



Business Meeting

NAACCR ANNUAL CONFERENCE

JUNE 13, 2018

WYNDHAM GRAND
PITTSBURGH, PENNSYLVANIA



20
18



8:15 AM
Grand Ballroom

naaccr.org

Business Meeting Agenda



- 8:15 AM
1. Call to Order, President's Welcome, and Report (pg. 3) Antoinette Stroup
 - a. Call for New Business from the Membership
- 8:15 AM
2. Minutes from 2017 Meeting (pg. 3) Antoinette Stroup
 - a. ACTION: Approval of 2017 Minutes
- 8:20 AM
3. Election Results and Destruction of Ballots (pg. 5) Kyle Ziegler
 - a. ACTION: Destruction of 2018 Ballots
- 8:25 AM
4. Highlights and Accomplishments (verbal) (pg. 5) Betsy Kohler
- 8:25 AM
5. Status on Strategic Management Plan (pg. 4) Antoinette Stroup
 - Steering Committee Reports
- 8:30 AM
6. Update on 2019 Proposed Bylaws Changes (Verbal) Antoinette Stroup
- 8:35 AM
7. Treasurer's Report (pg. 34) Maria Schymura
 - Financial Oversight
 - Operations
 - Audit
 - Financials Status

8:35 AM
8. Support of All Kinds 2017-2018 (pg. 46) Antoinette Stroup

8:40 AM
9. Nominations for Nominating Committee (Verbal) (pg. 47) Antoinette Stroup
a. Nominating Committee Formation 2018-2019 Antoinette Stroup
b. ACTION: Appoint Nominating Committee Chair Antoinette Stroup

8:45 AM
11. Adjournment (pg. 47) Antoinette Stroup

Appendix of Documents

- Registry Certification (pg. 48)
- Current Standing Rules (pg. 57)
- Current Bylaws (pg. 50)
- Organizational Charts (pg. 62)



1. **Call to Order, President’s Welcome, and Report**
 - a. **Call for New Business from the Membership**



2. **Minutes from 2017 Meeting**
 - a. **ACTION: Approval of 2017 Minutes**

NAACCR Annual Business Meeting Minutes

Albuquerque, New Mexico

June 21, 2017

1. **Call to Order, President’s Welcome, and Report** **Chuck Wiggins**

Written materials were offered to those attending as they entered the meeting. President Chuck Wiggins welcomed everyone and called the meeting to order at 8:15 AM local time. An electronic voting system was utilized. A quorum was tallied and verified.

2. **Approval of Minutes From 2016 Meeting** **Chuck Wiggins**

No comments or corrections were given for the 2016 meeting minutes. A motion was made to approve the minutes as written. The motion was seconded. No oppositions were voiced the motion was carried.

ACTION: The 2017 Business Meeting Minutes were approved as written.

3. **Election Results and Destruction of Ballots** **Kyle Ziegler**

62 of 82 voting members voted (76%) for four open board positions. Treasurer was filled by Maria Schymura from New York State Cancer Registry. Isaac Hands from Kentucky Cancer Registry, Deirdre Rogers, PhD, MS, CTR, from Mississippi Cancer Registry, and Randi Rycroft from Colorado Central Cancer Registry were elected to fill the 3 Representatives-at-Large positions. Kyle thanked the fellow members of the nominating committee, Bobbi and Maureen. He also thanked Dustin Dennison and Charlie Blackburn at NAACCR for their support.

- a. **Destruction of Ballots**

Kyle motioned for the destruction of the election ballots and it was seconded. There were none opposed to the motion and it was carried.

ACTION: The election ballots were destroyed.

4. **Highlights and Accomplishments** **Betsy Kohler**

- Betsy directed attendees to the program for accomplishments in the past year. She shared that the

NAACCR Registry of the Future Conference was a huge success, she also thanked NAACCR's sponsors including NCRA for all their support.

- NAACCR was able to gain additional funds through additional work performed.
- VPR has made great progress over the last year.
- Please see 2017 Annual Meeting Report for additional details.

Betsy thanked all Board and Committee members as well as her staff for their hard work in new initiatives that were taken on in the past year.

5. Progress on Strategic Management Plan

Chuck Wiggins

Chuck referred everyone to the printed materials for updates. He mentioned that Nan Stroup was very knowledgeable about efforts in the SMP.

6. Steering Committee Updates and Committee Reports

Chuck Wiggins

Chuck urged everyone to view the Steering Committee reports provided to attendees for details on work being carried out in the NAACCR committees.

7. Financial Status Report

Bruce Riddle

Bruce Riddle, Treasurer, directed attendees to view the financial information in the hard copy packet and to see the NAACCR website for additional information. He mentioned that NAACCR had an operating budget of nearly two million with approximately 50% going directly to personnel costs. Approximately 63% of revenue comes from the U.S. Department of Health and Human Services with the largest expense being the Annual Meeting. There are five main grants/contracts that were overseen by the Executive Director.

Bruce urged everyone to review printed materials for the extensive details provided.

8. Support of All Kinds

Chuck Wiggins

Chuck thanked all of the organizations that have contributed to NAACCR in the past year.

9. Nominations for Nominating Committee 2017-2018

Chuck Wiggins

The following individuals were nominated and accepted: Ginger Williams, Kyle Ziegler, and Sarah Nash.

ACTION: The 2017-2018 nominating committee members were elected.

a. Appoint Nominating Committee Chair

Chuck appointed Kyle Ziegler as the chair and he agreed to serve in this role.

10. New Items from the Floor

Chuck Wiggins

No new items were raised.

11. Adjournment

Chuck Wiggins

Chuck referred members to the appendix of documents including Registry Certification, Bylaws, Standing Rules and Organizational Charts. The meeting adjourned at 8:33 AM local time.



3. Election Results and Destruction of Ballots

a. ACTION: Destruction of 2017 Ballots

The NAACCR Nominating Committee is pleased to announce the results of 2018 membership voting for officers. Three Representatives-At-Large were elected. Congratulations to Wendy Aldinger (Pennsylvania Cancer Registry), Angela Meisner (New Mexico Tumor Registry), and Kyle Ziegler (Cancer Registry of Greater California) for being elected to the NAACCR Board. In addition, Frank Boscoe (New York State Cancer Registry) was elected to President-Elect. The Committee thanks all of the candidates who were nominated this year and the member registries for their participation.

NAACCR Nominating Committee



4. Highlights and Accomplishments

June 2018

NAACCR Business Meeting

Major Effort in 2018- --2018 Changes

Major commitment of time, energy and subject matter expertise from NAACCR members working on:

Site Specific Data Items (SSDI): meeting once a week from January-April and twice a week from May-December 2017 for 1.5 hours each time with 20 members (additional work one hour week by subset of this group, and meeting preparation work). Included selecting, defining and developing rules for SSDIs.

Uniform Data Standards: meeting 2-3 times per month with 30 members to review and refine 223 new data items, preparation and review of Standards Volume II Data Dictionary, Version 18.

ICDO-3 Implementation Group- Met at least monthly 14 members to refine and incorporate ICDO-3 histology changes into cancer surveillance practice.

Edits WG (44 members) met at least twice a month August through May to develop edits for all of the new data items and update edits for data items no longer collected.

Stage Edits TF (25 members) developed edits for all of the SSDI's, Summary stage 2018, AJCC 8th edition, and EOD fields. These were then sent to the full edits WG for review. This group met twice a month from Sept-March.

Development of Implementation Guidelines for 2018 and the Concurrent Abstracting Statement - Group met to provide instruction and guidance to central registries, hospital registries, and software vendors for implementing these fundamental changes.

Production of 2018 Implementation Webinars (August 2017, October 2017, December 2017, March 2018) for members on the various changes for 2018; and, 2018 Vendor Webinars (November 2017 and February 2018).

Development and updating of Implementation Page on the NAACCR Website, including Education Calendar.

2018 implementation Education committee (12 members) met monthly December through May to develop education calendar and develop webinar related 2018 topics. Grade and Radiation webinars were presented in May.

Coordination and oversight of the process, monitoring of timelines, preparation of communication, responding to member concerns.

Governance and Finance

Increased value of investments portfolio with Rate of Return of 13.62%

Revenue from webinar subscriptions has been growing.

Secured training contract with Illinois.

Obtained NCI Conference Grant to support Annual Conference for next 4 years (including current meeting). Represents new funding as this grant was discontinued a few years ago.

Competed for and won sub-contract award with Battelle to use VPR process in Camp LeJeune study, a CDC/ATSDR funded study.

Audit Low Risk Auditee designation; successfully completed 2017 audit

Maintained CEO Gold Standard designation

Standardization and Registry Development

Developed an action plan to fully implement the XML standard for NAACCR by 2020, including raising awareness, webinars for registries and vendors, updated tools, integration into Call for Data, and modifications to the Data Standards Volume II Data Dictionary.

Produced report on efforts to improve timeliness of reporting (Assessment of Central Cancer Registry Timeliness and Reporting Standards Task Force).

Supported the work of Uniform Data Standards and Site Specific Data Items WGs to establish new standards for 227 new 2018 data items.

Developed a Concurrent Abstracting Statement

Updated NIH Common Data Element Repository with NAACCR Data Dictionaries.

Released Data Standards and Data Dictionary, Version 18 (released March 2018 with several revisions) and Data Exchange Standards and Record Descriptions, Version 18 (released March 2018, revised May 2018)

Produced three webinars on Implementation of 2018 Changes

Released 2018 Implementations and Timelines with monthly updates

Revising the Pathology Laboratory Electronic Reporting (Standards Volume V) to accommodate biomarker reporting and updating the standard overall.

Working on developing guideline documents and tools that address issues related to electronic physician reporting.

Professional Development

CTR Prep series continues to attract 60--70 participants per series, 3 times per year

NAACCR hosted and or participated in the following educational/informational presentations:

Monthly webinar series-12

CTR Prep series -3 8 week sessions

Implementation timeline webinars-4

Grade webinar – 2 (1000 people registered for each)

Radiation webinar-2 (1000 people registered for each)

State Association meetings-3

Veterans Association annual meeting-1

NAACCR Talks-5 (see below)

ISCR contract-(5 AJCC workshops, 3 Solid Tumor Workshops, 3 Basic Training Workshops)

Planned and coordinated NAACCR's first Hackathon to engage potential IT professionals into the world of cancer surveillance.

Developed Policies and Procedures for Student Oral Presentations and Posters.

Developed and analyzed survey on member issues concerning recruitment and retention of staff.

Consulted with NAACCR office and CDC on an interim training program for Puerto Rico following Hurricane Maria devastation.

Provided educational webinars on data collection, operational and analytical topics of interest to cancer surveillance community.

Planned and coordinated an IT enhancement to the Understanding Central Cancer Registries course with an additional 8 modules in development.

Assessing comprehensive training plans from two registries for adaptation to the general membership.

Communications:

Communicated regularly with membership via social media, NAACCR Review, NAACCR Narrative, and NAACCR Forum.

New NAACCR Forums were established concerning XML, SSDI and 2018 Implementation.

Updates to NAACCR website were made to improve information sharing.

Research and Data Use:

Developed proposal to add vital status and date of death to certification process.

Coordinated major improvements to the NAACCR Geocoder

Working on cancer control map story.

Working on revamping the Researcher Registry Indicators Database and combining it with CDC maintained data base to develop a comprehensive database for researchers interested in using registry data.

Forty (40) requests for NAACCR CiNA Public Use Dataset in 2017-2018 (compared to 17 last year).

Produced the 26th consecutive addition of Cancer in North America (CiNA)

Produced five webinars targeting epidemiology and research staff:

Guiding the Way to XML Data Exchange Implementation
Isaac Hands, Kentucky Cancer Registry
4/26/2018

Cancer in Vulnerable Populations Mike Spittel, NIH; Kelly Blake, NCI; Emily Yang, Yale; Scarlett Gomez, California Cancer Registry 10/19/2017

On-Line Interactive Tool to Improve the Understanding of Survival Statistics Paul Lambert, University of Leicester 9/14/2017

Identifying Target Areas for Colorectal Cancer Screening in Louisiana Through Geospatial Analysis
Lauren Maniscalco, Louisiana Tumor Registry; Kevin Henry, Temple University; Yong Yi, Louisiana Tumor Registry 8/10/2018

Geocoder Webinar Dan Goldberg, TAMU; Philip Crider, IMS; Recinda Sherman, NAACCR
7/20/2017

Eight studies were reviewed by NAACCR IRB for compliance and the Scientific Review Committee reviewed 10 papers this year (3 last year).

The Research Application Proposal Review Committee reviewed 12 new applications for use of CiNA data sets, 2 of which were rejected.

Virtual Pooled Registry:

Conducted hashed inter-registry linkage between CT, NJ, and NY to assess methods for deduplication and held in-person meeting to reconcile discrepancies and suggest potential rules for automated reconciliation.

Developed a web-based VPR Cancer Linkage System to track progress of studies and pertinent details for workflow and study management.

Developed VPR-CLS application review criteria, form, and approval process and established Research Review Committee.

Compiled information on IRB/registry use of Central IRB and Templated IRB/Registry Application

Identified study cohort and registries to test the VPR-CLS application, review, linkage, and match count reporting process.

Worked with IMS and member registries to test, enhance and improve Match*Pro linkage software and present training at pre-conference workshop (June 2018).

Global Initiatives:

Continued to work with Caribbean Public Health Agency to develop the Caribbean Hub of the International Association of Research on Cancer Global Initiative for Cancer Registration.

Produced Caribbean Registry Manual, Data Collection and Operating Procedures Module

Participated in data evaluations and feedback to two Caribbean countries

Served as faculty at the Sixth African Caribbean Cancer Consortium Scientific and Training Conference in Miami (October 2017) speaking on evaluating registry data for reporting and research.

Served as faculty at the ASEAN Cancer Registry Forum in March 2018 in Bangkok. Provided two power-point presentations with voice over rather than attend in person.

Strategic Alliances:

Conducted in-person meeting with CDC leadership in November 2017 and attended Canadian Council for Cancer Registries in Ottawa, ON, Canada in March 2018.

Developed new strategic alliance with Battelle.

Reassessing with our partners and stakeholders methods to coordinate future major changes in the cancer surveillance system.

Developed plans to enhance member services (via volunteer coordinator) and support advocacy efforts.

Invited to nominate Network Member to International Association of Cancer Registries Board of Directors.

Other/General:

Successfully managed all NAACCR Grants, Contracts, Cooperative Agreements, and related administrative requirements.

Sourced and negotiated upgraded abstract submission, scheduling and speaker bio system for 2019 annual conference

Renegotiated agreement with AV company for annual conference

Initiated modified investment strategies to decrease fees, increase return, and fine tune investment model with Portfolio Manager.

Improved web site search functionality, Narrative Newsletter, Causeway, and other service-oriented technologies.



5. Status on Strategic Management Plan



The North American Association of
Central Cancer Registries, Inc.

NAACCR: Working together to make every cancer count.

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

Strategic Management Plan

The North American Association of Central Cancer Registries, Inc. (NAACCR), is an association of more than 100 sponsoring, sustaining, and full members representing population-based central cancer registries and other cancer surveillance organizations in all U.S. states and Canadian provinces; leading federal agencies, including the U.S. Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI); Canadian partner organizations, including the Canadian Council of Cancer Registries, Statistics Canada (StatsCan), Canadian Partnership Against Cancer (CPAC), national cancer organizations like the American Cancer Society (ACS), the Commission on Cancer (CoC), and the National Cancer Registrars Association (NCRA); as well as many other cancer surveillance entities. This diverse but dedicated group is united through NAACCR to ensure the development and promotion of high-quality, population-based cancer registries across North America.

Central cancer registries play an essential role in our understanding of cancer, its diagnosis, treatment, and prevention by ensuring that accurate and timely population-based data are available for use in cancer control, epidemiologic research, public health programs, and patient care to reduce the burden of cancer. NAACCR has a long history of accomplishment and continues to be a leader in cancer surveillance by assuring standardization, enhancing the quality of data through analysis and certification, and expanding data use through innovative approaches.

In June 2011, NAACCR launched its first comprehensive Strategic Management Plan (SMP) designed to provide a robust blueprint for the future. The plan was developed to articulate the five priority areas essential to the mission of NAACCR in light of the rapidly changing technical and professional environment within which it operates. These priority areas included: (1) strategic alliances, (2) standardization and registry development, (3) research and data use, (4) communications, and (5) professional development.

The SMP defined the work to be undertaken from 2011-2016, which required an adaptable and nimble approach to manage change effectively. Steering Committees were created to lead the overall planning, implementation, and monitoring of their assigned priority area and for keeping the organization informed of emerging issues.

Working groups, advisory groups, and task forces were created around specific tasks with timelines and expected outcomes. A committee structure that aligned with the mission and goals of NAACCR was slowly rolled out and completed in June 2013.

Quickly thereafter, the Steering Committees began to address needs, solve problems, and advance towards the successful completion of priority area goals.

Board and Priority Area Accomplishments (2011-2016)

After implementation of the SMP, both the Board and the Steering Committees have forged ahead, realizing a number of accomplishments and successes. Progress has been made on major priority area goals and several new endeavors have been undertaken to advance cancer surveillance and meet the needs of the registry community.



Crosscutting Board Accomplishments and NAACCR Initiatives

During the past 4 years, the Board embarked on a number of innovative endeavors designed to strengthen NAACCR's internal capacity to meet its mission. At the same time, the NAACCR community launched several crosscutting projects aimed at advancing the cancer surveillance field. These include:

- Developing a matrix-style committee structure designed to be flexible and nimble.
- Recruiting Steering Committee leadership and key members.
- Enhancing membership on the Board by seeking new representatives from diverse backgrounds.
- Expanding financial resources through strategic grantsmanship.
- Co-hosting the International Association of Cancer Registries (IACR) Annual Conference in Ottawa in conjunction with the 2014 NAACCR Annual Conference.
- Playing a key role as an international partner in the establishment of the Caribbean Hub of the Global Initiative for Cancer Registration with IARC, NCI, and CDC; and providing consultation and support to international registries throughout the Caribbean.
- Establishing protocols and conducting pilot studies to establish the Virtual Pooled Registry-Cancer Linkage System (VPR-CLS) for cohort matching to all cancer registries; and, obtaining cooperation from 45 central cancer registries to participate in the Camp LeJeune pilot test of the VPR-CLS.
- Guiding the design of C-Change's Geographic Intervention Project.
- Achieving an 80% participation rate in NAACCR Interstate Data Exchange (41 of 55 potential central registries).
- Identifying and funding new staff positions to support research and the VPR-CLS; and identified other avenues for filling gaps in resources needed to carry out the SMP (i.e., interns, federal funding announcements).



Steering Committee Activities & Accomplishments



Standardization & Registry Development

- Implemented a change management process.
- Monitored national health information technology (IT) initiatives and submitted comments on national initiatives including:
 - the HL-7 ballot process for the Implementation Guide for Ambulatory Reporting;
 - the Meaningful Use (MU) Stage 3 Proposed Rule; and,
 - the American Society for Clinical Oncology (ASCO) Treatment Summary and Survivorship Care Plan.
- Assisted CDC with MU implementation.
- Advised on the transition from Collaborative Stage to directly coded T, N, and M staging guidelines.
- Defined an XML-based data exchange standard and produced an XML conversion tool to convert an existing flat file to the XML standard.
- Recommended changes to Standards Volume II Data Dictionary to accommodate electronic health record reporting.
- Completed a comparison of the NAACCR Standards Volume V and the HL7 Version 2.5.1 Implementation Guide, Electronic Laboratory Reporting to Public Health, Release 2, Draft Standard for Trial Use.

- Facilitated discussions around future needs and direction for NAACCR through the Registry of the Future sessions at the NAACCR Annual Conferences and NAACCR Webinars.
- Defined an approach for creating a web-based venue and clearinghouse for tools and other products that may be shared among NAACCR members.
- Included 12-month data in the NAACCR Call for Data.
- Published and released several guidelines, including:
 - Discharge and Claims Data Best Practices Guide;
 - Data Item Consolidation Manual and TNM Consolidation Guidelines;
 - Revised Death Clearance Manual;
 - Standards Volumes I and II on an annual basis;
 - Volume V supplement; and,
 - ICD-O-3 Implementation Guidelines.



Research & Data Use

- Published Cancer in North America (CINA) Monographs annually, and marked the 25th Edition of this publication series.
- Introduced Stage Data to Cancer in North America in the Incidence Volume in 2013.
- Introduced Cancer in North America Volume Four: Cancer Survival in the United States and Canada in 2016.
- Initiated the Virtual Pooled Registry-Cancer Linkage System (VPR-CLS), facilitating record linkages across multiple registries.
- Improved the speed and accuracy of the Automated Geospatial Geocoding Interface Environment (AGGIE) system, and developed the capacity to geocode Puerto Rico.
- Launched the Training Videos, including 19 webinars aimed at researchers and analysts, and continued to host pre-conference workshops and other training sessions for cancer researchers and registry staff.
- Expanded the Cancer Control Indicators Task Force, identifying core indicators for use in cancer control, to create a report with state/province rankings on these indicators.
- Reviewed new proposals and manuscripts for Institutional Review Board (IRB) compliance through the IRB Workgroup.
- Hosted an information webinar and submitted comments to the Department of Health and Human Services' Notice of Proposed Rule Making (NPRM) for the Federal Policy for the Protection of Human Subjects (aka: "Common Rule").
- Reviewed and approved numerous applications for CINA data use by NAACCR members through the Research Application Review (RapR) Workgroup.
- Reviewed publications that used CINA data.



Communications

- Highlighted the value of cancer surveillance research to external stakeholders by:
 - Creating and distributing a video explaining NAACCR and cancer surveillance for public use (see [YouTube NAACCR Explainer Video here](#)).
 - Developing and distributing the NAACCR Video Toolkit for the promotion to all central cancer registries, which is available in DropBox here: [NAACCR Video Toolkit Document](#).
 - Launching the NAACCRReview Blog (see <http://news.naaccr.org/>).
 - Expanding and enhancing NAACCR's social media presence through Facebook (NAACCR, Inc.) and Twitter (@NAACCR).
- Proposed a Communication Plan and Best Practices for Communications.

- Worked with two communications interns to implement communications strategies. Began planning for the NAACCR website redesign.
- Developed and implemented the Workspace Collaboration Tool on NAACCR Causeway (see <https://naaccr.causewaynow.com/site/login>).
- Created infrastructure and processes for timely release of publications and other NAACCR accomplishments through press releases and social media outlets.
- Implemented live streaming for the first time at the NAACCR 2016 Annual Conference.



Professional Development

- Planned and initiated a learning management system (LMS) to provide educational opportunities in a more flexible and efficient way.
- Developed a survey course called “Understanding Population Based Central Cancer Registries,” which will be free and available to all NAACCR members through the LMS by December, 2016.
- In collaboration with the Research and Data Use Steering Committee, enhanced the understanding of epidemiologic relevance to data collection by expanding webinar offerings through Cancer Surveillance Webinars, journal club presentation, and NAACCR Review (<http://news.naaccr.org/>). Go to <http://naaccr.org/EducationandTraining/TownHallWebinars.aspx> for recorded webinars.
- Continued to provide extensive Certified Tumor Registrar (CTR) training through NAACCR’s monthly webinar series and CTR-prep course.
- Through strong partnerships with subject matter experts, began the development of a comprehensive educational plan for NAACCR to ensure that central cancer registry staff are well equipped with the knowledge and skills needed for the changing informatics, research, and clinical data used in cancer care and surveillance.
- Developed a concept map on data collection from the educational plan.



Strategic Alliances

- The Strategic Alliances Steering Committee has collaborated with the following key organizations over the past 5 years:
 - Co-Sponsored the 2015 Annual Conference with IACR.
 - Collaborated with ACS, NCI, and CDC on Annual Reports to the Nation.
 - Guided the design of C-Change’s Geographic Intervention Project.
 - Held face-to-face meetings with several key partners including the CDC, NCI, ACS, and others to discuss ways to collaborate efficiently on initiatives of mutual interest.
 - Served as active member of the following leadership groups: National Coordinating Council for Cancer Surveillance, Comprehensive Cancer Control National Partnership, International Comprehensive Cancer Control Partnership, IACR, Union for International Cancer Control, C-Change.
 - Maintained liaisons with and/or actively participates on committees of the following key organizations: American Joint Commission on Cancer, American College of Surgeons, American Public Health Association, American Lung Association, Council of State and Territorial Epidemiologists, College of American Pathologists, Joint Public Health Informatics Taskforce, HL7 Anatomic Pathology Workgroup, National Cancer Registrars Association, Population Association of America, various state cancer registry associations, various academic institutions and universities.

Monitoring and Review

Steering Committees monitor progress towards reaching goals on an ongoing basis as one of their key responsibilities. Progress on objectives and strategic steps are assessed at every Steering Committee meeting. In addition, Board Liaisons work with Steering Committees to bridge any gaps or address emerging issues that might arise. The Board and Steering Committee Chairs meet annually to conduct an in-depth assessment of the SMP and address challenges and barriers that impact progress. The NAACCR Annual Conference has also served as a venue for communicating progress in each of the five priority areas, and meetings have been held to report on progress and discuss concerns. At the same time, additional member focus groups have been organized to capture more critical feedback. Throughout this effort, Steering Committees and the Board have made adjustments and updates to the SMP when necessary.

Towards the end of 2015, the Board and Steering Committees made plans to conduct a thorough review of the progress made during the past 5 years and update or revise the plan to ensure NAACCR continues to advance central cancer registries.

From January 19-21, 2016, the NAACCR Board and Steering Committee Chairs came together to engage in a comprehensive assessment of progress during the past 5 years and an exploration of new directions or programs that might be needed to sustain the continued success of NAACCR. In preparation for that meeting:

- A review of progress on the current SMP was undertaken by Steering Committees;
- Board members reviewed NAACCR's contributions to its vision and mission;
- A key stakeholder survey was completed to obtain feedback on both the benefits and costs of the SMP and the committee restructuring; and
- An updated analysis of NAACCR strengths, weaknesses, opportunities and threats (SWOT) was outlined.

At the meeting:

- Progress in each priority area was assessed and an intensive evaluation of goals and objectives was undertaken;
- Process evaluations were completed and changes considered; and,
- Crosscutting issues were considered and strategies to address them were proposed.

At the end of this meeting, Steering Committees worked to update each priority area. They made recommendations for the continuation of key functions and activities, revision or deletion of some objectives and new goals and objectives. Crosscutting areas and priority area plans are provided below.

NAACCR Advancing to the Next Level

If NAACCR is to advance its core values and seize emerging opportunities to continue to meet its mission, it must be prepared to embrace new strategies to adapt to change and move forward. During the January meeting, a number of critical crosscutting issues were identified that may require new strategies to leverage NAACCR's substantial and diverse talent, including:

- Some of NAACCR's mission-critical projects entail dynamic and integrated collaborations that cross priority areas, requiring mechanisms designed to build connections across specialties and enhance cross-fertilization of ideas. Although the current structure is working well across some priority areas, the need for enhancements designed to foster communication, collaboration, and excellence remain.
- The scope of work for the Standardization and Registry Development Steering Committee may not be sustainable under the current structure and may require a judicious realignment to assure NAACCR's success in meeting the goals and objectives of the SMP.
- Priority Area Networks (PANs) have been underutilized, and the need to reassess how to effectively engage members to share ideas and strategies, explore innovative solutions, and collaboratively learn within as well as across priority areas is critical.
- An effective approach to sunseting work groups and task forces needs to be implemented upon completion of objectives.
- Internal communication within and across Steering Committees needs significant strengthening to improve efficiencies, and more importantly, to identify activities that would benefit from increased collaboration.
- Efforts to inform membership to assure transparency and expand feedback loops must be deliberate, consistent, and timely.

- Strong leaders are necessary to manage the Steering Committees and work groups. Recruitment for key positions is mission critical. Member engagement, especially among those new to NAACCR, remains a challenge and should be addressed. Additionally, burnout and succession planning require attention. These issues require attention, not only from the Board, but also from all state and provincial registry directors whose programs benefit from the innovation and support that NAACCR provides.

After careful consideration, the following steps were recommended:

1. The Board should re-establish the NAACCR SMP Work Group to follow-up on these recommendations and evaluate progress.
2. Evaluation of work distribution across priority areas, especially for the Standardization & Registry Development Steering Committee, needs to take place at the Board and Steering Committee levels.
3. The NAACCR SMP Work Group should review best practices and recommend several strategies to engage members.
4. An assessment tool to guide the lifespan of working groups and task forces should be implemented across all Steering Committees to reduce risk of mission drift and assure high-functioning, successful work groups and task forces.
5. A formal mechanism to apprise the Communications Steering Committee of important actions and newsworthy developments within priority areas should be established.
6. Town Hall meetings, greater use of social media, and member assessment surveys should be used on an ongoing basis to provide transparency and capture member feedback.
7. Member engagement, recruitment, and leadership development require significant attention by the Board, Steering Committees, and all Registry Directors. New approaches to reduce burnout and improve succession planning should be included. Adapting best practices and model programs from successful non-profit associations should be considered.

Moving forward and focusing on the next 5 years, additional crosscutting issues were identified and strategies to address them were considered:

1. A marketing plan is needed to raise awareness of the valuable role that NAACCR plays in the cancer surveillance community and improve its branding to its key stakeholders and other pertinent constituents. Specific strategies include:
 - Conducting market research on best strategies to raise awareness of NAACCR
 - Initiating focus groups of key stakeholders and interested public
 - Seeking member feedback
 - Developing marketing materials such as a professional quality annual report, research findings, and promotional brochures
 - Expanding and targeting NAACCR's social media campaign to key stakeholders and interested public
 - Solidifying NAACCR's brand by providing consistent messaging across all levels
 - Leveraging existing member connections to key organizations and audiences at the national, state, and local levels
 - Preparing a tool to guide central registries at state and local levels in marketing their value
2. The Sponsoring Member Organization (SMO) communication efforts should be expanded to improve the dialogue with standard setters, members, and key constituents on topics important to the surveillance community.
 - Providing a sounding board for member concerns and recommendations through new feedback channels (such as member surveys)
 - Seeking ways to assure a smoother transition when standards are changed.
3. A coordinated approach aimed at building strategic alliances with current and new stakeholders should be initiated across the NAACCR membership.
 - A database of NAACCR members who have relationships with current or potential strategic stakeholders at the state and local level should be created to leverage connections.

- Materials and training to help volunteers reach out to various organizations should be developed.
- A NAACCR campaign to inform and educate leaders from the cancer surveillance, clinical care, research, and cancer control communities should be implemented.

Strategic Management Plan Goals & Objectives 2016-2021

Priority Area 1: Strategic Alliances

Rationale: The need to strengthen and expand relationships with key stakeholders, especially SMOs, remains critical for NAACCR. Changes in personnel at various organizations necessitate renewed efforts to strengthen and secure the kind of working relations among SMO members that will be required to meet future challenges. For similar reasons, the strategic development of new and continuing partnerships in the clinical, data analytics, and global arenas remains a priority.

Major Goal: Strengthen relationships with SMOs and existing partners, while establishing new alliances with key organizations to promote the NAACCR mission.

Objective 1: Cultivate productive working relationships with standard setters by facilitating open communications and purposeful actions.

Objective 2: Enhance existing relationships and build new strategic alliances that benefit cancer registries and support NAACCR's mission.

Priority Area 2: Standardization and Registry Development (S&RD)

Rationale: Standardization and registry development continues to be a mission-critical role that must move forward so that central registries are adequately prepared to adapt rapidly and successfully to changing developments in cancer surveillance. Emerging technologies, genetic and clinical advances, survivorship issues, electronic medical records, and "Big Data" are transforming the way central cancer registries function. For these reasons, the S&RD priority area must continue to maintain its efforts to assure the highest quality data for central registries while seeking innovative strategies to develop the cancer registry of the future.

Goal 1: Prepare for the cancer surveillance system of the future – a system that is more timely, responsive, and adaptable to change.

Objective 1: Analyze how cancer surveillance systems will interface with electronic health data and continue to assess semantic interoperability issues.

Objective 2: Engage and remain current with national/international efforts regarding electronic health records and other IT technologies.

Goal 2: Provide consensus standards and best practices for the collection and processing of cancer and patient information.

Objective 1: Ensure the maintenance of standards volumes and implementation guidelines that are consensus-based, reflect a comprehensive vetting process, and conform to interoperable content and transmission standards.

Objective 2: Develop methods to simplify the death clearance process and make it more efficient and cost-effective.

Objective 3: Facilitate automation of record consolidation by developing general principles and consolidation guidelines.

Objective 4: Provide guidelines to central registries that will improve the timeliness of cancer reporting.

NEW!! Goal 3: Provide the documentation, tools, and training that enables the NAACCR community to transition from the fixed-width data exchange standard to the NAACCR XML data exchange standard.

Objective 1: Author, publish, and maintain documentation for the XML standard and related processes and tools.

Objective 2: Design, implement, and support software tools and processes that enable the NAACCR community to adopt the XML standard.

Objective 3: Plan and coordinate pilot projects with NAACCR members that demonstrate the utility, practical use, and extensibility of the XML standard.

Objective 4: Identify and obtain sources of funding for the software development and support of the XML standard.

Objective 5: Provide training and communication of the XML standard along with related software tools and processes via websites, conference calls, presentations at the NAACCR Annual Conference, and other relevant venues that provide broad coverage and accessibility to the NAACCR community.

NEW!! Goal 4: Explore innovative uses of cancer registries by identifying emerging initiatives and new roles that bring value-added benefits to cancer surveillance, research and cancer control.

Objective 1: Identify new strategies to assess and monitor cancer survivorship care plans.

Objective 2: Monitor advances in cancer surveillance, control and research to identify potential roles for cancer registries.

Priority Area 3: Research and Data Use

Rationale

The fundamental value of centralized cancer registries is the high-quality data that allows innovative research, reliable cancer surveillance and improved cancer control. The Research and Data Use Steering Committee plays a vital role in assuring promotion and access to registry data in a systematic and user-friendly way. Significant advances in technology and science offer new opportunities and challenges for cancer surveillance. Data analytics and “Big Data” are presenting new ways to analyze both structured and unstructured data to provide new insights and directions in our understanding of cancer. It is essential that NAACCR keeps pace with these developments by making certain that central registries are positioned to make the fullest possible contribution to future research in epidemiology, cancer prevention and control, and, in particular, clinical outcomes.

Goal 1: Develop efficient, centralized processes to improve access to North American population-based cancer registry data for linkages, research, surveillance, and other applications.

Objective 1: Promote the use of high-quality and timely registry data by enhancing the annual Call for Data and the various NAACCR CINA data products.

Objective 2: Develop a voluntary process to combine limited data from multiple registries to facilitate record linkage research.

Objective 3: Maintain and enhance tools to inform researchers about state- and province-specific research experience, interests, and processes to initiate research.

Objective 4: Increase accessibility to NAACCR's CINA products by periodically evaluating data access policies and processes.

Objective 5: Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public.

NEW!! Goal 2: Improve the research capacity of NAACCR Member Registries, and enhance data use capabilities.

Objective 1: Strengthen NAACCR Member Registry capacity in research and data use.

Objective 2: Strengthen NAACCR's internal capacity to support research activities.

Priority Area 4: Communications and Policy Development

Rationale: Communicating a unified understanding of purpose to members, outside stakeholders, and the public is the critical role performed by the Communication Steering Committee. Keeping members informed of advances in the field, reporting progress towards reaching SMP goals and objectives, sharing success stories among members, and providing opportunities from member input are just a few of the important steps necessary to assure openness and transparency within NAACCR. At the same time, a platform for sharing information with the broader cancer surveillance community, and the public in general, is essential to bringing a greater awareness of NAACCR member interests to wider audiences. Finally, as an association representing the interests of central cancer registries, NAACCR must develop and promulgate carefully crafted policy statements on critical issues of national relevance to its members and the broader public they serve. These statements will be issued through the Communications Steering Committee.

Goal 1: Serve as the voice for NAACCR members on key issues involving central cancer registries.

Objective 1: Use modern methods such as internet-based technologies to capture and share member views, opinions, and perspectives on important registry issues.

Objective 2: Release position papers and policy statements, as appropriate, that support registries, cancer surveillance, and the NAACCR mission as required by the Board, NAACCR membership, or steering committees.

Objective 3: Serve as a united voice for policy issues and position statements that promote NAACCR's mission or benefit central cancer registries.

Goal 2: Promote the sharing of expertise, knowledge, procedures, and best practices among NAACCR members to ensure efficiency and reduce redundancy of effort.

Objective 1: Promote the Causeway Workspace Collaboration resource on the NAACCR website where members may post informational items that may be of value to other NAACCR members.

Objective 2: Develop an area on the NAACCR website where members may ask other members for guidance with particular issues or suggest a problem for collaborative solution efforts.

Objective 3: Enhance NAACCR's use of web-based and technology-driven communication systems to improve information sharing and promote adoption of best practices, and develop a more global distribution list for outward communication.

Objective 4: Provide a venue and act as a clearinghouse for sharing software products, SAS or other programs, algorithms, tools, and/or templates to make them more widely available and minimize duplication of effort.

Priority Area 5: Professional Development

Rationale: The development and training of skilled CTRs, epidemiologists, IT specialists, and registry managers remains essential to the future of centralized registries. New technologies and advances in genetics and molecular biology are informing clinical and cancer control strategies. Informatics, analytics, and molecular epidemiology are combining to push for change in the way registries function. Personnel are being asked to do more with less, as budgets are cut and the complexity of work responsibilities increases. Enhanced training and professional development will remain an essential priority of NAACCR.

In addition, an aging workforce creates a demand for succession planning to establish a talented pool of future leaders for central registries. Programs to develop management, leadership, and strategic thinking proficiencies will grow. NAACCR needs to work collaboratively with other key agencies to address this serious concern.

Goal 1: Partner with other professional organizations to address recruitment and retention issues and delineate NAACCR's role in national retention and recruitment efforts.

Objective 1: Develop and implement strategies to retain personnel in central registries by enhancing career opportunities for individuals with diverse skill sets such as epidemiology, operations, statistics, and information technology.

Objective 2: Support collaborative approaches to make career opportunities more attractive to individuals with skill sets and expertise to build and implement the cancer registry of the future.

Goal 2: Develop a comprehensive multidisciplinary training program that provides cross training and leadership skills to ensure that professional personnel in NAACCR member organizations possess the requisite skill sets required to excel in the rapidly changing cancer surveillance environment.

Objective 1: Continue to provide educational venues to assist development of registry personnel in scientific, operational, technological, management, and data use issues.

Objective 2: Assist registries in the development of IT skill sets, including database management, information security, health information exchange/transfer, knowledge of cancer reporting requirements, reporting sources, file formats, coding schemas, and business needs.

Objective 3: Create a comprehensive training program that includes core competencies in the areas of leadership, management, registry operations, epidemiology/statistics, IT, and data security to prepare members for management positions and to provide for a talented and reliable supply of future NAACCR leaders.



THE NAACCR WOW Initiatives

As part of its first SMP from 2011-2016, the **WOW** project was originally proposed to challenge the cancer surveillance community to take on a big-picture problem that would have a transformative impact on the field.

WOW projects are complex problems within the cancer surveillance community that require innovative and collaborative solutions that cross all priority areas and bring together outside partners. In 2012, NAACCR identified the VPR-CLS as its first **WOW** project:

1. **Virtual Pooled Registry-Cancer Linkage System:** The creation of a resource to support multi-state or nationwide research with one application and one file submission will continue. This resource will also have the capacity to support inter-registry de-duplication, cohort-based research studies, clinical trials, and U.S. Food and Drug Administration (FDA) required post-marketing surveillance. Not only will the VPR-CLS facilitate linkages, but also a simultaneous goal is to develop a Central IRB, which could function as a universal IRB for VPR-CLS eligible studies. In addition, a template IRB application is being developed to streamline the IRB process.

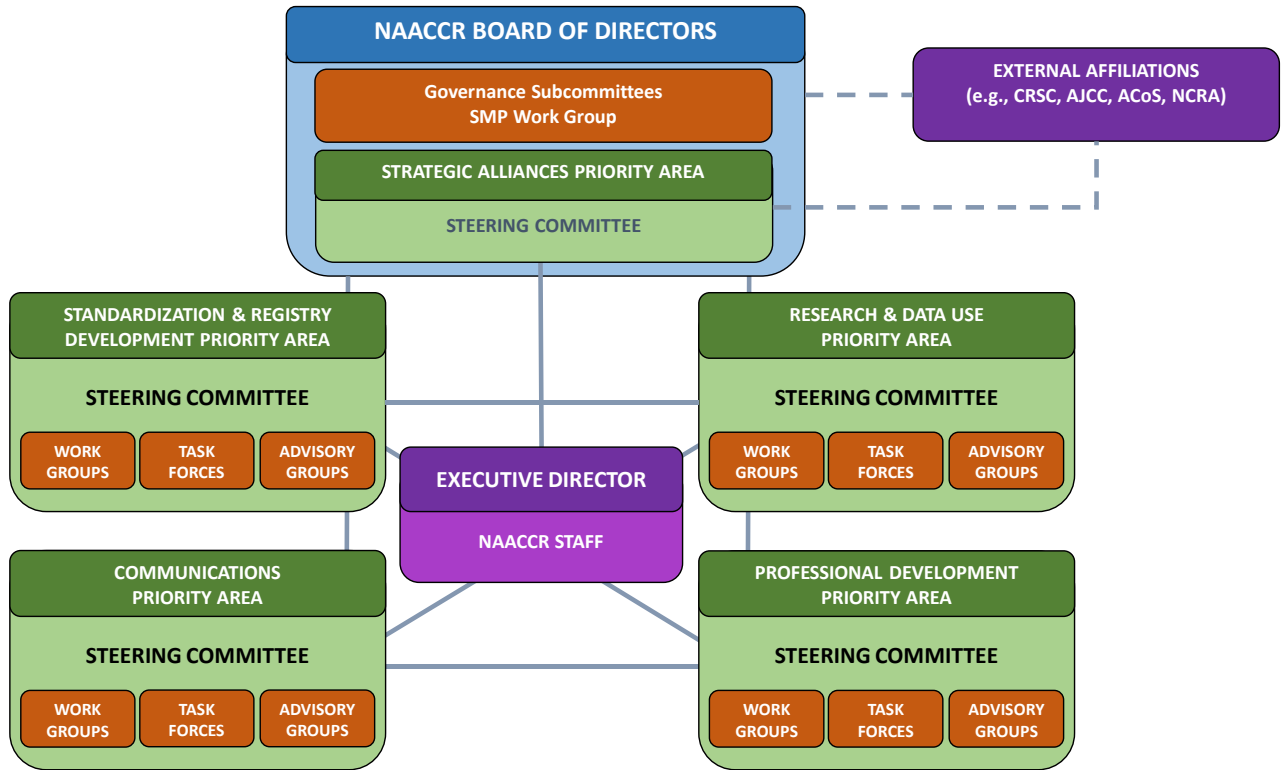
NEW!! In this new SMP, several other innovative initiatives are also being developed. These include:

2. **Technical Assistance for International Cancer Registries:** NAACCR has been an active partner in establishing and supporting the Caribbean Hub for the Global Initiative for Cancer Registration, sponsored by the World Health Organization (WHO) and IARC. In addition, NAACCR has established an international membership category, and is working to provide education, training, and other resources through portal access on our website. We are also building a mentorship and training program through twinning to assist registries in other parts of the world in their effort to measure the burden of cancer and develop effective cancer control programs.
3. **Registry of the Future Expert Leadership Panel:** An expert leadership conference that brings some of the world's top leaders in cancer surveillance together to vision the cancer registry of the future using critical thinking and innovative problem solving techniques.
4. **Review Registry Certification:** Explore the need for modifications to current Gold and Silver certification levels, or the addition of a new level of certification. Criteria to be considered may include data sharing, de-duplication between states, and other activities that improve the overall quality of North American data and data use.

Strategic Management Plan: Conclusions

In a rapidly changing environment with significant challenges and opportunities, progress must continue. To succeed in such an environment, NAACCR must balance its retention of core values while embracing new strategies to ensure that it meets the challenges and leverages opportunities. NAACCR and its members have worked diligently over the past 5 years to lay the foundation to move forward while remaining true to its mission. This new SMP maintains core principles, yet builds new capacity and positions NAACCR ready to adapt as necessary. A flexible structure is in place and refinements are being made to address the need to handle overarching issues in a way that encourages multidisciplinary solutions. Finally, this SMP will continue to ensure that NAACCR is equipped to meet the demands and to make every cancer count.

Appendix
NAACCR COMMITTEES and WORKGROUP STRUCTURE



Organizational Structure

The responsibilities of a Steering Committee include the following:

- Leads and develops its priority area.
- Plans, interprets, and sets overall direction for the priority area.
- Develops annual and long-term work plans.
- Assures that major goals, objectives, and tasks are organized and achieved.
- Assists with developing timelines and strategies for work groups and task forces.
- Works with working groups and or task forces as needed.
- Identifies talent and subject matter experts and facilitates collaboration.
- Assures that the member interests align with various tasks and activities for the completion of SMP goals and objectives.
- Controls scope and manages approved resources.
- Generates and facilitates innovative problem-solving and open communication across multidisciplinary members and groups.
- Encourages relationship building across priority areas.
- Monitors progress and tracks timelines.
- Identifies emerging issues within assigned priority areas and advises the Board if these require integration in future SMP enhancements.
- Reports regularly to the Board and NAACCR members.
- Serves as a sounding board for new ideas and opportunities for growth.
- Assesses the need for changes to any SMP priority area.

Definitions

- **Committee:** A group of team members who *accept responsibility for major goals and objectives*. Committees tend to be *ongoing* and with no identified endpoints or anticipated termination.
- **Working Group:** A group of experts brought together to accomplish *a measurable objective*, a major project, or a defined activity such as Edits Work Group, Physician Reporting Work Group, CINA Editorial Review Work Group, and the Research Application Review Work Group. Working groups usually have a defined scope and are technically focused with specific recurring or *ongoing deliverables*.
- **Task Force:** A group of team members with complementary skills brought together to accomplish a defined and specific task in a *set period*. Task Forces are often *need-based or event-driven* and then disbanded upon completion of work. Examples of possible task forces include ELR Messaging Comparison Task Force, Primary Payer Crosswalk Task Force, NAACCR Geocoder Task Force, and the Website Redesign Task Force .
- **Advisory Group:** A group of volunteers that plays a strong supportive role to the Steering Committee by identifying opportunities for growth and development, and serving as a sounding-board for specific initiatives being vetted by the Steering Committee.

Abbreviations

ACS – American Cancer Society
ASCO – American Society of Clinical Oncology
CDC – Centers for Disease Control and Prevention
CINA – Cancer in North America
CoC – Commission on Cancer
CPAC – Canadian Partnership Against Cancer
CTR – Certified Tumor Registrar
FDA – Food and Drug Administration
HL7 – Health Level 7
IACR – International Association of Cancer Registries
IARC – International Association for Research on Cancer
ICD-O-3 – International Classification of Diseases for Oncology 3
IRB – Institutional Review Board
IT – Information Technology
LMS – Learning Management System
MU – Meaningful Use
NAACCR – North American Association of Central Cancer Registries
NCI – National Cancer Institute
NCRA – National Cancer Registrar’s Association
RapR – Research Application Review
SMO – Sponsoring Member Organization
SMP – Strategic Management Plan
S&RD – Standardization and Registry Development
StatsCan – Statistics Canada
SWOT – Strengths, weaknesses, opportunities and threats
TNM – Tumor Nodes Metastasis staging system
VPR-CLS – Virtual Pooled Registry Cancer Linkage System
WHO – World Health Organization
XML – Extensible Markup Language



**Strategic Management Plan 2016-2021
Communications & Policy Development
Steering Committee Report**



Report Date: 6/1/2018

Representatives / Board Liaisons: Lori Swain

Frank Boscoe

Reporting Period: Start Date: 6/1/2017 End Date: 5/31/2018

Were there any significant changes to the Steering Committee or the goals and objectives of this Priority Area since your last report? No

What were some of the most salient accomplishments during this reporting period? (Limit to 1-3 highlights)?

1. Review and updates to the NAACCR Communications Plan; rebranding and technology of NAACCR Narrative Newsletter.
2. Promotion and support of World Cancer Day.
3. *The naaccr.org web site was updated as necessary and NAACCR web site search engine optimization completed which improved search capabilities on naaccr.org.*

Please provide an update for each of the objectives below, including progress to date and relevant work groups and task forces, where appropriate. For more information about the 2016-2021 SMP, go to <https://www.naaccr.org/strategic-management-plan>.

Goal 1: Serve as the voice for NAACCR members on key issues involving central cancer registries.

Objective 1: Use modern methods such as internet-based technologies to capture and share member views, opinions, and perspectives on important registry issues.

Update: Utilization of social media, NAACCRReview, NAACCR Narrative, and NAACCR Forums to facilitate two-way communication among the NAACCR Membership as well as the Cancer Surveillance Community.

Objective 2: Release position papers and policy statements, as appropriate, that support registries, cancer surveillance, and the NAACCR mission as required by the Board, NAACCR membership, or steering committees.

Update: No position papers or statements were requested of the committee for promotion during this period.

Objective 3: Serve as a united voice for policy issues and position statements that promote NAACCR's mission or benefit central cancer registries.

Update: No requests for policy issues and statements were requested of the committee for promotion during this period.

Goal 2: Promote the sharing of expertise, knowledge, procedures, and best practices among NAACCR members to ensure efficiency and reduce redundancy of effort.

Objective 1: Promote the Causeway Workspace Collaboration resource on the NAACCR website where members may post informational items that may be of value to other NAACCR members.

Update: The Causeway collaborative workspace platform was updated as necessary and promoted among committees. Usage increased during the reporting period as well as the number of committees using the platform. The video tutorial was also updated during this period.

Objective 2: Develop an area on the NAACCR website where members may ask other members for guidance with particular issues or suggest a problem for collaborative solution efforts.

Update: The NAACCR Forums have been expanded to new areas including XML, SSDI and 2018 Implementation topics. These platforms provide an easy to use method of communicating and collaborating directly with NAACCR and other members.

Objective 3: Enhance NAACCR's use of web-based and technology-driven communication systems to improve information sharing and promote adoption of best practices, and develop a more global distribution list for outward communication.

Update: The naaccr.org web site was updated as necessary. Members of the committee provided guidance to the NAACCR staff on search engine optimization, communication of NAACCR's mission on a more prominent place on the web site, Newsletter reconfiguration and branding, as well as promotion and use of the NAACCRReview, social media, and Forums.

Objective 4: Provide a venue and act as a clearinghouse for sharing software products, SAS or other programs, algorithms, tools, and/or templates to make them more widely available and minimize duplication of effort.

Update: The NAACCR ListServ continues to be an effective means for dissemination of information regarding these topics. The release of 2018 Implementation Documentation, SSDI efforts, and educational opportunities continue to be shared through the NAACCR ListServ and website.

Strategic Management Plan 2016-2021

**Professional Development (PD)
Steering Committee Report**



Report Date: May 29, 2018

Chair/Co-Chairs: Frances Ross
Mignon Dryden

Reporting Period: 6/1/17 to 5/30/18

Were there any significant changes to the Steering Committee or the goals and objectives of this Priority Area since your last report? No Yes

If yes, please describe:

What were some of the most salient accomplishments during this reporting period? (Limit to 1-3 highlights)?

1. The NAACCR Member Awards Program has been incorporated as part of the Professional Development Steering Committee activities June 2017.
2. Will hold a Hackathon prior to the 2018 Annual Conference in Pittsburgh for Informatics students to generate interest in Cancer Registries and to learn about software related to cancer data.
3. A task force was formed, drafted and completed the Policies and Procedures for Student Oral Presentations and Posters.

Please provide an update for each of the objectives below, including progress to date and relevant work groups and task forces, where appropriate. For more information about the 2016-2021 SMP, go to <https://www.naaccr.org/strategic-management-plan>.

Goal 1: Partner with other professional organizations to address recruitment and retention issues and delineate NAACCR's role in national retention and recruitment efforts.

Objective 1: Develop and implement strategies to retain personnel in central registries by enhancing career opportunities for individuals with diverse skill sets such as epidemiology, operations, statistics, and information technology.

Update: The committee continues work on the Action Plan for Recruitment and Retention strategies aimed at cancer surveillance personnel, specifically central cancer registrars, cancer informatics staff, student and young investigators. A survey of members was conducted in March in order to quantify and identify specific R&R needs. A presentation of the analysis of the survey results will be shared at the Annual Meeting.

Objective 2: Support collaborative approaches to make career opportunities more attractive to individuals with skill sets and expertise to build and implement the cancer registry of the future.

Update: The Action Plan for Recruitment and Retention strategies as mentioned in Objective 1 will address this as well.

Goal 2: Develop a comprehensive multidisciplinary training program that provides cross training and leadership skills to ensure that professional personnel in NAACCR member organizations possess the requisite skill sets required to excel in the rapidly changing cancer surveillance environment.

Objective 1: Continue to provide educational venues to assist development of registry personnel in scientific, operational, technological, management, and data use issues.

Update: The NAACCR Webinar Series continues to offer pertinent information on data collection and other operational issues. Specific topic webinars, such as one on XML or the Research and Data Use Cancer Surveillance Webinar series address technological, scientific, and data use issues.

Objective 2: Assist registries in the development of IT skill sets, including database management, information security, health information exchange/transfer, knowledge of cancer reporting requirements, reporting sources, file formats, coding schemas, and business needs.

Update: NCI staff were recommended and recruited to update the IT sections of the Survey Course with an anticipated 8 modules to be completed by June 2018.

Objective 3: Create a comprehensive training program that includes core competencies in the areas of leadership, management, registry operations, epidemiology/statistics, IT, and data security to prepare members for management positions and to provide for a talented and reliable supply of future NAACCR leaders.

Update: Staff from the New Jersey and Kentucky cancer registries provided their education and training plans as guides for the committee to develop a comprehensive training program.

Strategic Management Plan 2016-2021
Research & Data Use (RDU)
Steering Committee Report



Report Date: 6/1/18

Chair/Co-Chairs: Hannah Weir, PhD

Susan T. Gershman, PhD

Reporting Period: Start Date 7/1/17 End Date 6/30/18

Were there any significant changes to the Steering Committee or the goals and objectives of this Priority Area since your last report? No Yes

What were some of the most salient accomplishments during this reporting period? (Limit to 1-3 highlights)?

1. Certification Task Force: Proposal to add vital status and date of death for certification.
2. Major improvements to NAACCR Geocoder
3. Increased CiNA Use

Please provide an update for each of the objectives below, including progress to date and relevant work groups and task forces, where appropriate. For more information about the 2016-2021 SMP, go to <https://www.naacr.org/strategic-management-plan>.

Goal 1: Develop efficient, centralized processes to improve access to North American population-based cancer registry data for linkages, research, surveillance, and other applications.

Objective 1: Promote the use of high-quality and timely registry data by enhancing the annual Call for Data and the various NAACCR CINA data products.

Update: Proposal to include vital status and date of death for certification is in process.

Objective 2: Develop a voluntary process to combine limited data from multiple registries to facilitate record linkage research.

Update: Virtual Pooled registry (VPR) project sent survey to registries regarding their participation in the VPR. NCI has secured funding for all registries. National-level de-duplication volunteer project in process, led by VPR initiative.

Objective 3: Maintain and enhance tools to inform researchers about state- and province-specific research experience, interests, and processes to initiate research.

Update: Cancer Control Indicators Task Force will create a “map story” with updated data. The ranked data will be visualized tabulated and as a map with text to provide contextual information that is important for interpretation. Researcher Registry Indicators Database (RRIDB) is in process of incorporating the CDC data on data access, IRB, etc. Confidentiality & Security Task Force work has begun.

Objective 4: Increase accessibility to NAACCR's CINA products by periodically evaluating data access policies and processes.

Update: Increased use of CiNA data through Public Use Dataset with 40 requests for access versus 17 last year. Research Application Proposal Review Committee reviewed 12 new applications (down from 17 last year due to increase in Public Use access), 2 were rejected. Scientific Review Board reviewed 10 papers for scientific merit versus 3 last year. IRB reviewed 8 papers for compliance (versus 6 last year) and 3 projects for additional data (same as last year). CiNA monographs completed in May.

Objective 5: Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public.

Update: Draft cancer fact sheets in process. Additional SES tract-level data for US included in call for data for data assessment and to create a summary SES Index (Yost variable)—all but 4 registries submitted the supplemental data. In coordination with NCI, tract-level population estimates for all US will be released soon. Created, implemented, and tested NAACCR Geocoder improvements and rolled out via SEER*DMS and on-line interactive.

Goal 2: Improve the research capacity of NAACCR Member Registries, and enhance data use capabilities.

Objective 1: Strengthen NAACCR Member Registry capacity in research and data use.

Update: VPR project testing new linkage software Match Pro.

Objective 2: Strengthen NAACCR's internal capacity to support research activities.

Update: Continue to provide researcher targeted NAACCR Talks—RDU Webinars

Guiding the Way to XML Data Exchange Implementation	Isaac Hands, Kentucky Cancer Registry	4/26/2018
Cancer in Vulnerable Populations	Mike Spittel, NIH; Kelly Blake, NCI; Emily Yang, Yale; Scarlett Gomez, California Cancer Registry	10/19/2017
On-Line Interactive Tool to Improve the Understanding of Survival Statistics	Paul Lambert, University of Leicester	9/14/2017
Identifying Target Areas for Colorectal Cancer Screening in Louisiana Through Geospatial Analysis	Lauren Maniscalco, Louisiana Tumor Registry; Kevin Henry, Temple University; Yong Yi, Louisiana Tumor Registry	8/10/2018
Geocoder Webinar	Dan Goldberg, TAMU; Philip Crider, IMS; Recinda Sherman, NAACCR	7/20/2017

Strategic Management Plan 2016-2021
Standardization & Registry Development (S&RD)
Steering Committee Report



Report Date: May 29, 2018

Chair/Co-Chairs: Lori Koch

Mary Jane King (resigned April, 2018)

Reporting Period: Start Date July 2017 End Date June 2018

Were there any significant changes to the Steering Committee or the goals and objectives of this Priority Area since your last report? X No Yes

What were some of the most salient accomplishments during this reporting period? (Limit to 1-3 highlights)?

4. Developed an action plan to fully implement the XML standard for NAACCR by 2020.
5. Reviewed the Registry of the Future report and identified key topics and action steps appropriate for the S&RD. Timeliness of reporting and new and emerging data sources were identified as important topics and are the focus of the S&RD in-person meeting at this year's NAACCR conference.
6. Because the S&RD has such a large workload, the steering committee developed new tools to assist work groups and task forces in keeping the committee informed including team charter and work plan templates. The steering committee is also extending invitations to work groups and task forces to provide updates at S&RD monthly meetings.

Please provide an update for each of the objectives below, including progress to date and relevant work groups and task forces, where appropriate. For more information about the 2016-2021 SMP, go to <https://www.naacccr.org/strategic-management-plan>.

Goal 1: Prepare for the cancer surveillance system of the future – a system that is more timely, responsive, and adaptable to change.

Objective 1: Analyze how cancer surveillance systems will interface with electronic health data and continue to assess semantic interoperability issues.

Update: The Physician Reporting Workgroup continues to meet. The current goals include continuing development of a CDA validation tool, another tool to transform EHR cancer reports from CDA HL7 to NAACCR layout, and developing guideline documents and tools that address issues related to electronic physician reporting.

Objective 2: Engage and remain current with national/international efforts regarding electronic health records and other IT technologies.

Update: The Health IT Advisory Group continues to meet.

Objective 3¹: Provide the documentation, tools, and training that enables the NAACCR community to transition from the fixed-width data exchange standard to the NAACCR XML data exchange standard.

Update: S&RD SC submitted and received approval from the NAACCR Board for an action plan to implement the XML standard. The resulting action plan included eight tasks:

1. Raising awareness of freely available tools for conversion of fixed-width files to NAACCR XML.
2. Updated the NAACCR prep tool, posted 10/25/2017, to allow input and output of NAACCR XML in time for the 2017 call for data.
3. Encourage and accept the 2017 NAACCR call for data in the most recent NAACCR XML format.
4. Assess the rate of registry participation in XML format for the 2017 call for data submission.
5. XML Work Group will be providing a NAACCR webinar in early 2018 for cancer registry software vendors to publicize the XML implementation plan and solicit information about vendor readiness.
6. By November 1, 2018, NAACCR will update its software tools for processing call for data files so they can natively consume NAACCR XML.
7. Require the 2018 and all later NAACCR Call for Data submission files in the most recent NAACCR XML format to achieve 80% participation by 2018.

NAACCR will no longer support fixed-width format files and will alter the 2020 Volume II Data Dictionary to reflect the new NAACCR XML standard.

Objective 4²: Assess Registry of the Future session outcomes to determine which objectives are S&RD responsibilities.

Update: Reviewed the report from June pre-conference and identified key topics and action steps appropriate for the S&RD.

1. Develop new objectives and task forces as needed specifically focusing on the first two objectives – Timeliness of Reporting and New and Emerging Data Sources.
 - a. Review data collection model in light of things like multi-gene molecular panels, genetic sequencing, tumor banks, and linkages to genomic data.
 - i. Invited speakers to present information on current practices and innovative methodology on this topic.

¹ This objective was integrated into Goal 1 after the 2016-2021 SMP was published (it was formerly Goal 3).

² This objective was added after the Registry of the Future Workshop that was conducted at the NAACCR 2017 Annual Conference.

- ii. S&RD will devote the in-person meeting at the NAACCR Annual Conference to discussion of this topic.
- b. Discuss evaluation of data sources
- c. Discuss characterization of cases that aren't submitted in a timely manner.

Goal 2: Provide consensus standards and best practices for the collection and processing of cancer and patient information.

Objective 1: Ensure the maintenance of standards volumes and implementation guidelines that are consensus-based, reflect a comprehensive vetting process, and conform to interoperable content and transmission standards.

Update:

Uniform Data Standards Work Group continues to review and approve new data items. SSDI Work Group finalized all new data items and posted a draft manual for review on the NAACCR website. The final document was published in May 2018.

Objective 2: Develop methods to simplify the death clearance process and make it more efficient and cost-effective.

Update: This objective is currently on hold.

Objective 3: Facilitate automation of record consolidation by developing general principles and consolidation guidelines.

Update: This objective is currently on hold.

Objective 4: Provide guidelines to central registries that will improve the timeliness of cancer reporting.

Update: Reviewed and approved the final report from the Assessing Central Cancer Registry Timeliness of Reporting Standards (ACCR-TRS) TF and provided report to the NAACCR Board for review and distribution to membership.

Goal 3³: Explore innovative uses of cancer registries by identifying emerging initiatives and new roles that bring value-added benefits to cancer surveillance, research and cancer control.

¹ Formerly Goal 4 in the 2016-2021 SMP.

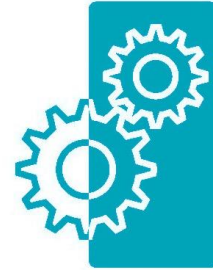
Objective 1: Identify new strategies to assess and monitor cancer survivorship care plans.

Update: This objective is currently on hold.

Objective 2: Monitor advances in cancer surveillance, control and research to identify potential roles for cancer registries.

Update: This objective is currently on hold.

Strategic Management Plan 2016-2021
Strategic Alliances Steering Committee Report



Report Date: June 2018

Chair/Co-Chairs: Chuck Wiggins
Lori Swain

Reporting Period: Start Date June 2017 End Date July 2018

Were there any significant changes to the Steering Committee or the goals and objectives of this Priority Area since your last report? No Yes

If yes, please describe:

What were some of the most salient accomplishments during this reporting period? (Limit to 1-3 highlights)?

1. Conducted in-person meeting with CDC leadership in November 2017 and attended Canadian Council for Cancer Registries in Ottawa, ON, Canada in March 2018.
2. Developed new strategic alliance with Battelle.
3. Reassessing with our partners and stakeholders methods to coordinate future major changes in the cancer surveillance system.

Please provide an update for each of the objectives below, including progress to date and relevant work groups and task forces, where appropriate. For more information about the 2016-2021 SMP, go to <https://www.naaccr.org/strategic-management-plan>.

Major Goal: Strengthen relationships with SMOs and existing partners, while establishing new alliances with key organizations to promote the NAACCR mission.

Objective 1: Cultivate productive working relationships with standard setters by facilitating open communications and purposeful actions.

Update: Met in-person with CDC in Atlanta in November 2017. Presented NAACCR overview and updates at Canadian Council for Cancer Registries in Ottawa in March 2018. Continue to meet regularly with standard setters, stakeholders and partners via conference call.

Objective 2: Enhance existing relationships and build new strategic alliances that benefit cancer registries and support NAACCR's mission.

Update: Established new strategic alliance with Battelle and will be working with them on new project 2018-2020.



6. Treasurer's Report

June 1, 2017 – May 31, 2018

Submitted by Maria J. Schymura, PhD, NAACCR Treasurer

Overview

This report is intended for the attendees of the Annual Business Meeting of NAACCR held in conjunction with the NAACCR Annual Conference. The NAACCR fiscal year runs from June 1st to May 31st. Therefore, this report incorporates audited information from the fiscal year that ended May 31, 2017. The operations and accounting policies of NAACCR are audited annually by an outside firm for the prior fiscal year. The firm that performed the audit for 2017 was Sikich, LLP. The full audit report was submitted to the NAACCR Board of Directors in September 2017.

Background

NAACCR was incorporated as a 501(c)(3) organization (exempt from income tax under the Internal Revenue Code) on October 27, 1992, in the State of California. NAACCR Offices are located at 2050 W. Iles, Suite A, Springfield, IL 62704-4194. NAACCR does business in the State of Illinois and files the appropriate state non-profit/business incorporation filings for the State of Illinois. By policy, 1987 was the official year that NAACCR was founded. Although based in Illinois, to comply with regulatory requirements, NAACCR annually files in excess of 30 documents to five states and the Federal government.

While the NAACCR Bylaws state "The Treasurer shall be responsible for overseeing the receipt and disbursement of all funds, establishing the budget for unrestricted funds, and managing all of funds of NAACCR," the policies established by the NAACCR Board of Directors give authority for actual management and operations of the funds to the Executive Director. For example, "The Executive Director shall have the authority to sign all consultant agreements, contracts, and sub-contracts from budgeted line items and approved activities that are paid from all-grants and contracts awarded to NAACCR and Fund 10 Unrestricted and Fund 15 Indirect budgets unless the agreement would bind the association beyond the scope of the grant or contract. With written permission of the Executive Director, the Chief Operating Officer may also sign such agreements on a case by case basis." The day-to-day fiscal operations are conducted by the Chief Operating Officer and the Comptroller with the approval and supervision of the Executive Director. The policies give the Executive Director appropriate authority to conduct NAACCR operations. "The Executive Director, as principal investigator of cooperative agreements, contracts, or grants, shall have full authority of all approved expenses. The ED shall inform the Board of any significant changes to the budgets of such agreements listed above at the next BOD meeting."

NAACCR generally operates at or near break-even status with some years slightly in the positive and others with a slight deficit if investments back to the organization are appropriate and tolerable.

Sources of Funds

Major funding for NAACCR comes from the National Cancer Institute (NCI) and the Centers for Disease Control and Prevention (CDC) in the form of grants and contracts. NAACCR received 65% of its revenues and other support from grants and contracts received from the U.S. Department of Health and Human Services for the fiscal year that ended May 31, 2017 as compared to 63% in 2016. Each of these grants and contracts comes with its own obligations and stipulations. These funds support the many operations and services that NAACCR provides its members and the cancer surveillance community. Most grants and contracts do not coincide with the NAACCR fiscal year and run on their own fiscal timeline.

The fiscal year 2017 grants and contracts are:

- CDC Cooperative Agreement Year 2017—funding for NAACCR that will develop, promote, and disseminate standards and best practices as well as increase the capacity of central cancer registries and CDC-funded programs to report cancer incidence data electronically.
- NCI Sole Source Contract—funding for large parts of NAACCR activities including wages and salaries, educational webinars, statistical analyses, committee support, and geocoding.
- NCI Global CR-CS—the purpose of this grant is to improve cancer surveillance in the Caribbean in partnership with NCI, CDC, IACR, and Caribbean Public Health Agency.
- NCI Virtual Pooled Registry Project—to streamline cohort linkage with multiple registries with one research application process, one research file submission, and one linkage process.

Additional funds come from the American Cancer Society, Annual Conference registrations, exhibitor income, webinar workshops and CTR prep courses, NAACCR consulting and educational offerings, and NAACCR membership dues. Membership dues accounted for about 2%-3% of NAACCR's total operating budget in 2017. In 2017 NAACCR had approximately \$2.1 million in annual operation.

Indirect Costs are the administrative overhead that keep an organization running. The costs include compensation not tied to a specific program, office space, utilities, audit costs, and insurance. NAACCR is required to negotiate a Federal Indirect Costs Rate. The Indirect Cost Rate for the period was 28.4% and that was negotiated with The Division of Cost Allocation of the U.S. Department of Health and Human Service, Office of Assistant Secretary for Administration and Management, Program Support Center.

Accounting Framework

Many NAACCR member registries exist within larger institutions such as a government agency or university. As such, their budget is either part of a larger whole or is separated out by the institution. Because NAACCR has so many sources of funds and corresponding outflows and exists unto itself, the outside auditors have recommended that NAACCR use an accrual basis of accounting.

This framework allows NAACCR to see itself as an institution with assets and liabilities, accounts payable, account liabilities, etc. At the end of a fiscal year, total assets and total liabilities and net assets should match.

Accounting Software

NAACCR uses a software package from Abila. This company is a privately owned company based in Austin, TX. Abila has more than 32,000 unique non-profit organizations, including government entities, universities, foundations, and a variety of other 501(c)(3) organizations as customers. It is well reviewed system. As in previous years, the license agreement is reasonable and does not impose any undue burden on NAACCR. The software is regularly updated. NAACCR executive staff continue to be extremely satisfied with the software.

Funds

Each of the grants and contracts is accounted for and looked at separately. The Board of Directors annually approves two separate budgets, Fund 10 and Fund 15. Fund 10 collects all unrestricted funds from Annual Conference registrations, exhibitor income, webinar series and CTR prep courses, and NAACCR membership dues and then spends them on various operations, mostly the Annual Conference and NAACCR training activities. We refer to the funds as being unrestricted because they are outside a governmental contract or other federal funding. Fund 15 takes the indirect and fixed fees from contracts and grants and funds the bulk of NAACCR day to day operations: portions of salary and wages, office expenses, professional services, and miscellaneous expenses. Similar to many institutional budgets, some salary and wages (i.e., percent of effort) and specific expenses such as travel are accounted for in a specific grant or contract.

Additional funds come from contributions by NAACCR's sponsors that are used to support specific programs.

Expenditures

For fiscal year 2017, approximately 45% of the budget went to support NAACCR personnel. This is decrease from the prior fiscal year because of funding and other personnel changes. NAACCR funds 10 Full-Time employees as well as various consultants, contractors, and subcontractors to operate the federal grants/contracts, business, and operations. NAACCR purchases insurance to protect the organization, the Board of Directors, and its officers. During the last fiscal year, NAACCR transacted with over 40 different vendors in amounts of \$5,000 or more.

The largest single categorical expense for NAACCR is the Annual Conference. The largest contracts are with IMS for work in producing the CINA products and other biomedical computing support services, and Texas A&M University for the Geocoder. These contracts are approved and controlled via the NCI Sole Source Contract.

Since the largest portion of NAACCR's budget is comprised of federal grants, contracts, or cooperative agreements, most of the expenditures are planned and accounted for as a result of the grant, contract, or agreement. Only a small portion of NAACCR's budget can be considered unrestricted.

Fiscal Controls

Primary responsibility for fiscal controls for revenues and expenditures rests with the Chief Operating Officer, who is assisted by the Comptroller. A review of all fiscal controls is conducted annually by the outside auditor and the Treasurer. The results of the audit are presented to the President and Board of Directors. NAACCR has an “Internal Control Narrative” that covers case receipts, electronic deposits, cash disbursements, bank reconciliation, and payroll among other topics. Any check over \$3,000 requires two signatures. All contracts are approved by the Board.

NAACCR bank accounts are with the Bank of Springfield, an FDIC member bank with offices in Springfield, IL. It is a regional bank with \$750 million dollars in assets. The certificates of deposit are with LPL Financials administered by the Bank of Springfield. Most of the certificates in 2017 were for 10 to 24 months in amounts ranging from \$50,000 to \$100,000.

Management of the Merrill Lynch portfolio is done under guidelines set by the Board of Directors. The performance and costs of the portfolio are reviewed annually by the Board with guidance of the Executive Director and Treasurer. During the reporting period June 2017 – May 2018 the NAACCR Board of Directors updated the investment strategy to advance the diversification of the portfolio, decrease portfolio operating expenses, and allow for more efficient adjustments to the portfolio to match market changes. After research by NAACCR’s 2016 – 2018 Board and Treasurer; during the most recent reporting period the Board opted for a hybrid approach, using primarily lower-cost exchange-traded funds (ETFs), but supplementing with a traditional mutual fund to fill a gap. This borrows from the advantages of both types of options.

Each month the Chief Operating Officer and Comptroller provide the Treasurer with a detailed summary of all financial activity from the start of the fiscal year to that point. These detailed summaries are generally between 75-100 pages in length. The contents included a summary balance sheet, statement of activities, monthly cash flow projects for each of 10 funds, summary of checking account activity, detail reports on income, expenditures, travel, salaries and fringe benefits. The Chief Operating Officer is available to the Treasurer to review the reports.

For the Board of Directors, the Chief Operating Officer provides a more condensed summary of financial activity.

Auditors Statement

Annually, NAACCR contracts with an independent auditor or certified public accounts to conduct an audit of the financial statements, financial disclosures, and internal controls. The current auditors, Sikich LLP, have reviewed NAACCR financial activities for several years and are familiar with NAACCR operations and personnel. The auditors produce a written report that is presented to the Board of Directors and then reviewed orally with them at a Board meeting. The last audit report, dated September 13, 2017 gave NAACCR a clean review including the distinguished Low Risk Auditee designation.

Reports to the NAACCR Board

On an annual basis, the NAACCR Board is provided with reports by the professional staff, including:

- a) Monthly summary of all financial activity
- b) Biannual Report of All Legal Filing Status
- c) IRS Form 990 (Tax Exempt Organization Tax Filing)
- d) Auditors Report

Future Financial Issues

NAACCR, similar to many public or quasi-publicly funded organizations, is always challenged with increasing services with and ever-expanding mission and needs while budgets generally remain flat or less than flat. This particular challenge is met by NAACCR Board of Directors, Committees, Staff, and Stakeholders working together to identify approaches for economizing our operations as well as prioritizing our financial obligations.

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES, INC.

STATEMENTS OF FINANCIAL POSITION

As of May 31,

ASSETS	2017	2016
Cash and cash equivalents	\$ 295,205	\$ 157,984
Grants receivable	273,811	339,130
Prepaid expenses	54,686	42,364
Certificates of Deposit	222,000	222,000
Investments	983,747	881,623
Total current assets	<u>1,829,449</u>	<u>1,643,101</u>
Furniture and equipment, net	53,509	21,371
TOTAL ASSETS	<u><u>\$ 1,882,958</u></u>	<u><u>\$ 1,664,472</u></u>
LIABILITIES AND NET ASSETS		
Accounts Payable	\$ 53,349	\$ 35,855
Accrued Liabilities	80,732	99,397
Deferred Revenue	260,827	224,327
Total liabilities	<u>394,908</u>	<u>359,579</u>
NET ASSETS		
Unrestricted	1,484,175	1,288,224
Temporarily restricted	3,875	16,669
Total net assets	<u>1,488,050</u>	<u>1,304,893</u>
TOTAL LIABILITIES AND NET ASSETS	<u><u>\$ 1,882,958</u></u>	<u><u>\$ 1,664,472</u></u>

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES, INC.

STATEMENT OF ACTIVITIES

For the Year Ended May 31, 2017

	Unrestricted	Temporarily Restricted	Total
REVENUES AND OTHER SUPPORT			
Grant and Contract Revenue	\$ 1,471,932	\$ -	\$ 1,471,932
In Kind Contributions	21,332	-	21,332
Conference Registration	167,875	-	167,875
Course Registration	12,845	-	12,845
Webinars	209,270	-	209,270
Membership Dues	67,800	-	67,800
Exhibitor Income	8,000	-	8,000
Consulting Fee Revenue	66,238	-	66,238
Investment income	41,857	-	41,857
Sponsorship	17,000	-	17,000
Miscellaneous income	15,651	-	15,651
Net realized and unrealized gain on investments	84,754	-	84,754
Net assets released from restrictions - Satisfaction of program restrictions	12,794	(12,794)	-
Total revenues and other support	2,197,348	(12,794)	2,184,554
EXPENSES			
Program services			
CDC Cooperative Agreement	333,487	-	333,487
Global CR-CS grant	68,459	-	68,459
Virtual Pooled Registry	162,743	-	162,743
NCI conference grant	20,000	-	20,000
NCI contract - sole source	560,886	-	560,886
American Cancer Society Grant	5,653	-	5,653
Conference and webinars	461,669	-	461,669
Total program services	1,612,897	-	1,612,897
Supporting services			
Management and general	388,500	-	388,500
Total supporting services	388,500	-	388,500
Total expenses	2,001,397	-	2,001,397
CHANGE IN NET ASSETS	\$ 195,951	\$ (12,794)	\$ 183,157
Net assets, beginning of year	1,288,224	16,669	1,304,893
NET ASSETS, END OF YEAR	\$ 1,484,175	\$ 3,875	\$ 1,488,050

See accompanying notes to financial statements.

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES, INC.

STATEMENT OF ACTIVITIES

For the Year Ended May 31, 2016

	Unrestricted	Temporarily Restricted	Total
REVENUES AND OTHER SUPPORT			
Grant and Contract Revenue	\$ 1,339,778	\$ -	\$ 1,339,778
In Kind Contributions	16,649	-	16,649
Conference Registration	187,810	-	187,810
Course Registration	11,250	-	11,250
Webinars	204,118	-	204,118
Membership Dues	79,221	-	79,221
Exhibitor Income	6,000	-	6,000
Consulting Fee Revenue	24,191	-	24,191
Investment income	54,502	-	54,502
Sponsorship	-	17,000	17,000
Miscellaneous income	20,593	-	20,593
Net realized and unrealized loss on investments	(49,205)	-	(49,205)
Net assets released from restrictions - Satisfaction of program restrictions	20,029	(20,029)	-
Total revenues and other support	1,914,936	(3,029)	1,911,907
EXPENSES			
Program services			
CDC Cooperative Agreement	316,440	-	316,440
Global CR-CS grant	21,024	-	21,024
Virtual Pooled Registry	106,064	-	106,064
NCI conference grant	23,946	-	23,946
NCI contract - sole source	531,076	-	531,076
American Cancer Society Grant	114,466	-	114,466
Conference and webinars	465,356	-	465,356
Total program services	1,578,372	-	1,578,372
Supporting services			
Management and general	376,875	-	376,875
Total supporting services	376,875	-	376,875
Total expenses	1,955,247	-	1,955,247
CHANGE IN NET ASSETS	\$ (40,311)	\$ (3,029)	\$ (43,340)
Net assets, beginning of year	1,328,535	19,698	1,348,233
NET ASSETS, END OF YEAR	\$ 1,288,224	\$ 16,669	\$ 1,304,893

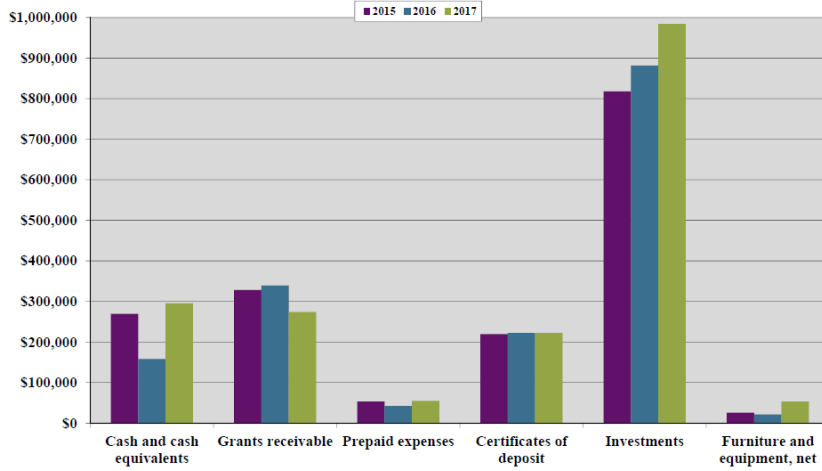
See accompanying notes to financial statements.

NAACCR, Inc.				
Balance Sheet				
<i>All Funds</i>				
As of February 28, 2018				
			Previous Month	Current Month
Assets				
	<i>Cash</i>			
		BOS Checking/Savings Account	180,994.26	166,413.18
		Flex Spending Account	3,645.73	2,705.21
	<i>Investments</i>			
		BOS/LPL Portfolio	229,583.61	230,492.33
		Merrill Lynch Portfolio	1,121,650.88	1,080,247.45
		<i>Subtotal Cash & Investments</i>	<u>1,535,874.48</u>	<u>1,479,858.17</u>
	<i>Receivables</i>			
		Accounts Receivable	5,900.00	5,350.00
		Indirect Funds Receivable	53,915.90	57,627.98
		Grants Receivable	216,471.06	232,746.13
		<i>Subtotal Receivables</i>	<u>276,286.96</u>	<u>295,724.11</u>
	<i>Prepays</i>			
		Prepaid Insurance	10,004.66	10,033.76
		Other Prepays	54,880.52	59,647.12
	<i>Other</i>			
		Total Equipment	170,537.84	170,537.84
		Accumulated Depreciation	(156,666.08)	(157,228.87)
Total Assets			<u>1,890,918.38</u>	<u>1,858,572.13</u>
Liabilities				
	<i>Current</i>			
		Accounts Payable	41,112.35	41,911.32
		Accrued Liabilities	123,486.77	118,971.42
		Deferred Revenue	166,839.00	153,034.00
Total Liabilities			<u>331,438.12</u>	<u>313,916.74</u>
Net Assets				
		Unrestricted Net Assets	1,428,811.02	1,428,811.02
		Temporarily Restricted Net Assets	19,633.00	19,633.00
		Change in Net Assets	111,036.24	96,211.37
Total Net Assets			<u>1,559,480.26</u>	<u>1,544,655.39</u>
Total Liabilities and Net Assets			<u>1,890,918.38</u>	<u>1,858,572.13</u>

Financial Statement Overview

Assets

(Page 3 of the audited financial statements)



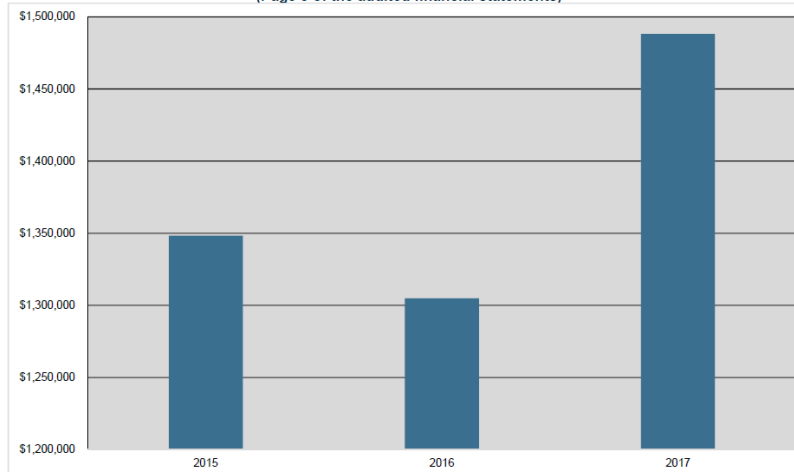
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Financial Statement Overview

Net Assets

(Page 3 of the audited financial statements)



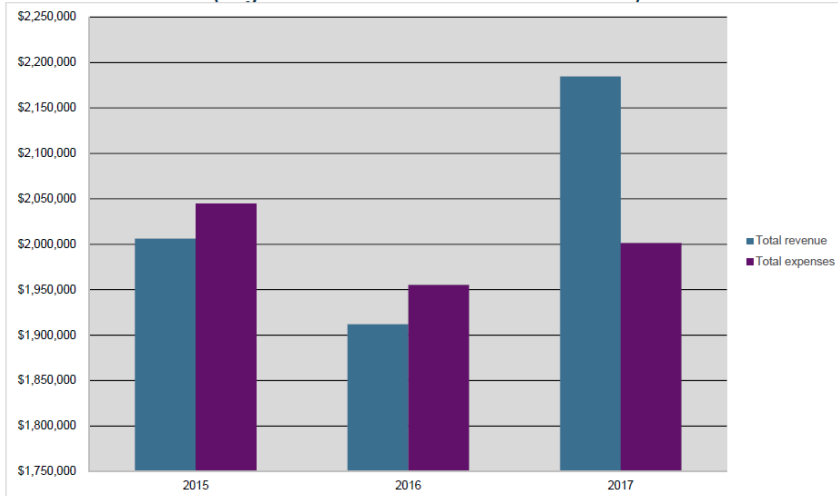
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Financial Statement Overview

Revenue vs. Expenses

(Page 4 of the audited financial statements)



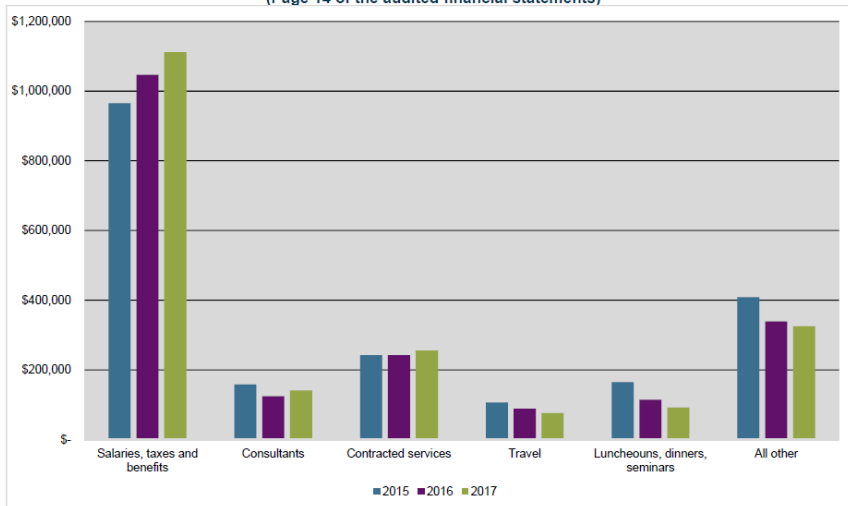
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Financial Statement Overview

Expenses

(Page 14 of the audited financial statements)



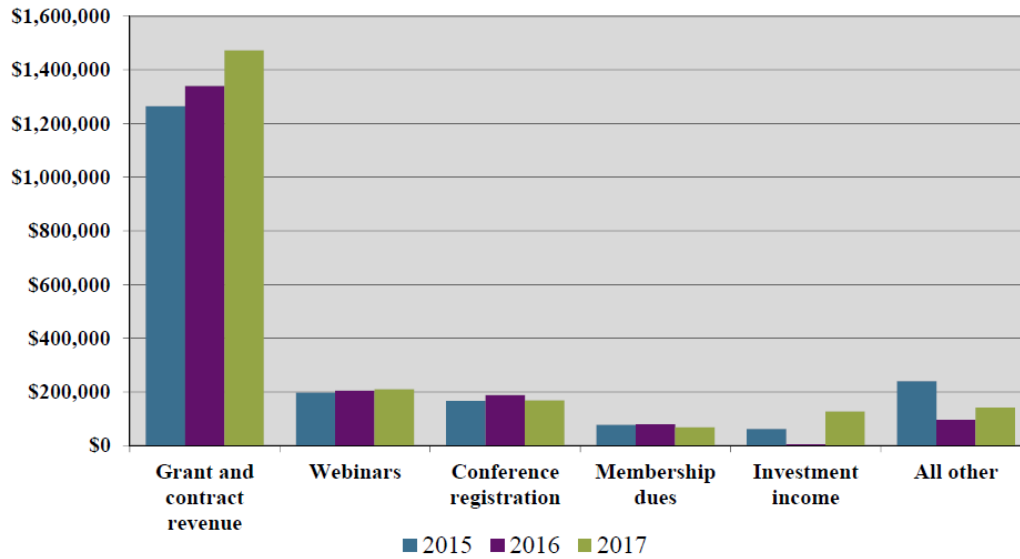
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Financial Statement Overview

Revenue

(Page 4 of the audited financial statements)





8. Support of All Kinds

Support of All Kinds from Sponsoring Organizations for 2017-2018

American Cancer Society - ACS

- Sponsor with Distinction (\$20,000) with dues
- 2017 Conference Exhibitor
- Phone bridge for teleconference calls
- Support to NAACCR Committees

American College of Surgeons - ACoS

- Dues
- Support to NAACCR Committees

American Joint Committee on Cancer - AJCC

- Support to NAACCR Committees

Canadian Cancer Registry – Statistics Canada

- Dues
- Support to NAACCR Committees

Canadian Partnership Against Cancer – CPAC

- Dues
- Support to NAACCR Committees

Centers for Disease Control & Prevention - CDC

- Cooperative agreement to support NAACCR infrastructure (\$425,000 in Yr 4)
- CDC phone bridge for conference calls. Assignment of three CDC teleconference bridge lines for committees.
- Dues
- Support to NAACCR Committees

National Cancer Institute - NCI

- Contract for Technical Assistance for Cancer Surveillance (7-year up to \$7.7 million currently in year 3), currently supporting three task orders: Cancer Surveillance (Stage Transition Projects), Virtual Pooled Registry, and Global CR-CS
- Phone bridge for teleconference calls of the Board and Program Committee
- Dues
- Support to NAACCR Committees

(Support of All Kinds Continued)

National Cancer Registrars Association - NCRA

- Liaison support to several NAACCR committees
- 2017 Conference Exhibitor
- Dues
- Support to NAACCR Committees

Public Health Agency of Canada - PHAC

- Dues
- Support to NAACCR Committees



9. Nominations for Nominating Committee

- a. **Nominating Committee Formation 2018-2019**
- b. **ACTION: Appoint Nominating Committee Chair**



10. Adjournment



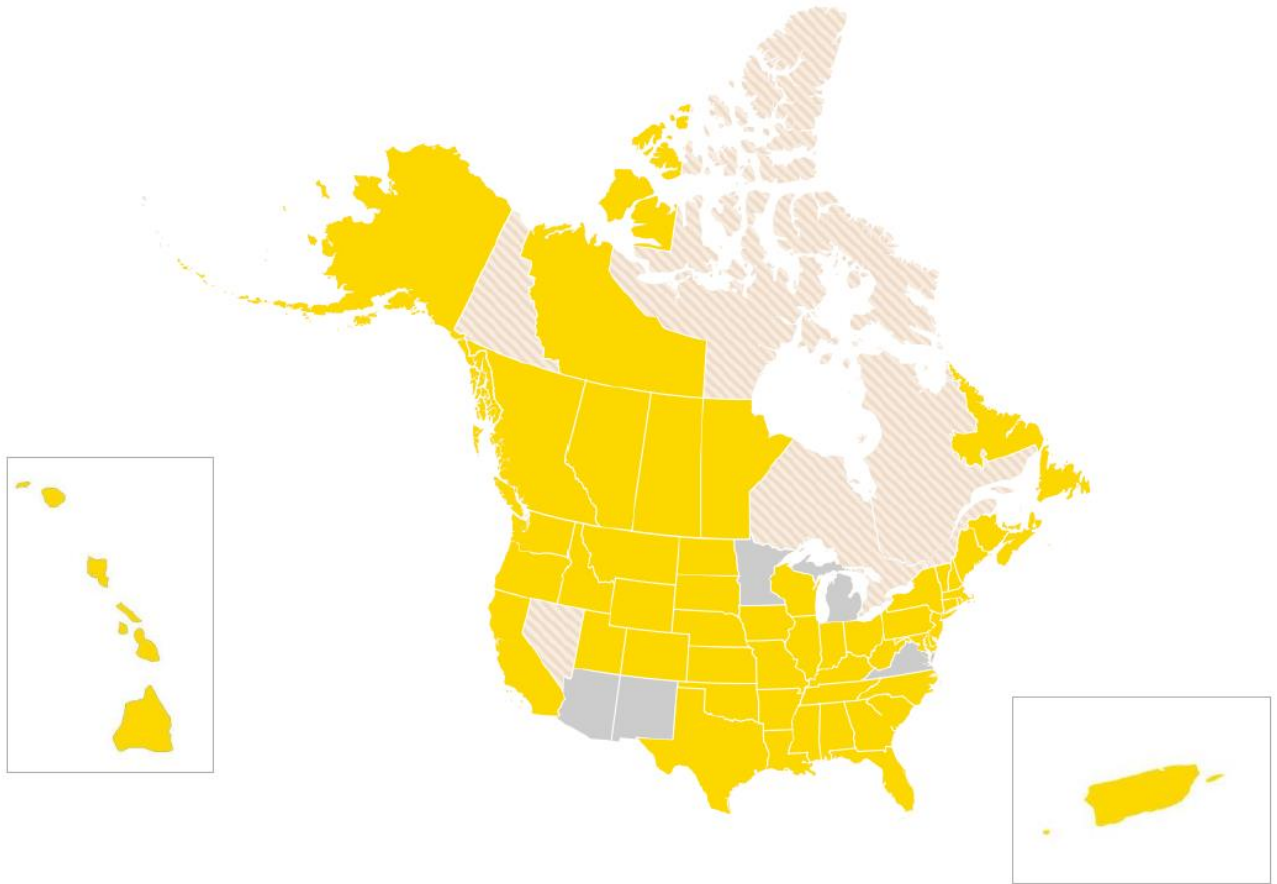
Appendix of Documents

Appendix documents are located on the following pages.

Registry Certification, Current Bylaws, Current Standing Rules, Organizational Charts



Registry Certification



Registry Certification Criteria for Quality, Completeness, & Timeliness of 2015 Data
Summarized Data Quality Indicators (Percentages)

Shading indicates that certification was not achieved, and the indicator that failed certification criteria.

Shading indicates that Silver certification status was achieved, and the indicator that resulted in Silver certification status.

Standard	Gold	95.0	2.0	2.0	3.0	2.0	3.0	1.0	100.0	100.0		
Standard	Silver	90.0	3.0	3.0	5.0	3.0	5.0	2.0	NA	NA		
Measurement Error		1.0	0.4	0.4	0.4	0.4	0.4	0.4	NA	NA		
Percent Missing/Unknown												
Registry	Award	Incidence Case Count	Completeness Adjusted for Duplicates**	Age	Sex	Race	County	DCO	Unresolved Duplicates (per 1000)	Percent Passed EDITS	Percent Passed INTER-RECORD EDITS	Timely
United States												
Alabama	Gold	26,453	99.7	0.00	0.00	1.30	0.80	2.40	0.00	100.0%	100.0%	Yes
Alaska	Gold	2,744	95.7	0.00	0.00	0.60	0.00	1.00	0.00	100.0%	100.0%	Yes
Arizona	Silver	30,842	93.9	0.00	0.00	2.40	0.00	3.20	0.20	100.0%	100.0%	Yes
Arkansas	Gold	16,889	100.9	0.00	0.00	1.50	0.70	2.80	0.60	100.0%	100.0%	Yes
California	Gold	166,679	97.4	0.00	0.00	2.40	0.00	1.40	0.40	100.0%	100.0%	Yes
Greater California	Gold	94,637	96.7	0.00	0.00	2.80	0.00	1.60	0.00	100.0%	100.0%	Yes
Greater Bay	Gold	32,493	107.6	0.00	0.00	1.40	0.00	1.00	0.00	100.0%	100.0%	Yes
Los Angeles	Silver	39,428	92.7	0.00	0.00	2.40	0.00	0.90	0.00	100.0%	100.0%	Yes
Colorado	Gold	22,562	97.8	0.00	0.00	0.80	0.00	2.50	0.00	100.0%	100.0%	Yes
Connecticut	Gold	20,802	114.8	0.00	0.00	1.30	0.00	0.40	0.00	100.0%	100.0%	Yes
Delaware	Gold	5,873	112.1	0.00	0.00	0.10	0.00	1.20	0.00	100.0%	100.0%	Yes
District Of Columbia	Not achieved	2,488	78.6	0.00	0.00	2.40	0.40	0.90	0.00	100.0%	100.0%	Yes
Florida	Gold	112,009	99.9	0.00	0.00	1.30	0.00	2.00	0.00	100.0%	100.0%	Yes
Georgia	Gold	49,568	105.7	0.00	0.00	0.20	0.00	1.40	0.00	100.0%	100.0%	Yes
Hawaii	Gold	7,134	107.4	0.00	0.00	1.10	0.00	1.30	0.00	100.0%	100.0%	Yes
Idaho	Gold	8,134	104.1	0.00	0.00	1.10	0.00	2.50	0.00	100.0%	100.0%	Yes
Illinois	Gold	68,549	105.5	0.00	0.00	1.00	0.00	2.20	0.80	100.0%	100.0%	Yes
Indiana	Gold	33,980	101.2	0.00	0.00	0.60	0.00	1.60	0.00	100.0%	100.0%	Yes
Iowa	Gold	17,880	107.6	0.00	0.00	0.60	0.00	1.20	0.00	100.0%	100.0%	Yes
Kansas	Gold	15,014	99.6	0.00	0.00	1.80	0.00	1.70	0.00	100.0%	100.0%	Yes
Kentucky	Gold	26,924	108.2	0.00	0.00	2.20	0.00	0.90	0.20	100.0%	100.0%	Yes
Louisiana	Gold	25,158	102.5	0.00	0.00	0.20	0.00	1.10	0.00	100.0%	100.0%	Yes
Maine	Gold	8,694	108.7	0.00	0.00	0.60	0.00	2.10	0.30	100.0%	100.0%	Yes
Maryland	Gold	30,929	105.8	0.00	0.00	0.40	0.70	2.50	0.00	100.0%	100.0%	Yes
Massachusetts	Gold	36,942	108.2	0.00	0.00	1.30	0.00	2.30	0.00	100.0%	100.0%	Yes
Michigan	Silver	53,208	98.7	0.00	0.00	0.40	2.70	1.10	0.70	100.0%	100.0%	Yes
Detroit	Gold	22,823	110.6	0.00	0.00	0.10	0.00	1.10	0.00	100.0%	100.0%	Yes
Minnesota	Silver	30,302	112.4	0.00	0.00	3.20	0.00	3.90	2.40	100.0%	100.0%	Yes
Mississippi	Gold	15,782	98.5	0.00	0.00	0.30	0.00	1.30	0.00	100.0%	100.0%	Yes
Missouri	Gold	32,958	102.2	0.00	0.00	0.20	0.00	2.60	0.40	100.0%	100.0%	Yes
Montana	Gold	5,918	103.7	0.00	0.00	0.80	0.00	2.30	0.00	100.0%	100.0%	Yes
Nebraska	Gold	9,854	107.6	0.00	0.00	0.70	0.00	1.20	0.00	100.0%	100.0%	Yes
Nevada	Not achieved	11,432	79.8	0.00	0.00	1.40	1.10	2.90	0.00	100.0%	100.0%	Yes
New Hampshire	Gold	7,983	108.6	0.00	0.00	1.00	0.00	0.80	0.00	100.0%	100.0%	Yes
New Jersey	Gold	51,048	109.4	0.00	0.00	2.80	0.00	1.40	0.00	100.0%	100.0%	Yes
New Mexico	Silver	9,091	91.2	0.00	0.00	1.70	0.10	3.60	0.10	100.0%	100.0%	Yes
New York	Gold	111,968	114.6	0.00	0.00	1.10	0.00	1.10	0.10	100.0%	100.0%	Yes
North Carolina	Gold	54,465	104.7	0.00	0.00	1.80	0.40	0.90	0.00	100.0%	100.0%	Yes
North Dakota	Gold	3,737	106.8	0.00	0.00	0.70	0.00	1.00	0.00	100.0%	100.0%	Yes
Ohio	Gold	65,426	100.7	0.00	0.00	1.30	0.00	2.30	0.00	100.0%	100.0%	Yes
Oklahoma	Gold	19,778	96.0	0.00	0.00	1.30	0.20	2.30	0.00	100.0%	100.0%	Yes
Oregon	Gold	19,891	94.9	0.00	0.00	0.40	0.10	2.20	0.00	100.0%	100.0%	Yes
Pennsylvania	Gold	79,340	108.5	0.00	0.00	1.70	0.00	2.40	0.70	100.0%	100.0%	Yes
Rhode Island	Gold	5,963	105.7	0.00	0.00	1.10	0.00	1.60	0.00	100.0%	100.0%	Yes
South Carolina	Gold	27,238	102.6	0.00	0.00	0.60	0.00	2.30	0.00	100.0%	100.0%	Yes
South Dakota	Gold	4,407	99.6	0.00	0.00	0.20	0.00	0.90	0.10	100.0%	100.0%	Yes
Tennessee	Gold	36,256	99.8	0.00	0.00	0.80	0.00	2.30	0.00	100.0%	100.0%	Yes
Texas	Gold	107,298	98.1	0.00	0.00	0.80	0.00	2.80	0.00	100.0%	100.0%	Yes
Utah	Gold	10,416	102.1	0.00	0.00	0.20	0.00	0.50	0.00	100.0%	100.0%	Yes
Vermont	Gold	3,626	99.8	0.00	0.00	0.70	0.00	0.60	0.40	100.0%	100.0%	Yes
Virginia	Silver	38,452	93.1	0.00	0.00	1.90	0.00	2.60	0.00	100.0%	100.0%	Yes
Washington	Gold	35,392	101.7	0.00	0.00	1.30	0.00	1.20	0.00	100.0%	100.0%	Yes
Seattle	Gold	26,034	113.3	0.00	0.00	1.40	0.00	0.40	0.00	100.0%	100.0%	Yes
West Virginia	Gold	11,548	99.1	0.00	0.00	0.80	0.00	1.00	0.00	100.0%	100.0%	Yes
Wisconsin	Gold	32,118	107.3	0.00	0.00	0.70	0.00	1.10	0.00	100.0%	100.0%	Yes
Wyoming	Gold	2,630	96.9	0.00	0.00	0.00	0.00	1.10	0.00	100.0%	100.0%	Yes
Wyoming - 3 yr mort	Gold	2,630	98.4	0.00	0.00	0.00	0.00	1.10	0.00	100.0%	100.0%	Yes
Puerto Rico	Gold	16,339	95.8	0.00	0.00	0.00	1.60	2.90	0.00	100.0%	100.0%	Yes
Canada												
Alberta	Gold	18,418	105.8	0.00	0.00	0.00	0.00	0.10	0.00	100.0%	100.0%	Yes
British Columbia	Gold	25,302	97.5	0.00	0.00	0.00	0.00	0.50	0.10	100.0%	100.0%	Yes
Manitoba	Gold	6,670	100.2	0.00	0.00	0.00	0.00	0.00	0.00	100.0%	100.0%	Yes
New Brunswick	Gold	4,824	108.3	0.00	0.00	0.00	0.00	0.10	0.30	100.0%	100.0%	Yes
Newfoundland and Labrador	Gold	3,592	105.1	0.00	0.00	0.00	0.00	0.70	0.00	100.0%	100.0%	Yes
Northwest Territories	Gold	138	135.5	0.00	0.00	0.00	2.10	0.00	0.00	100.0%	100.0%	Yes
Nova Scotia	Gold	6,391	107.3	0.00	0.00	0.00	0.00	1.00	0.10	100.0%	100.0%	Yes
Nunavut	Not achieved	66	84.9	0.00	0.00	0.00	0.00	na	0.00	100.0%	100.0%	Yes
Ontario	Not achieved	76,133	98.7	0.00	0.00	0.00	0.00	na	0.00	100.0%	100.0%	Yes
Prince Edward Island	Gold	954	117.8	0.00	0.00	0.00	0.00	0.30	0.00	100.0%	100.0%	Yes
Quebec	No Data											
Saskatchewan	Gold	5,553	102.6	0.00	0.00	0.00	0.00	0.40	0.00	100.0%	100.0%	Yes
Yukon	Not achieved	162	174.3	0.00	0.00	0.00	0.00	na	0.00	100.0%	100.0%	Yes



Current Bylaws

North American Association of Central Cancer Registries, Inc. (NAACCR) 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, nor 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 organization'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 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 for any NAACCR Board position, a runoff election will be held. If there is a tie in the runoff election, the election will be determined 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 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 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.

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. Committees

The Association will maintain a Nominating Committee. As deemed necessary, additional Committees may be created by the membership or Board of Directors to carry on the affairs of the Association. The composition, size, and duties of the committees shall be set forth in the Standing Rules.

Section 2. 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 3. 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 committee. The Executive Director may serve as a member of 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 committee. They may serve as a member of 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. Proposed Amendments

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. Amendment Submissions(s)

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. Voting on Amendments

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. Notification of Amendments to the Membership

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) (Amended by vote of membership, Annual Conference 06/23/2010) (Amended by vote of membership, Annual Conference 06/06/2012)



Current Standing Rules

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

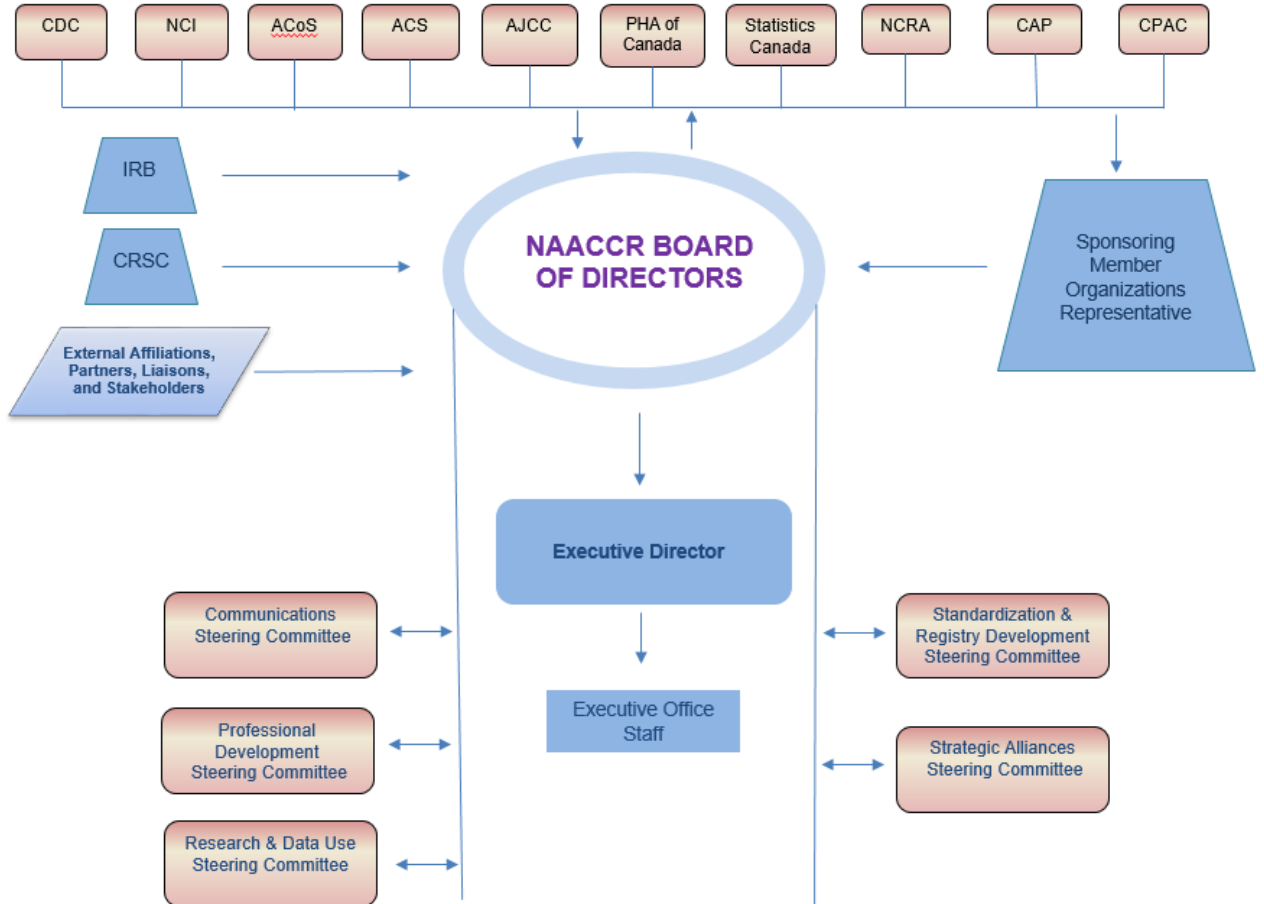
- A. The Board of Directors sets the fiscal year.

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 Revised 06/19/2011

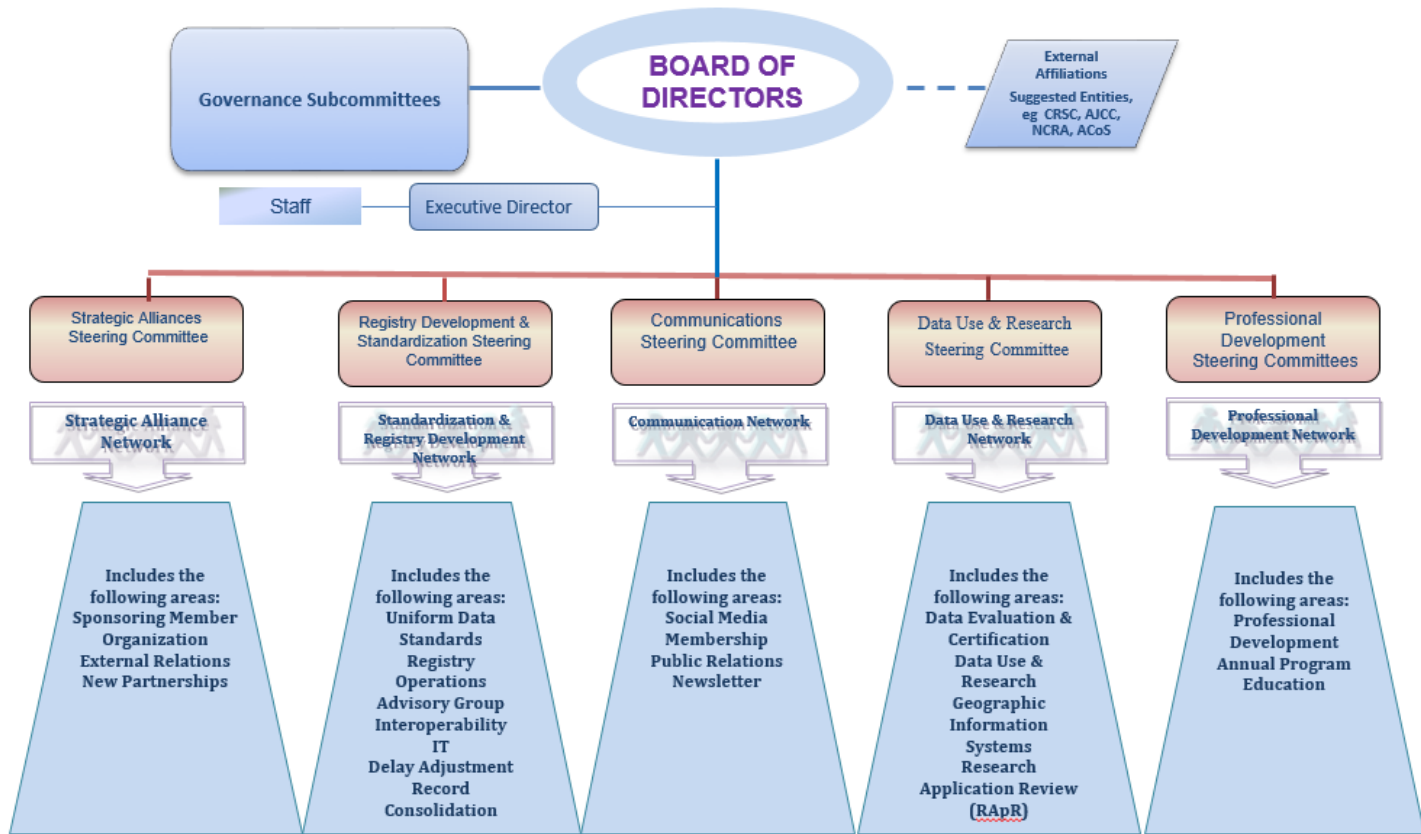


Organizational Charts

NAACCR Organizational Relationships



NAACCR Committee Organization Chart



NAACCR Executive Office Organizational Chart as 1/1/18

