financial <ul style="list-style-type: none"> ·Based on the enrollment history for ongoing courses and the timeliness of topics for Advanced Courses, the PMET will develop attendance estimates for each course. ·The PMET will work with the lead instructor, Program Committee, and NAACCR Director of Administration to develop a course budget and fee structure based on expected attendance such that the course will break even at the minimum expected enrollment. The budget will include provisions for travel, honoraria, food, A-V, and room rentals. This budget will be developed far enough in advance so that Board review, if needed, can be obtained prior to the preliminary conference announcement. ·If the expected attendance is too low to allow offering a course at a reasonable fee, the PMET or the Education Committee chair will provide the Board with a recommendation that the course not be offered that year. The Board will make a final determination prior to announcement of the course. ·An honorarium of \$200 will be offered to each presenter, according

Policy Issue	Date	Year	Org Unit	Decision
Board - Insurance (1)	10/5	1993	Board	to the budget for each course. The honorarium should be assured from workshop fees or other meeting income, if necessary. [Revised 02/15/2006]
Education - Short Course announcements	8/3	1993	Education	Insurance to bond the Board will not be purchased as it is very expensive and probably unwarranted. [Rescinded 06/06/05]
Finance - Signature Authority on Checks (1)	10/5	1993	Board	All short course announcements and correspondence must occur on organization (Board) letterhead to avoid confusion about sponsorship. [Rescinded 06/06/05]
Finance - Signature Authority on Checks (2)	1/21	1998	Board	Any check made to the Treasurer must be signed by both the President and the Treasurer. [Rescinded 06/10/2002]
Finance - Signature Authority on Checks (3)	2/17	1999	Board	All checks written from NAACCR accounts will require two signatures. Monthly bank statements will be reconciled by an independent book keeper. Amended: 2/17/99. [Rescinded 06/10/2002.]
General - Membership in Am Med Informatics Assoc	4/26	1994	Board	All checks written for less than \$500 require only one signature. [Rescinded 06/06/05]
Membership - Use of Directory	4/26	1994	All	Any membership will be undertaken by individuals and not the organization. [Rescinded 06/06/05]
				Membership directories may only be used for official business of the organization; any other use must have permission of the Board. [Rescinded 06/06/05]

Policy Issue	Date	Year	Org Unit	Decision
Newsletter - Advertising				
	4/26	1994	Board	Paid advertisements will not be accepted; members may use the newsletter to announce employment opportunities at no cost. [Rescinded 06/06/05]
Newsletter - Mailing costs				
	10/5	1993	Executive	NCI has agreed to cover the costs for the mailing of the newsletter. [Rescinded 06/06/05]
Staff - ExecDir spending Authority on Fund 10				
	8/16	2000	Board	The Executive Director must have Board approval for any unbudgeted expense from unrestricted funds (Fund 10) of more than \$5,000. [Amended 02/16/2005]
Staff - ExecDir Spending Authority on Fund 10 (2)				
	02/16	2005	Board	The Executive Director must have Board approval for any unbudgeted expense from unrestricted funds (Fund 10) of more than \$5,000 in one fiscal year. The Board will be notified simultaneously of an unbudgeted expense. (Rescinded April 18, 2007)



NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES BYLAWS

ARTICLE I. Scope and Purpose

The North American Association of Central Cancer Registries, Inc. (NAACCR), the Association, 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.

ARTICLE II. Membership

Section 1. Classification of Membership

The four classes of membership shall be:

A. Full: Full member organizations are central registries, which are, or have the potential to become, population-based registries.

B. Individual: Individual members are those persons who are not currently working in a member organization who have demonstrated career and professional commitments and interests that are consistent with or complementary to those of NAACCR. Candidates for Individual Membership must be able to demonstrate involvement or activity in one or more of the following areas: cancer epidemiology, patient care, cancer control, cancer registration, professional education, research, and biostatistics. Each candidate must make a commitment to support NAACCR through active participation in the activities of the Association. Individual members shall be entitled to participate and vote as a member of committees, subcommittees or work groups. Individual members may chair subcommittees or work groups. Individual members may not chair a committee, vote on matters brought before the Membership at the Annual Meeting, vote for or hold an elected position in the Association.

C. Sponsoring: Sponsoring member organizations are national professional or national governmental organizations primarily involved in any of the following areas: cancer epidemiology, patient care, cancer control, cancer registration, professional education, research, or biostatistics. Each sponsoring member organization shall be entitled to one vote on each matter submitted to membership vote. No action taken by the Association shall be construed as committing any sponsoring member organization to a prescribed course of action. Each sponsoring member organization may designate one or more representatives from such organization to participate in the Association's affairs on

behalf of such organization. Representatives of sponsoring member organizations may be a member of and chair a committee. Only one representative of a sponsoring member organization shall be entitled to cast that organizations's vote.

D. Sustaining: Sustaining member organizations are organizations interested in promoting the purposes of the Association. No action taken by the Association shall be construed as committing any sustaining member organization to a prescribed course of action. Each sustaining member organization may designate one or more representatives from such organization to participate in the Association's affairs on behalf of such organization. Sustaining member organizations shall not be entitled to vote, and their representatives shall not be entitled to hold office. Representatives from sustaining member organizations may be a member of and chair a committee.

Section 2. Application for Membership

Application for membership shall be submitted in a manner prescribed by the Board of Directors.

Section 3. Resignation

Any member may resign by submitting a resignation in writing to the Executive Director.

Section 4. Application for Continuing Membership

Each member shall submit an application for continuing membership every three years. This application for continuing membership shall be submitted in a manner prescribed by the Board of Directors.

ARTICLE III. Officers

Section 1. Officers

The Officers of the Association shall be:

- A. President
- B. President-Elect
- C. Six Representatives-At-Large
- D. Sponsoring Member Representative
- E. Treasurer
- F. Immediate Past President

Section 2. Eligibility

An individual who has been a representative in the Association of a full member organization for one year prior to nomination shall be eligible to hold the following offices: President, President-Elect, Representative-at-Large, and Treasurer. To be eligible for the office of President-Elect, a representative must, prior to the election, have served for one year as a member of the Board of Directors or as a chair of a NAACCR committee. To be eligible for Representative-at-Large or Treasurer, an individual must, prior to the election, have served as a member of a NAACCR committee. One Sponsoring Member Representative from among the

sponsoring member organizations shall be elected by the sponsoring member organizations to serve on the Board of Directors.

Section 3. Term of Office

The term of office for President, Representatives-At-Large, Sponsoring Member Representative, and Treasurer shall be two years or until a successor is elected. Individuals in these positions may serve a second consecutive two-year term, if re-elected, not to exceed a total of four consecutive years in the same position. The limit of four consecutive years may be exceeded when consecutive terms are served in different board positions. The term of office for President-Elect and Immediate Past President shall be one year. The Representatives-At-Large shall be elected on a rotating basis. Officers shall assume office at the conclusion of the Annual Meeting of the members at which they are elected.

Section 4. Vacancies

A. All vacancies, except the office of the President and the Sponsoring Member Representative, may be filled for the unexpired term by appointment by the President with the approval of the Board of Directors.

B. A vacancy in the office of President shall be filled for the remainder of the term of office by vote of the Board of Directors.

C. A vacancy in the office of the Sponsoring Member Representative shall be filled for the remainder of the term by a special vote of the Sponsoring Members.

D. A vacancy in the office of President-Elect shall be filled by a special election of the voting members. A vacancy occurring within sixty (60) days prior to assuming the Presidency shall be filled by a vote of the voting members at the next Annual Business Meeting.

Section 5. Nominations and Election

A. Subject to the approval of the Board of Directors, the Nominating Committee shall develop rules and regulations for the conduct of the nomination and election of officers.

B. Elections shall be by mail ballot. The Nominating Committee shall be responsible for the preparation of the ballot. The Executive Director, or his/her designee, shall mail the ballot pursuant to the rules and regulations of the Nominating Committee including reasonable deadlines for the return of ballots.

C. Election shall be decided by plurality vote of the votes cast. In case of a tie, the election shall be decided by lot conducted by the Board of Directors.

D. Election of the Sponsoring Member Representative will be by special vote of the Sponsoring Members.

Section 6. Duties of Officers

A. President: The President shall function as the Chief Executive Officer of the Association. Unless specified otherwise, the President shall appoint all committee chairpersons. The President or his/her designee shall be a member, ex-officio, of each committee. The President's ex-officio status is without vote.

B. President-Elect: The President-Elect shall succeed to the office of President at the conclusion of his/her term of office. The President-Elect may appoint the Standing Committee Chairpersons for his/her term of office prior to assuming the Office of President.

C. Representatives-At-Large: The Representatives-At-Large shall serve as primary liaison officers with cancer registries and facilitate the exchange of information and the organization of projects.

D. Sponsoring Member Representative: The Sponsoring Member Representative shall serve as primary liaison with sponsoring members to provide a formal mechanism for inter-organizational activities.

E. Treasurer: The Treasurer shall be responsible for overseeing the receipt and disbursement of all funds, establishing the budget for unrestricted funds, and managing all funds of NAACCR.

F. Immediate Past President: The Immediate Past President shall assist in the business of the Association.

ARTICLE IV. Meetings of the Membership

Section 1. Meetings

A. The Annual Business Meeting of the members of the Association shall be held in conjunction with the Annual Conference. The time and place of the meeting shall be determined by the Board of Directors.

B. Special meetings may be called by the Board of Directors.

Section 2. Notification

The official call and notice of any meeting shall be sent by mail at least 30 days prior to the scheduled meeting, and shall include the agenda and a description of each matter requiring special consideration or action.

Section 3. Quorum

A quorum for any meeting of members shall be a majority of the members registered at the meeting. In the absence of a quorum, no action can be taken by the members at a called meeting.

Section 4. Action

A. Action by the members shall require the affirmative vote of a majority of the members entitled to

vote who are present at a meeting at which a quorum has been established.

B. No action can be taken by the members at a special meeting except as to matters described in the notice of the special meeting.

C. When voting on general matters or as a member of a committee either as an NAACCR representative or a representative of another organization, members and NAACCR staff must recuse themselves from discussion and voting if the voting issue places them in a conflict of interest.

ARTICLE V. Board of Directors

Section 1. Composition

The Board of Directors shall be composed of the elected officers of the Association and the Executive Director.

Section 2. Duties

The Board of Directors shall:

A. Act for the Association between scheduled meetings of the membership, be responsible for the management of the business and professional affairs of the Association, and take other actions as required to implement the stated purposes of the Association.

B. Define the duties of the officers in a manner consistent with the bylaws.

C. Create and dissolve committees in addition to the Standing Committees.

Section 3. Meeting of the Board of Directors

A. The Board of Directors shall meet just prior to the Annual Business Meeting of the Association and at such times as deemed advisable during the year on call of the President and majority of the Board.

B. A quorum shall be a majority of the members of the Board of Directors.

C. Action by the Board of Directors shall be by resolution adopted by the affirmative vote of a majority of the members of the Board present at a meeting at which a quorum is present. Presence at a meeting may be in person or by telephone, provided that each member present is able to hear all other members present.

Section 4. Minutes and Notification of Action Taken

A. All action taken by the Board of Directors shall be recorded in the minutes of the Board.

B. Minutes of the Board of Directors shall be available to the membership of the Association upon request.

ARTICLE VI. Committees

Section 1. Standing Committees

The Standing Committees of the Association shall be Bylaws, Communications, Data Evaluation and Certification, Data Use and Research, Education, Information and Technology, Nominating, Program, Registry Operations, and Uniform Data Standards. The composition, size, and duties of the committees shall be set forth in the Standing Rules. Unless specified otherwise, the Chairperson of each committee shall appoint committee members.

Section 2. Special Committees

As deemed necessary, Special Committees may be created by the membership or Board of Directors to carry on the affairs of the Association.

Section 3. Eligibility

Any full, sponsoring, or sustaining member representative in good standing for one full year prior to appointment shall be eligible to be appointed as Chairperson of a Committee.

Section 4. Vacancies

Vacancies in committee chairs and presidential appointments shall be filled by appointment by the President. All other vacancies, on a committee shall be filled by the Committee Chairperson.

ARTICLE VII. NAACCR Staff

Section 1. Executive Director

The Board may appoint an Executive Director who shall perform all duties as designated by the Board. The Executive Director shall serve on the Board of Directors as an ex officio member without vote. The Executive Director cannot hold office or chair a Standing Committee. The Executive Director may serve as a member of standing committees and may chair ad hoc committees, work groups, and subcommittees. The Executive Director, or his/her designee, shall be responsible for the preparation of a record of all proceedings, and for the general correspondence of the Association.

Section 2. Staff

A. NAACCR staff cannot hold office or chair a Standing Committee. They may serve as a member of standing committees and may chair ad hoc committees, work groups, and subcommittees.

B. The Staff will be responsible for the custody of the organizational records and of all proceedings of the Association.

ARTICLE VIII. Executive Office

Section 1. Organizational Records

The organizational records and proceedings of the Association will be located at the Executive Office.

Section 2. Office Location

The Executive Office will be designated by the Board.

ARTICLE IX. Financial Administration

Section 1. Fiscal Agent

The Board will designate the fiscal agent.

Section 2. Fiscal Year

The fiscal year of the Association shall be determined and established by the Board of Directors.

Section 3. Annual Dues

A. Annual dues shall be paid in the amounts determined and established by the Board of Directors.

B. Dues shall be payable by December 31st of each fiscal year.

C. Sponsoring Members provide fiscal support to the Association at a level and type (direct, in-kind, or combination) to be determined by the Board of Directors. Sponsoring members will define their type of fiscal commitment to the Treasurer on the first day of each fiscal year and will be declared delinquent if not defined by December 31st of each fiscal year.

Section 4. Audit

The financial records of the Association shall be audited each year in the manner determined and established by the Board of Directors.

ARTICLE X. Parliamentary Authority

The rules contained in the current edition of *Robert's Rules of Order, Newly Revised*, shall govern the Association in all cases to which they are applicable and in which they are consistent with these Bylaws, special rules of order, and any Standing Rules the Association may adopt.

ARTICLE XI. Amendment to the Bylaws

Section 1.

Amendment to these Bylaws may be proposed by the Board of Directors or any Committee. Any

voting member may propose amendments provided such amendments are accompanied by written endorsement of at least five (5) additional voting members.

Section 2.

Proposed amendments to these Bylaws shall be submitted in the prescribed form to the Chair of the Bylaws Committee at least ninety (90) days prior to the Annual Business Meeting.

Section 3.

A two-thirds (2/3) vote of the voting members present at the Annual Business Meeting of the Membership at which a quorum has been established shall be required to adopt any amendment. Unless stated otherwise, the amendments shall become effective upon adoption.

Section 4.

A copy of the proposed amendments shall be sent to the voting members at least thirty (30) days prior to the Annual Business Meeting.

ARTICLE XII. Dissolution of the Association

Voluntary dissolution of the Association may be effective only by consent evidenced by written and signed ballots of three-fourths (3/4) of all voting members. Notice of the intent to dissolve the Association must be mailed to each voting member at least four (4) weeks prior to the date set for the ballots to be counted. Ballots for this purpose shall be enclosed with the notice of intent.

(Approved by vote of membership, Annual Conference 4/28/92)
(Amended by vote of membership, Annual Conference 4/93)
(Amended by vote of membership, Annual Conference 4/27/94)
(Amended by vote of membership, Annual Conference 4/20/95)
(Amended by vote of membership, Annual Conference 4/02/97)
(Amended by vote of membership, Annual Conference 4/22/98)
(Amended by vote of membership, Annual Conference 4/07/99)
(Amended by vote of membership, Annual Conference 4/19/00)
(Amended by vote of membership, Annual Conference 06/06/01)
(Amended by vote of membership, Annual Conference 06/12/02)
(Amended by vote of membership, Annual Conference 06/11/03)
(Amended by vote of membership, Annual Conference 06/08/05)



**NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES, INC.
(NAACCR)**

STANDING RULES

I. Standing Rules

- A. Unless specified otherwise, the Board of Directors shall establish and amend the Standing Rules necessary to carry on the business of NAACCR.
- B. The Board of Directors shall notify the membership of any changes to the Standing Rules in the official NAACCR publication following such changes. Standing Rules shall be published and made available to the membership.
- C. Any Standing Rule adopted by the Board of Directors may be rescinded by a two-thirds (2/3) vote of the voting membership at an Annual Business Meeting.
- D. All committee meetings of NAACCR held at the annual meeting are open for observation to all members of NAACCR.

II. Bylaws Committee

- A. This committee shall consist of three (3) members. The President shall appoint one (1) of the three (3) members to act as the Chair. The President shall also appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.
- B. The committee receives and reviews all proposed amendments to the Bylaws. The committee shall be responsible for distributing proposed amendments to the membership at least thirty (30) days prior to action being taken at the annual business meeting.

III. Communications Committee

- A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.
- B. The committee shall be responsible for the NAACCR newsletters, press releases, press conferences, and oversight and direction of the content of the NAACCR website.

IV. Data Evaluation and Certification [DEC] Committee

- A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.
- B. The committee shall evaluate member data submissions on an annual basis and determine and evaluate parameters to identify and assess high quality data for various data uses, including objective certification standards.

V. Data Use and Research [DUR] Committee

- A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.
- B. The committee shall gather, review, and consider data from member organizations for publication. Insofar as resources are available, the committee shall prepare a publication of cancer incidence and mortality data. It is responsible for identifying issues related to the release of various types of data by central cancer registries and providing recommendations and guidelines on these issues, including confidentiality; oversees the NAACCR Research Program; develops a research agenda for the organization; and conducts abstract review for the scientific program of the Annual Conference.

VI. Education Committee

- A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.
- B. The committee shall determine the educational needs of the Association and shall propose methods of meeting those needs including but not limited to the offering of short-term training courses.

VII. Information and Technology Committee

- A. This committee shall consist of a chair, one (1) representative from at least three (3) full

members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

- B. The committee shall be responsible for developing the standard format for data exchange among members and for developing standards to ensure the security and accuracy of transmitted data.

VIII. Nominating Committee

- A. The Nominating Committee shall consist of three (3) members nominated and elected by the voting Membership at the annual business meeting. The President shall appoint the Chair from the three elected candidates. The President also shall appoint a Board of Directors liaison to the committee. No member of this committee may designate an alternate with voting powers to participate in any meeting for which the appointed member is absent.
- B. The Nominating Committee shall secure candidates for the office of President-Elect, Treasurer, and Representative-at-Large as appropriate, and shall prepare a ballot to be distributed to the membership. The committee shall receive the completed ballots, tally the votes, and present the results of the election to the membership at the annual business meeting. The Nominating Committee shall also secure candidates from the Sponsoring Member Organizations for the position of Sponsoring Member Organization Representative to the NAACCR Board of Directors, and prepares a ballot to be disseminated to the Sponsoring Member Organizations. The Nominating Committee shall receive the completed ballots, tally the votes, and present the results of the election to the Board of Directors.

IX. Program Committee

- A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President also shall appoint a Board of Directors liaison to the committee. The President shall appoint the Chair, who should be a member of the host registry for the Annual Conference. The standing committee should also include the previous year's chair, a representative of the host registry for the upcoming year, and a member from both the Education and Communications Committees. The President shall also appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.
- B. The committee shall be responsible for the program for the Annual Conference and working with the conference planner to set guidelines for meeting logistics and locations.

X. Registry Operations Committee

- A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President shall appoint the Chair

from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting..

- B. The committee shall provide a forum for discussion of methodological issues as they apply to the policies, procedures and operations of a central cancer registry and shall provide suggested models and developing standards for the policies, procedures, and operations of central cancer registries. The committee shall facilitate the peer-to-peer exchange of information on methods, procedures, and policies among registries.

XI. Uniform Data Standards Committee

- A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations, Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

B. The Committee shall provide a formal mechanism to review and recommend proposed changes in data codes and/or the addition of new items submitted by NAACCR members to ensure that data remain comparable among central registries. Further, the committee shall provide a formal mechanism for reviewing and recommending edits of NAACCR approved data items.

XII. Fiscal Year

- A. The Board of Directors sets the fiscal year.

XIII. Chief Executive Officer Functions

- A. The Chief Executive Officer is the President. The President, in cooperation with the Treasurer and the Executive Director, brings the annual organizational budget to the Board of Directors for approval. The President also brings *ad hoc* budget items in excess of \$5000, and not pre-approved by the Board, and all Committee budget requests to the Board for approval. For items, \$5000 or less, the Executive Director has signatory authority. All *ad hoc* requests in committee budgets must be approved by the Board. The President has the sole signature authority for binding the organization at amounts in excess of \$5000. The CEO signs all tax filing documents and all applications, forms, or any official documents that bind the organization by requesting a signature of the CEO or organizational head.

Approved by Board: 5/15/96
Revised: 3/31/97
Revised: 6/5/97
Revised: 6/17/98
Revised 4/05/99
Revised 11/17/99
Revised 05/17/00
Revised 04/12/2002
Revised 06/09/2005