



June 21, 2017
**NAACCR 2017
Business Meeting**
8:15 am - 8:45 am
Ballroom C



AGENDA AND MATERIALS

Breaking Barriers in Cancer Surveillance



Business Meeting Agenda



1. Call to Order, President's Welcome, and Report (pg. 2) Chuck Wiggins
 - a. Call for New Business from the Membership
 2. Minutes from 2016 Meeting (pg. 2) Chuck Wiggins
 - a. ACTION: Approval of 2016 Minutes
 3. Election Results and Destruction of Ballots (pg. 4) Kyle Ziegler
 - a. ACTION: Destruction of 2017 Ballots
 4. Highlights and Accomplishments (verbal) (pg. 4) Betsy Kohler
 5. Status on Strategic Management Plan (pg. 4) Chuck Wiggins
 - Steering Committee Reports
 6. Treasurer's Report (pg. 24) Bruce Riddle
 - Financial Oversight
 - Operations
 - Audit
 - Financials Status
 7. Support of All Kinds 2016-2017 (pg. 32) Chuck Wiggins
 8. Nominations for Nominating Committee (verbal) (pg. 33) Chuck Wiggins
 - a. Nominating Committee Formation 2017-2018 Chuck Wiggins
 - b. ACTION: Appoint Nominating Committee Chair Chuck Wiggins
 9. New Items from the Floor (pg. 33) Chuck Wiggins
 10. Adjournment (pg. 33) Chuck Wiggins
- Appendix of Documents
- Registry Certification (pg. 34) - Current Bylaws (pg. 35)
 - Current Standing Rules (pg. 41) - Organizational Charts (pg. 45)

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

- i** 2. **Minutes from 2016 Meeting**
 - a. **ACTION: Approval of 2016 Minutes**

**NAACCR Annual Business Meeting Minutes
St. Louis, Missouri
June 15, 2016**

- 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 1:40 PM local time. An electronic voting system was utilized.
- 2. Approval of Minutes From 2015 Meeting Chuck Wiggins

No comments or corrections were given for the 2015 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 2015 Business Meeting Minutes were approved as written.
- 3. Election Results and Destruction of Ballots Bobbi Matt

69 of 82 voting members voted (84%) for five open board positions. President-Elect was filled by Antoinette Stroup, PhD from New Jersey. Frank Boscoe, PhD, from New York, Chris Johnson, from Idaho, and Heather Stuart-Panko, from Saskatchewan Canada were elected to fill the 3 Representatives-at-Large positions. Sponsoring Member Organization Representative was filled by Lori Swain, from NCRA. Bobbi thanked the fellow members of the nominating committee, Jim and Kyle. She also thanked Dustin Dennison and Charlie Blackburn at NAACCR for their support.

Chuck asked for a round of applause for members of the nominating committee and all new board members.

- a. Destruction of Ballots

Bobbi motioned for the destruction of the election ballots and it was seconded. There were none present 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 NAACCR was able to gain additional funds for the operating budget while lowering operating costs, in part, by moving the main office to a new location.
 - Angela Martin and Castine Clerkin were hired for Training and VPR positions respectively.
 - Please see 2016 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 mentioned that Nan Stroup (President-Elect) had provided a comprehensive overview of the revised Strategic Management Plan the day before in a Plenary Session. The plan has been approved by the Board and goes into effect immediately. He thanked everyone who was involved for their efforts.
6. Steering Committee Updates and Committee Reports Chuck Wiggins
Since Committee Reports were covered in the same session as the Strategic Management Plan Chuck asked if any Chairs had additional comments they would like to share. No comments were made.
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 45% 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 six cooperative agreements that were overseen by the Executive Director. Bruce complimented NAACCR's Executive Director, COO and Comptroller for their oversight of the NAACCR finances.
8. Supports of All Kind Chuck Wiggins
Chuck listed and thanked all of the organizations that have contributed to NAACCR in the past year.
9. Nominations for Nominating Committee 2016-2017 Chuck Wiggins
The following individuals were nominated and accepted: Bobbi Matt, Maureen MacIntyre, and Kyle Ziegler.
ACTION: The 2016-2017 nominating committee members were elected.
 - a. Appoint Nominating Committee Chair
Chuck appointed Bobbi Matt as the chair and she agreed to serve in this role.
10. New Items from the Floor Chuck Wiggins
Betsy shared that NAACCR will be implementing a discussion board as a new communication tool for the membership. Additional details will be provided soon.
11. Adjournment Chuck Wiggins
The meeting adjourned at 2:10 PM 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 2017 membership voting for officers. Maria Schymura, New York has been elected as Treasurer. The new Representatives-at-Large are Isaac Hands, Kentucky, Deirdre Rogers, Mississippi and Randi Rycroft, Colorado. The Committee thanks all of the candidates who were nominated this year and the member registries for their participation.

NAACCR Nominating Committee members:

Bobbi Jo Matt

Maureen MacIntyre

4. Highlights and Accomplishments (verbal)

A verbal report will be provided.

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).



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 NAACCR Review Blog (see <http://news.naacccr.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.naacccr.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.

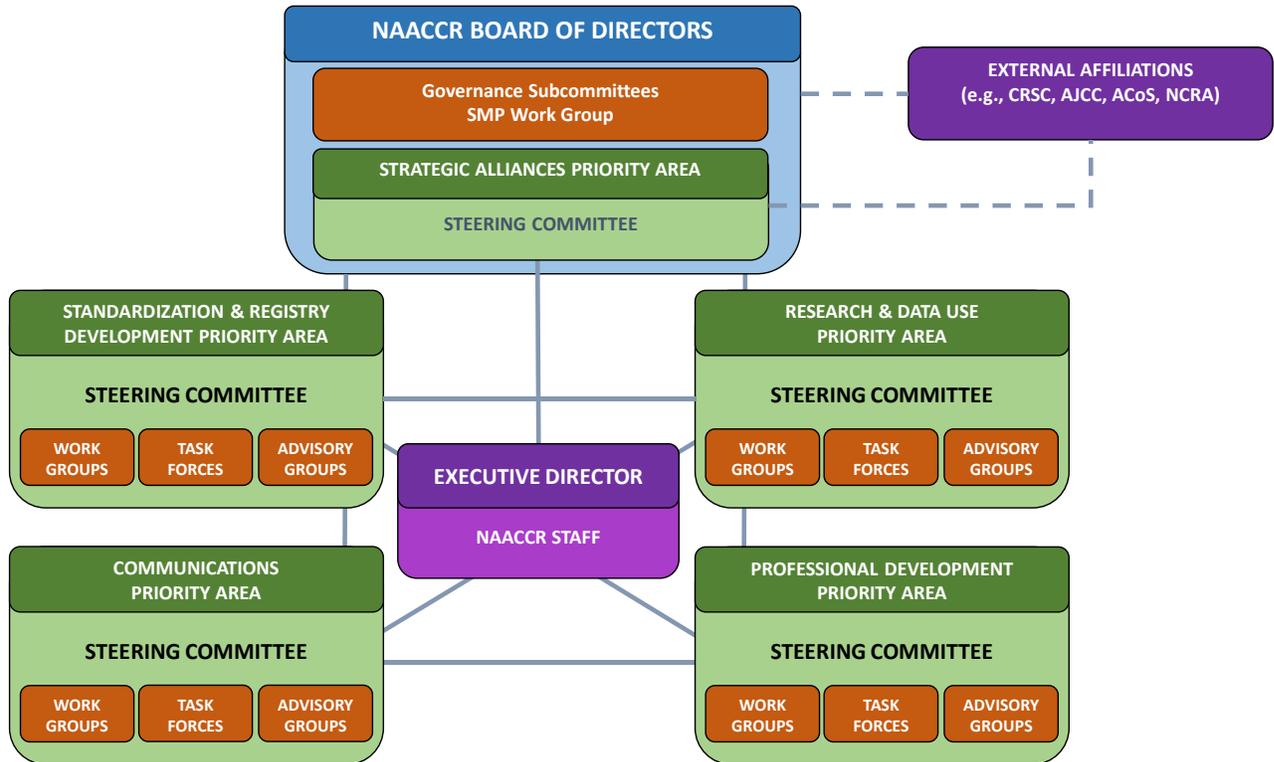
Strategic Management Plan: Conclusions

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



Committee / Group Annual Report June 2016 – May 2017

Committee / Group Name: Communications Steering Committee

Parent Committee (if Subcommittee, Workgroup, or Task Force Report): n/a

Chair Name: Laura Ruppert, MHA

Co-Chair Name: Annette Hurlbut, RHIT, CTR

PURPOSE / GOALS

Develop and strengthen internal and external NAACCR communications and bring a greater awareness of NAACCR member interests to wider audiences.

Purpose: Develop and strengthen internal and external NAACCR communications and bring a greater awareness of NAACCR member interests to wider audiences.

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: Develop position papers and policy statements, as appropriate, that support registries, cancer surveillance and the NAACCR mission.

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: Develop a resource on the NAACCR website where members may post 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: Move NAACCR's use of web-based and technology-driven communication systems forward to improve information sharing, and promote adoption of best practices.

ACHIEVEMENTS AND ACTIVITIES OVER PAST YEAR

The Communications Steering Committee (CSC) has maintained its membership and continues to be a vibrant voice for NAACCR members and a sounding board for NAACCR staff regarding communication initiatives.

NAACCR's eTools for Communications:

- Causeway
- ListServ
- NAACCR Forum
- NAACCR Narrative
- NAACCRReview

- NAACCR.org website
- Social Media (Facebook; LinkedIn; Twitter, Flickr)

The NAACCR Editorial staff, led by Chandrika Rao, works collaboratively to improve the reader experience through story/column ideas and format changes for The Narrative. Four quarterly issues have been produced this year.

NAACCRReview, NAACCR's blog posts, led by Becky Cassady.

Special thanks to NAACCR staff, Dustin and Charlie, for their work on revamping of the NAACCR.org website.

The Social Media Working Group (WG), led by Robin Malicki, has done a tremendous job of managing the organization's social media presence. The Social Media WG continues to share information thru the social media platform of Twitter, LinkedIn, Facebook, and posts pictures following the Annual Conference via Flickr.

NAACCR Forum platform was established to give the NAACCR community a place to discuss various topics regarding the cancer surveillance world. The Forum intended to be a place for individuals to respectfully voice concerns, ask questions and solicit collaboration from NAACCR colleagues.

The Committee continues in partnership with NAACCR to develop content and move NAACCR's use of web-based and tech-driven communication systems forward.

The CSC played a part as decision maker for the annual NAACCR Conference giveaway items. The Social Media WG also developed a campaign for members to promote the conference using social media.

Additionally, CSC members will be at the Communications booth along with NAACCR staff to interact with members,

FUTURE PLANS

promote Twitter participation, and recruit writers and NAACCR Narrative contributors.

The CSC started small and worked within the Committee to develop materials to promote NAACCR 2017 Conference, reaching out to the organization thru ePoll within the NAACCR Narrative.

A survey tool and PowerPoint presentation highlighting the NAACCR Communication eToolkit was created to be presented at the NAACCR 2017 Conference.

The Communications Plan and Best Practices will continue to be use used to promote NAACCR to internal and external audiences.

ACKNOWLEDGEMENTS

This is definitely an amazing team supported by even more amazing NAACCR staff who keep us posted on the activities of NAACCR for communicating to the wider audience.

The CSC would like to acknowledge our Board Liaisons, Lori Swain and Winny Roshala, who served us well throughout the year with inspiring suggestions and unwavering support along the way.

On behalf of the NAACCR CSC and NAACCR membership, we want to thank the NAACCR Staff, Charlie and Dustin, for their support. Without their support, the publication of the NAACCR Narrative and other materials would not be as efficiently conducted to meet the needs of our membership.

Lastly, and most importantly, a special thanks from the CSC to Annette Hurlbut who has served on the CSC since 2009 and in the capacity as Chair or Co-Chair since 2011. Her tireless service and dedication to the CSC has been a key component to the success of the committee. While she is taking a well-deserved break from the committee, we are so happy we will still see her smiling face at NAACCR Annual conferences going forward.



Committee / Group Annual Report June 2016 - May 2017

Committee / Group Name: Professional Development Steering Committee

Co-Chairs Name: Mignon Dryden and Frances Ross

PURPOSE / GOALS

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

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.

ACHIEVEMENTS AND ACTIVITIES OVER PAST YEAR

Continued to have the Survey Course -- a series of webinars titled "Understanding Population-Based Cancer Registries" recorded and uploaded to the NAACCR Learning Management System.

Will hold an IT Round Table Forum at the NAACCR 2017 Conference to explore ideas for retention and recruitment of Informatics professionals in the Cancer Registry Community.

Began to develop an Action Plan for Recruitment and Retention strategies aimed at cancer surveillance personnel, specifically central cancer registrars, cancer informatics staff, student and young investigators.

FUTURE PLANS

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

Support collaborative approaches to make career opportunities more attractive to individuals with skill sets and expertise to build and maintain the cancer registries of the future.

Incorporate the NAACCR Member Awards Program as part of the Professional Development Steering Committee activities starting June 2017.

Work with other standard setters (SEER, NPCR, CoC, Canada) to coordinate educational opportunities specifically on stage.

ACKNOWLEDGEMENTS

Thank you to the Professional Development Steering Committee; thanks to our NAACCR Board Liaisons, Deirdre Rogers and Bruce Riddle, and special thanks to the NAACCR staff, Jim Hofferkamp, Angela Martin, and Recinda Sherman.



Committee / Group Annual Report June 2016 – May 2017

Committee / Group Name: Research and Data Use Steering Committee

Chair Name: Susan Gershman

Co-Chair Name: Hannah Weir

PURPOSE / GOALS

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

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

ACHIEVEMENTS AND ACTIVITIES OVER PAST YEAR

- CINA 2017 is on schedule for release in May. Includes delay adjusted rates by registry and survival data.
- Cancer Control Indicators Task Force
 - Recinda Sherman and Susan Gershman presented “Using Cancer Registry Data: Cancer Control Indicators” at the Opening Plenary, NCRA Annual Educational Conference, Washington < DC, April 6, 2017.
- Survival Analysis Work Group
 - Members assessed November 2016 submission data for fitness for use in the CINA Survival volume and assisted the CINA Editorial Work Group with the publication.
 - Members of the Survival Analysis Work Group submitted a manuscript for publication on the topic of the North American Cancer Survival Index.
 - CINA Deluxe applications requesting access to survival data are being reviewed by the Research Application Review Work Group and members of the Survival Analysis Work Group are assisting with the first such uses of CINA survival data.
 - Members were involved in a survival analysis workshop held in conjunction with the NAACCR conference in Albuquerque. A highly-experienced international faculty presented a stimulating and intensive 4-day course on the principles, methods and applications of cancer survival with population-based data.
- The Research Application Review Workgroup
 - Reviewed and commented on 17 CINA applications (16 accepted, 1 declined)
 - Provided the Public Use file to 17 researchers.
- Virtual Pooled Registry
 - Completed second pilot test linkage between NCI’s US Radiologic Technologists cohort study and 45 registries.
 - Created a Templated IRB/Registry Application.
 - Tested hashed/encrypted inter-registry deduplication between Colorado and Idaho
- IRB reviewed 6 papers for compliance, reviewed 3 projects that requested additional data, and continued annual monitoring for all open CINA IRB projects.

- Scientific Editorial Review Board has reviewed 4 papers for scientific merit
- Journal Club and Surveillance Webinars: available @ <http://www.naacr.org/EducationandTraining/TownHallWebinars.aspx>

Webinar Topic	Presenter	Data
Virtual Pooled Registry	Castine Clerkin	June, 2016
Registry of the Future	Nan Stroup	September 29, 2016
Data Visualization	Dave Stinchcomb	October 12, 2016
Geo-spatial mapping and modelling presentation	Prithwish De	November 2016
Personalized Medicine (Dana-Farber Cancer Institute)	Dr. Kate Janeway	February 15

FUTURE PLANS

Goals for next year:

- Survival Analysis Work Group members will:
 - Assess November 2017 submission data for fitness for use in the CINA Survival volume and assist the CINA Editorial Work Group with the publication.
 - Assist researchers with projects that include approved uses of CINA Deluxe survival data.
- Virtual Pooled Registry
 - Vet the Templated IRB/Registry Application and a Templated Data Use Agreement to determine additional needs and registry/IRB acceptance
 - Develop and implement a Central IRB for review of minimal risk linkage studies.
 - Perform a second test of the hashed deduplication process with registries from NY, NJ, CT, and GA.
- Certification Task Force and Fitness for Use Workgroup will begin work on potential enhancements to certification.

ACKNOWLEDGEMENTS

We would like to thank Recinda Sherman for her excellent work in supporting the work of the RDU Steering Committee and for participating in and leading several Task Forces.



Committee / Group Annual Report June 2016 – May 2017

Committee / Group Name: Standardization & Registry Development Steering Committee

Chair Name: Randi Rycroft, Colorado Central Cancer Registry

PURPOSE / GOALS

- Prepare for the cancer surveillance system of the future – a system that is more timely, responsive, and adaptable to change.
- Provide consensus standards and best practices for the collection and processing of cancer and patient information.
- 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.
- Explore innovative uses of cancer registries by identifying emerging initiatives and new roles that bring value-added benefits to cancer surveillance.

ACHIEVEMENTS AND ACTIVITIES OVER PAST YEAR

S&RD Restructure/New Leadership -- S&RD committee members and NAACCR Board members met in person at the March 2017 NAACCR Board/Steering Committee Chairs meeting to discuss the need for committee restructure given the large workload of this SC. We discussed our options developed a roadmap for moving forward. Highlights of the meeting included: 1) Making the decision not to split up S&RD; 2) Agreed on a functional organizational chart to represent all the workgroups, task forces, and advisory groups under S&RD purview; 3) Committed to better communication flow within S&RD and horizontally between S&RD and other NAACCR committees and with external partners; 4) Devise better methods for tracking WG and TF progress, which will likely include tools to visualize progress. The SC has also secured new leadership beginning July 2017. Mary Jane King of Cancer Care Ontario and Lori Koch of the Illinois State Cancer Registry will take over as co-chairs. S&RD will also have new Board Liaisons who will be assigned at the June 2017 Board of Directors meeting.

Assessment of Central Cancer Registry Timeliness & Reporting Standards (ACCR-TRS) TF (Lead: Nan Stroup) - The TF continues its work to evaluate whether the NAACCR community should update standards for timeliness of reporting. The TF hosted a webinar in September 2016 to present the results of a survey conducted earlier in 2016. The 12-month Data TF provided some data analysis of the 12-month file to inform our work. The TF held one focus group session to gain additional clarification on some of the survey questions and plans to host 2 additional focus groups after July. The TF has also requested a special data analysis from volunteer registries to assess how many cases might be able to be reported sooner than 6 months. Once focus group data and special analysis data are reviewed, the TF will provide a report and suggested next steps to the S&RD Steering Committee.

XML Implementation WG (Lead: Isaac Hands) – The WG released the NAACCR XML Data Exchange Standard Implementation Guide v 1.2 in March 2017. In November 2016 the WG solicited voluntary participation from registry software vendors and central cancer registries to implement the NAACCR XML Data Exchange Standard as a format

option between hospital and central cancer registries. The results of these transmission pilot projects will be presented at the NAACCR 2017 Annual Conference.

Uniform Data Standards WG (Leads: Cheryl Moody, Suzanne Schwartz) – UDS reviewed, finessed, and approved an unprecedented number of new data items in anticipation of Standards Volume II, Version 18 implementation.

SSN Unavailability (Lead: Lori Havener) – S&RD formed a TF to examine the issue of increasingly unavailable SSNs in source records and the related issue of CMS removing SSN from Medicare cards and replacing it with a Medicare Beneficiary Identifier (MIB). The TF recommended that 1) S&RD convene a TF to develop standard linkage algorithms that do not require SSN; 2) S&RD convene a TF to develop educational material on the importance of SSN to central registries and how it's used, targeting data managers and all reporting sources; 3) Include implementation of MBI in 2018 Implementation Guidelines. S&RD will take these recommendations and move the project forward.

NAACCR Volume V Revision TF Update (Lead: Sandy Jones and Joshua Mazuryk) – Group continues to review Volume V (electronic pathology report standards). The group is incorporating work on biomarker transmission standards and investigating the utility of a new path-only record layout.

FUTURE PLANS

Registry of the Future – S&RD will incorporate into its work plan any pertinent action items from the Registry of the Future session at the June 2017 Annual Conference.

Assessment of Central Cancer Registry Timeliness & Reporting Standards (ACCR-TRS) TF (Lead: Nan Stroup) – Next steps for this group include hosting additional focus groups with registries, compile data obtained from special registry data analysis. The overall goal remains to make a recommendation to the Board on whether it should consider changing timeliness standards for central registries.

NAACCR Volume II process: S&RD will review the overall timeline and process for updating Standards Volume II and provide feedback. There may be opportunities to streamline this process.

ACKNOWLEDGEMENTS

NAACCR Board of Directors, all NAACCR Office staff, S&RD Steering Committee Members, Work Group and Task Force Leads. Special thanks to Winny Roshala and Eric Durbin who have served S&RD as Board Liaisons and will be rotating off effective June 2017.



6. Treasurer's Report

Treasurer's Report

Present to the NAACCR 2017 Annual Business Meeting

Submitted by Bruce Riddle, NAACCR Treasurer, June 1, 2017

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, written in Spring 2017, incorporates audited information from the fiscal year that ended May 31, 2016, and provisional (unaudited) information for 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. That report is usually presented to the NAACCR Board of Directors in September. This report also incorporates information from the auditor's report dated September 29, 2016.

This report is not significantly different from the prior year's report. It contains the same information updated for Fiscal Year 2016.

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 about 30 documents to six 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 broad 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."*

It is a tribute to the hard work of the Executive Director, Chief Operating Officer, and Comptroller that NAACCR that for the first time in 25 years, NAACCR had a very small operating deficit for Fiscal 2016, that the outside auditors have not found any significant issues, and that NAACRR has had success in being continuously funded by its major strategic partners.

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 63% 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, 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. Some of the grants and contracts do not coincide with the NAACCR fiscal year.

The fiscal year 2016 grants and contracts are:

- CDC Cooperative Agreement Year 2016
- 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.
- NCI Conference Grant—funding for elements of the NAACCR Annual Conference.

The CDC Cooperative Agreement is up for renewal this year.

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 account for about 3% of NAACCR's total operating budget. In round numbers, NAACCR is a \$2 million annual operation. The base operations of NAACCR run about \$1 million per year.

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 is 28.2% 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. An important component of grants management is keeping the Indirect Cost Rate at a level where if a grant expires, the administrative overhead costs are still covered.

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. Quoting from the most recent auditor's report:

Revenues are reported as increases in unrestricted net assets unless use of the related assets is limited by donor-imposed restrictions. Expenses are reported as decreases in unrestricted net assets.

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 (<http://www.abila.com/>), 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 on a number of public web sites. The license agreement seems reasonable and does not impose any undue burden on NAACCR. The software is regularly updated. NAACCR executive staff are satisfied with the software. Previously, Abila was known as Sage Nonprofit

Solutions (NPS), but ownership and brand changed in July 2013. NAACCR uses a second product from Abila, NETFORUM, to run its membership database. The auditor, Sikich, provides consulting to NAACCR on use of accounting 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 2016, approximately 50% of the budget went to support NAACCR personnel. This is an increase from the prior fiscal year because the NAACCR Executive Office hired a full-time employee as a result of an additional award by the National Cancer Institute. NAACCR funds an Executive Director, Chief Operating Officer, Information Technology Administrator, Program Manager of Standards, Comptroller, Program Manager of Education, Manager of Data Use and Research, Trainer/Program Coordinator, and a Program Manager of Virtual Pooled Registry. NAACCR provides a standard benefit package including health insurance, health care flexible spending accounts, life insurance, and a 401(K) program. NAACCR purchases insurance to protect the organization, the Board of Directors, and its officers.

Other major expenses include contracted services, 12.3%; Annual Conference luncheon, food, and similar activities, Annual Conference receptions, and another related seminars and activities, 9.5%; consulting fees, 6%; and travel, 4.5%. In rough numbers, these costs total about 82% of total NAACCR operations. During the last fiscal year, NAACCR transacted with 39 different vendors in amounts of \$5,000 or more.

The largest single categorical expense for NAACCR is the Annual Conference which ran, for fiscal year 2016, at about \$220,952. With much practice, the Annual Conference has become a well-oiled operation for the NAACCR Office staff and the vendor partners: Venue West and Peak Audio Visual.

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.

As noted above, NAACCR uses software from Abila (Sage Software) for internal accounting and payroll. This software has built-in reports that provide tools for fiscal oversight.

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 are 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.

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. For example, the February 2016 summary was 77 pages. 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 August 26, 2015, gave NAACCR a clean review.

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 being squeezed by an expanding mission and needs (e.g., compare the size and scope of a NAACCR 15 Volume II to a NAACCR 6 Volume II) while budgets remain flat or less than flat. NAACCR receives funding for a specific task and that amount remains fixed over the years. This particular challenge is met by NAACCR staff and the Board of Directors working together to identify approaches for economizing our operations as well as prioritizing our financial obligations.

Presentation of Financial Results

The following exhibits provide a broad overview of the financial position of NAACCR and a window into its activities and accomplishments. None of these stand on their own and need to be taken in context.

Exhibit A: Statement of Financial Position, May 31, 2016 and 2015, from page 3 of Financial Statements, Financial Statements and Independent Auditor's Report For the Years Ended May 31, 2016 and 2015.

Exhibit B: Statement of Activities, for the year ended May 31, 2016, and 2015 from page 4 of Financial Statements, Financial Statements and Independent Auditor's Report For the Years Ended May 31, 2015 – 2016 as well as 2014-2015.

Exhibit C: Balance Sheet, All Funds, As of February 28, 2017.

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES, INC.

STATEMENTS OF FINANCIAL POSITION

As of May 31,

	<u>2016</u>	<u>2015</u>
ASSETS		
Cash and cash equivalents	\$ 157,984	\$ 269,478
Grants receivable	339,130	328,480
Prepaid expenses	42,364	53,156
Certificates of Deposit	222,000	219,719
Investments	<u>881,623</u>	<u>817,496</u>
Total current assets	<u>1,643,101</u>	<u>1,688,329</u>
Furniture and equipment, net	<u>21,371</u>	<u>25,973</u>
TOTAL ASSETS	<u>\$ 1,664,472</u>	<u>\$ 1,714,302</u>
LIABILITIES AND NET ASSETS		
Accounts Payable	\$ 35,855	\$ 62,145
Accrued Liabilities	99,397	74,279
Deferred Revenue	<u>224,327</u>	<u>229,645</u>
Total liabilities	<u>359,579</u>	<u>366,069</u>
NET ASSETS		
Unrestricted	1,288,224	1,328,535
Temporarily restricted	<u>16,669</u>	<u>19,698</u>
Total net assets	<u>1,304,893</u>	<u>1,348,233</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 1,664,472</u>	<u>\$ 1,714,302</u>

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 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
Restricted 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	<u>1,914,936</u>	<u>(3,029)</u>	<u>1,911,907</u>
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	<u>1,578,372</u>	<u>-</u>	<u>1,578,372</u>
Supporting services			
Management and general	376,875	-	376,875
Total supporting services	<u>376,875</u>	<u>-</u>	<u>376,875</u>
Total expenses	<u>1,955,247</u>	<u>-</u>	<u>1,955,247</u>
CHANGE IN NET ASSETS	<u>\$ (40,311)</u>	<u>\$ (3,029)</u>	<u>\$ (43,340)</u>
Net assets, beginning of year	<u>1,328,535</u>	<u>19,698</u>	<u>1,348,233</u>
NET ASSETS, END OF YEAR	<u>\$ 1,288,224</u>	<u>\$ 16,669</u>	<u>\$ 1,304,893</u>

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES, INC.

STATEMENT OF ACTIVITIES

For the Year Ended May 31, 2015

	Unrestricted	Temporarily Restricted	Total
REVENUES AND OTHER SUPPORT			
Grant Revenue	\$ 1,264,122	\$ -	\$ 1,264,122
In Kind Contributions	18,935	-	18,935
Conference Registration	165,675	-	165,675
Course Registration	21,450	-	21,450
Webinars	197,859	-	197,859
Membership Dues	77,250	-	77,250
Exhibitor Income	127,009	-	127,009
Consulting Fee Revenue	46,717	-	46,717
Investment income	59,370	-	59,370
Restricted Sponsorship	-	24,000	24,000
Miscellaneous income	1,613	-	1,613
Net realized and unrealized gain on investments	2,270	-	2,270
Net assets released from restrictions - Satisfaction of program restrictions	27,022	(27,022)	-
Total revenues and other support	<u>2,009,292</u>	<u>(3,022)</u>	<u>2,006,270</u>
EXPENSES			
Program services			
CDC Cooperative Agreement	305,545	-	305,545
NCI conference grant	17,460	-	17,460
NCI contract - sole source	552,716	-	552,716
American Cancer Society Grant	128,490	-	128,490
Conference and webinars	652,890	-	652,890
Total program services	<u>1,657,101</u>	<u>-</u>	<u>1,657,101</u>
Supporting services			
Management and general	387,682	-	387,682
Total supporting services	<u>387,682</u>	<u>-</u>	<u>387,682</u>
Total expenses	<u>2,044,783</u>	<u>-</u>	<u>2,044,783</u>
CHANGE IN NET ASSETS	<u>\$ (35,491)</u>	<u>\$ (3,022)</u>	<u>\$ (38,513)</u>
Net assets, beginning of year	1,364,026	22,720	1,386,746
NET ASSETS, END OF YEAR	<u>\$ 1,328,535</u>	<u>\$ 19,698</u>	<u>\$ 1,348,233</u>

NAACCR, Inc.
 Balance Sheet
All Funds
 As of March 31, 2017

	Previous Month	Current Month
Assets		
<i>Cash</i>		
BOS Checking/Savings Account	185,869.06	200,355.25
Flex Spending Account	3,785.26	1,170.45
<i>Investments</i>		
BOS/LPL Portfolio	226,774.89	227,724.06
Merrill Lynch Portfolio	975,011.81	975,996.10
<i>Subtotal Cash & Investments</i>	<u>1,391,441.02</u>	<u>1,405,245.86</u>
<i>Receivables</i>		
Accounts Receivable	1,700.00	1,700.00
Indirect Funds Receivable	56,265.01	58,881.73
Grants Receivable	266,485.18	269,712.95
<i>Subtotal Receivables</i>	<u>324,450.19</u>	<u>330,294.68</u>
<i>Prepays</i>		
Prepaid Insurance	853.56	1,501.84
Other Prepays	32,479.24	33,937.09
<i>Other</i>		
Total Equipment	167,922.56	167,922.56
Accumulated Depreciation	<u>(151,863.62)</u>	<u>(152,613.25)</u>
Total Assets	<u><u>1,765,282.95</u></u>	<u><u>1,786,288.78</u></u>
Liabilities		
<i>Current</i>		
Accounts Payable	34,012.02	53,106.41
Accrued Liabilities	121,426.13	140,402.12
Deferred Revenue	131,022.75	149,169.00
Total Liabilities	<u>286,460.90</u>	<u>342,677.53</u>
Net Assets		
Unrestricted Net Assets	1,292,181.66	1,292,181.66
Temporarily Restricted Net Assets	12,427.00	12,427.00
Change in Net Assets	174,213.39	139,002.59
Total Net Assets	<u>1,478,822.05</u>	<u>1,443,611.25</u>
Total Liabilities and Net Assets	<u><u>1,765,282.95</u></u>	<u><u>1,786,288.78</u></u>



8. Support of All Kinds

Support of All Kinds from Sponsoring Organizations for 2016-2017

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
- Phone bridge for teleconference calls
- Support to NAACCR Committees

American Joint Committee on Cancer - AJCC

- Dues
- 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

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

- Nominating Committee Formation 2017-2018**
- ACTION: Appoint Nominating Committee Chair**



10. New Items from the Floor



11. Adjournment



Appendix of Documents

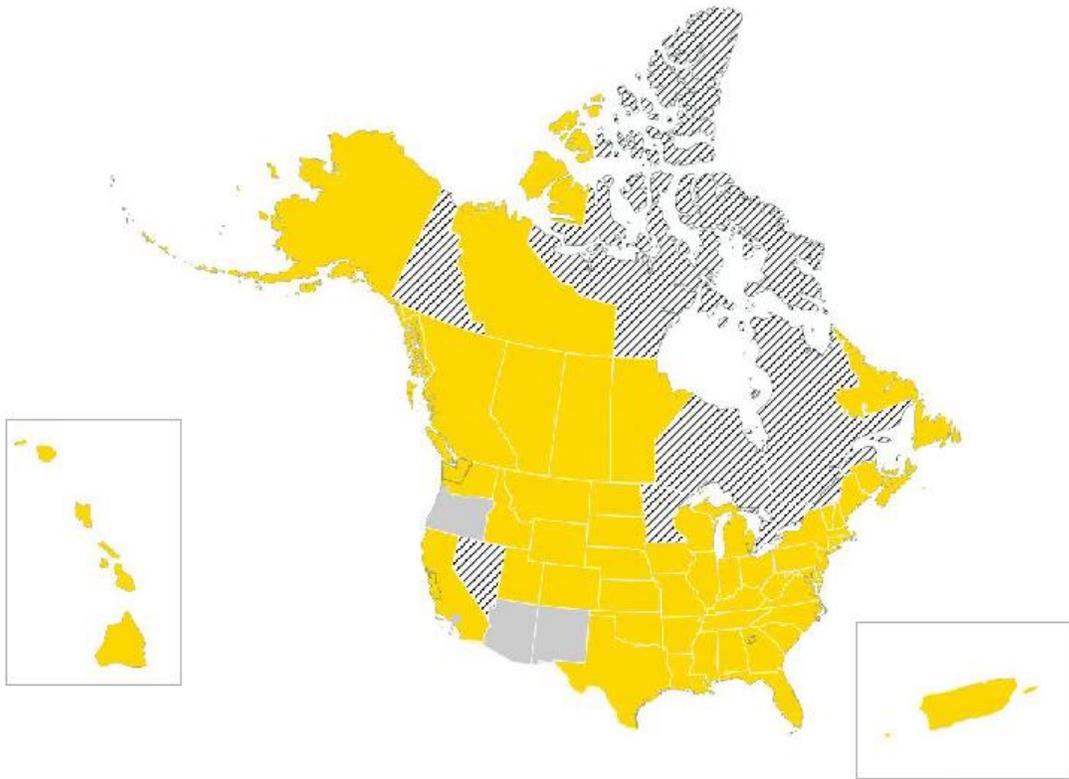
Appendix documents are located on the following pages.

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



Registry Certification

Registry Certification on Quality, Completeness, and Timeliness of 2014 Data





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.

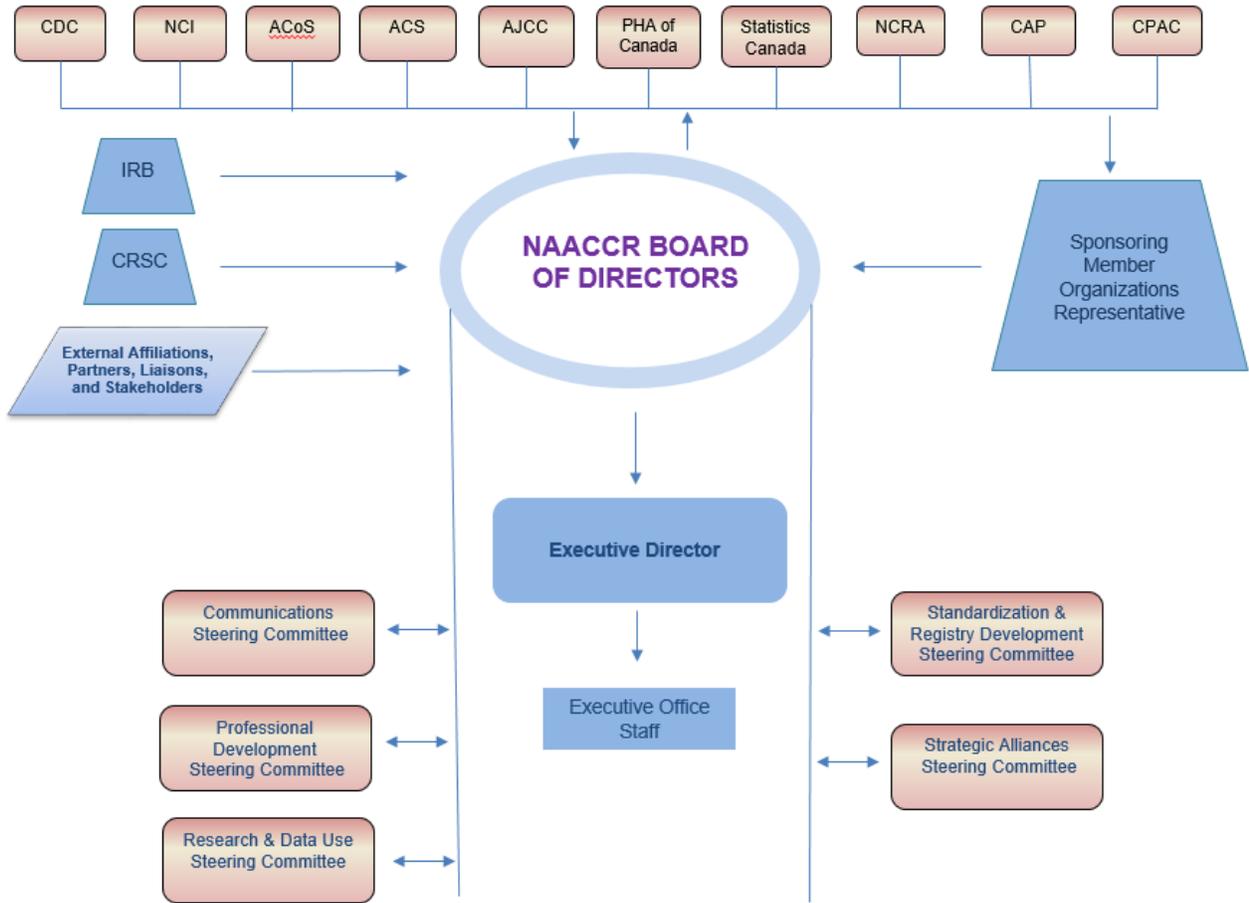
XII. Fiscal Year

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

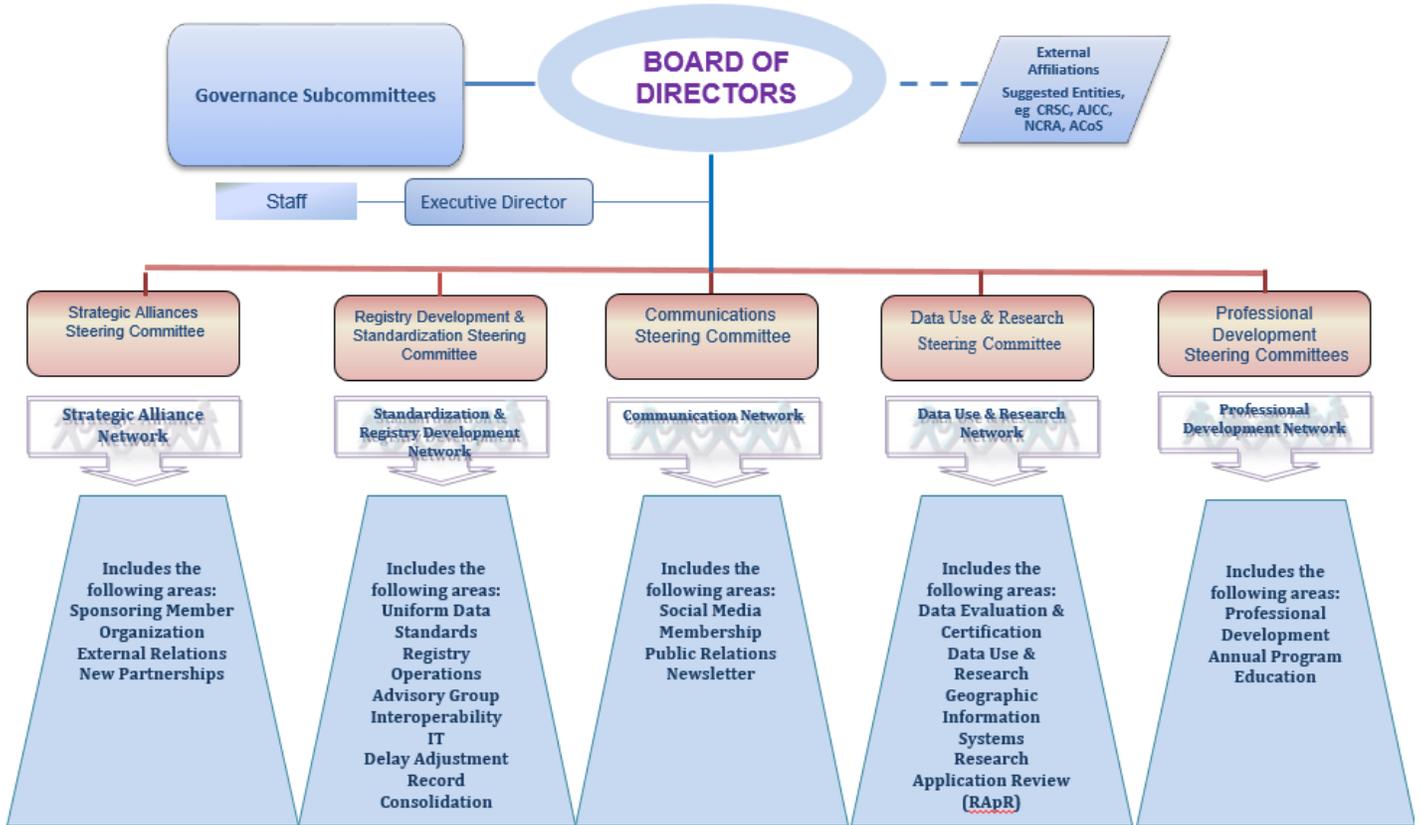
Approved by Board: 5/15/96 Revised: 3/31/97 Revised: 6/5/97 Revised: 6/17/98 Revised 4/05/99 Revised 11/17/99
Revised 05/17/00 Revised 04/12/2002 Revised 06/09/2005 Revised 06/19/2011



NAACCR Organizational Relationships



NAACCR Committee Organization Chart



NAACCR Executive Office Organizational Chart as 1/1/17

