NAACCR
Committee Guidelines

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Revised June 2021
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North American Association of
Central Cancer Registries

NAACCR Committee Guidelines

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1. Background and Purpose

NAACCR has a long history of accomplishments conducted through its membership. For many years the work was completed by standing committees, subcommittees, and work groups. In 2011, the NAACCR Board approved the [2011 – 2016 NAACCR Strategic Management Plan](#) (SMP). The SMP defines five priority areas: 1) Strategic Alliances, 2) Standardization and Registry Development, 3) Research and Data Use, 4) Communications, and 5) Professional Development. Steering Committees were created to oversee the implementation of the goals and objectives for each of the priority areas.

Priority Area 1: Strategic Planning and Alliances
Strategic planning is a critical Board responsibility required to ensure that NAACCR can continue to fulfill its mission now and into the future. Board members must be able to understand the issues and evaluate opportunities for and risks to accomplishing NAACCR's mission. Strategies developed by this Steering Committee will relate to all the NAACCR priority areas: Research and Data Use, Standardization and Registry Development, Professional Development, and Communications and will also focus on partnerships and alliances as well as sustainability and succession planning for the organization. Because the world of cancer surveillance can change rapidly, NAACCR must frequently evaluate existing strategies for needed modifications and look for gaps where new strategies are required. This committee will formulate and analyze strategy recommendations for full Board consideration and oversee the Strategic Management Plan revision process.

Priority Area 2: Standardization and Registry Development (S&RD)
Standardization and registry development continue to be mission-critical roles 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.

Priority Area 3: Research and Data Use (R&DU)
The fundamental value of centralized cancer registries is the high-quality data that allows innovative research, reliable cancer surveillance and improved cancer control. The R&DU 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.

Priority Area 4: Communications
Communicating a unified understanding of purpose to members, outside stakeholders, and the public is the critical role performed by the Communications 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 broad public they serve. These statements will be issued through the Communications Steering Committee.

Priority Area 5: Professional Development
The development and training of skilled CTRs, epidemiologists, IT specialists, and registry managers remains essential to the future of central 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.

2. Standing Rules

The composition, size, and purpose of the NAACCR Board of Directors (Board), Board Subcommittees, and Steering Committees (associated with the priority areas identified in the SMP) are described in the NAACCR Standing Rules. Unless otherwise specified in the Standing Rules, the Board of Directors may establish or amend them as necessary to carry out NAACCR business. The current Standing Rules as published on the NAACCR website take precedence over this document wherever there is conflicting information.

3. Steering Committees Structure and Membership

3.1. Strategic Planning and Alliances Steering Committee

Purpose:	Develop organizational strategy and strengthen and expand relationships with key stakeholders.
Composition:	
Chair/Co-chairs	Appointed by President
Members	- Executive Director - President - Past-President or President-Elect - Board Member - Any number of stakeholders appointed by the chair/co-chair and/or President
BOD Liaison(s):	No
Voting rights:	Each committee member may vote
Alternates:	No.

3.2. Communications Steering Committee

Purpose:	Develop and strengthen internal and external NAACCR communications and bring a greater awareness of NAACCR member interests to wider audiences.
Composition:	
Chair/Co-chairs	Appointed by President
Members	• One (1) representative each from at least three (3) full member organizations • One (1) representative each from relevant sponsoring organizations appointed by sponsoring organization
BOD Liaison(s):	Yes, non-voting. Appointed by President
Voting rights:	Each committee member may vote, except for the BOD Liaison(s).
Alternates:	Allowed. Alternates may vote

3.3. Research and Data Use Steering Committee

Purpose:	Facilitate the expansion of data use for research, cancer prevention and control, and clinical outcomes; and improve access to pooled data across states and provinces for research.
Composition:	
Chair/Co-chairs	Appointed by President
Members	• One (1) representative each from at least three (3) full member organizations • One (1) representative each from relevant sponsoring organizations appointed by sponsoring organization
BOD Liaison(s):	Yes, non-voting. Appointed by President
Voting rights:	Each committee member may vote, except for the BOD Liaison(s).
Alternates:	Allowed. Alternates may vote

3.4. Professional Development Steering Committee

Purpose:	Address workforce issues for the surveillance community, skill development, and training needs of the NAACCR community.
Composition:	
Chair/Co-chairs	Appointed by President
Members	• One (1) representative each from at least three (3) full member organizations • One (1) representative each from relevant sponsoring organizations appointed by sponsoring organization
BOD Liaison(s):	Yes, non-voting. Appointed by President
Voting rights:	Each committee member may vote, except for the BOD Liaison(s).
Alternates:	Allowed. Alternates may vote

3.5. Standardization and Registry Development Steering Committee

Purpose:	Facilitate mission-critical role of NAACCR to prepare central registries to adapt rapidly and successfully to changing developments in cancer surveillance to assure the highest quality data for central registries while seeking innovative strategies to develop the cancer registry of the future.
Composition:	
Chair/Co-chairs	Appointed by President
Members	- One (1) representative each from at least three (3) full member organizations - One (1) representative each from relevant sponsoring organizations appointed by sponsoring organization
BOD Liaison(s):	Yes, non-voting. Appointed by President
Voting rights:	Each committee member may vote, except for the BOD Liaison(s).
Alternates:	Allowed. Alternates may vote

4. Other Special Committees

4.1. Nominating Committee

Purpose:	Secure candidates for the offices of President-Elect, Treasurer and Representative-at-Large as needed 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 receive the completed ballots, tally the votes, and present the results of the election to the Board of Directors.
Composition:	Top three vote recipients of the annual general election.
Chair/Co-chairs	Elected by the incoming Nominating Committee by the end of the month elected.
Members	One (1) representative each from at least three (3) full member organizations nominated and elected by the voting membership.
BOD Liaison(s):	No
Voting rights:	Each committee member may vote.
Alternates:	No

4.2.   Program Committee

Purpose:	The committee shall be responsible for the program for the Annual Conference and work with the conference planner to set guidelines for meeting logistics and locations.
Composition:	
Chair/Co-chairs	Appointed by President from host registry
Members	- One (1) representative each from at least three (3) full member organizations - One (1) representative each from relevant sponsoring organizations appointed by sponsoring organization - Chair from previous year - One (1) representative each from the host registry for the upcoming year. - One (1) representative each from the Professional Development Steering Committee and the Communications Steering Committee.
BOD Liaison(s):	Yes, non-voting. Appointed by President
Voting rights:	Each committee member may vote, except for the BOD Liaison(s).
Alternates:	Allowed. Alternates may vote

4.3.   Scientific Editorial Board (SEB)

Purpose:	The purpose of the SEB is to organize and implement a peer-review process for scientific work by NAACCR committee(s) or researchers who use NAACCR data that results in manuscripts for public dissemination. The work is based on data that are not in the public domain. Scientific documents for public dissemination prepared by or for NAACCR must be reviewed by the SEB prior to release or publication.
Composition:	
Chair/Co-chairs	Appointed by President
Members	- Reviewers who agree to serve a five-year term. *Ad hoc* reviewers may be used to ensure that persons knowledgeable about the content of the manuscript conduct reviews.
BOD Liaison(s):	Yes. Appointed by President, if necessary
Voting rights:	Each committee member may vote
Alternates:	No

4.4. Institutional Review Board (IRB)

Purpose:	The purpose of the NAACCR IRB is to provide human subject protection oversight on all projects that are sponsored by NAACCR or that use NAACCR data files prepared from the aggregation of registries' data through the annual Call for Data or through special studies using criteria to protect human subjects. While there is no longer a separate NAACCR IRB approval process due to changes in the Common Rule, a simplified, automated annual monitoring process will be necessary for researchers to complete to ensure access to the data. IRB members will also review manuscripts for compliance with DUA and suppression rules. IRB members will continue to meet biannually to resolve any potential issue with data release and protection of NAACCR data.
Composition:	
Chair/Co-chairs	Appointed by President
Members	• All primary and alternate members of the IRB are invited by the President to serve for a three-year term. • Appointments will follow the guidelines of the IRB to ensure a diverse IRB and one that meets federal rules. • Primary members serve terms are staggered to maintain continuity of a majority of the membership over the end of each term. • Members can serve for three consecutive terms if invited. Primary and alternate members are expected to attend at least half of all scheduled IRB meetings during each year of their term.
BOD Liaison(s):	No
Voting rights:	Each committee member may vote.
Alternates:	Allowed. Alternates may vote to meet quorum of members.

5. Work Groups, Task Forces and Advisory Groups

The Steering Committees were created to lead the overall planning, implementation, and monitoring of their priority area. Work groups, task forces and advisory groups are typically created by the steering committee around specific tasks with timelines and expected outcomes.

Work groups, task forces, and advisory groups, through the chair (or co-chairs), are responsible for reporting activities to their parent Steering Committee.

In special circumstances the Board may also assign work groups, task forces and advisory groups for purposes that fall outside of the purview of the SC.

Work Groups – Work Groups may be formed, and a Chair selected, at the discretion of the Steering Committee. These groups report directly to their respective Steering Committee. Work Groups should be established to accomplish a measurable objective, a major project, or a defined activity with specific recurring or ongoing deliverables (e.g., Edits Work Group).

Task Forces –Task Forces may be formed, and a Chair selected, at the discretion of the Steering Committee. These groups report directly to their respective Steering Committee. Task Forces should be

established to accomplish a clearly defined task within a specific time period. Task Forces are often need-based or event-driven and then disband upon completion of work.

Advisory Groups: Advisory Groups may be formed, and a Chair selected, at the discretion of the Steering Committee. These groups report directly to their respective Steering Committee. Advisory Groups should be established to identify opportunities for growth and development and serve as a sounding-board for specific initiatives being vetted by the Steering Committee.

6. General Rules of Operation

6.1.   Appointing Steering Committee Chair (or Co-Chairs)
In April, prior to the NAACCR Annual Conference, the incoming President appoints the Steering Committee Chair for a two-year term. The President may ask proposed chairs to complete an application if needed. Steering Committee Chair terms begin at the end of the NAACCR Annual Conference to coincide with the Presidential term. Chairs can be asked to serve a second consecutive two-year term, not to exceed a total of four consecutive years. Chairs can serve unlimited non-consecutive terms as appointed by the President. In the event of a midterm vacancy of a Chair/co-Chair, the President will select a candidate to act as Chair/co-Chair for the remainder of the term. A mid-term appointment does not affect a person's eligibility to serve two two-year consecutive terms following the mid-term appointment. Chairs can remain on Steering Committees or, when requested by the President, Chair a different Steering Committee. Only representatives of full, sponsoring, or sustaining members can Chair a Steering Committee.

Co-Chairs may be appointed at the discretion of the President and in consideration of the needs of the organization as well as the sitting Chair and Steering Committee. Co-Chairs should serve staggered terms so that an incoming Co-Chair serves at least one year with an experienced Co-Chair. Co-Chairs are expected to share duties and responsibilities of leading the Steering Committee during the term.

6.2.   Chair Responsibilities
The SC in-person meeting at the NAACCR Annual Conference serves as the first Steering Committee meeting for the year.

- Attend new SC chair orientation. Appoint Steering Committee members adhering to NAACCR Standing Rules.
- Orient new Steering Committee members to goals and objectives, set ground rules for member participation, and establish the schedule of meetings and conference calls at the beginning of each year.
- Develop an annual budget for Steering Committee activities and submit it to the Executive Director by March 1 of each year.
- In April of each year, review the Steering Committee structure (including work groups, task forces, and advisory groups) and provide a list of all groups and their members to the NAACCR office.
- Evaluate Steering Committee member participation annually prior to the NAACCR Annual Conference and confirm recommitment of current members.
- Ensure that ongoing participation is not exclusionary of other representatives who would like to be active in NAACCR.
- Review meeting minutes and secure Steering Committee approval.

- Assign priority area tasks to and provide oversight for the work of all work groups, task forces, and advisory groups, and establish a regular communication mechanism.
- Refer all policy decisions to the Board for approval when these are considered controversial, affect the general membership, or involve a survey of the membership.
- Develop process for review/approval of Steering Committee (including work groups, task forces and advisory groups) documents/products.
- Ensure that all Steering Committee products include proper attribution of funding source(s), both those provided directly to NAACCR in terms of grants, cooperative agreements, or contracts, and the in-kind contributions of volunteers.
- Ensure that all products include a suggested citation statement that adheres to the NAACCR citation format.
- Ensure Board liaison is aware of approval and estimated release date to report to the Board.
- At least two months in advance of the Board of Directors meeting, provide the Board of Directors with notification of upcoming documents, products and/or major issues needing review. This notification is necessary to allow the Board sufficient time to plan the appropriate review mechanism. These documents, products and/or major issues need to be provided to the Board of Directors at least one month prior to their scheduled review.
- Review the Steering Committee charter and the Strategic Management Plan progress at least bi-annually.
- Revise goals and objectives as needed but at least annually at the mid-year combined Board/Chair in-person meeting.
- Prepare an annual status report of Steering Committee activities and progress on completion of goals and objectives for submission to the NAACCR office one month prior to the NAACCR Annual Business Meeting.
- Prepare an article annually about Steering Committee activities or related topics or issues for the NAACCR Narrative.
- Refer all requests for NAACCR participation in external organization activities to the President so that he or she can appoint a NAACCR representative.
- Notify all prospective members when they have been added to the Steering Committee roster.
- Agenda items that require a vote should be voted on either during the meeting or using a software tool (e.g., SurveyGizmo).

6.3.   Committee Member Responsibilities
Participation in any Steering Committee, work group, task force, or advisory group is open to all members of NAACCR, in accordance with the Standing Rules.

The specific responsibilities of committee members are to:
- Be actively involved in the cancer surveillance field.
- Regularly attend meetings. The Chair may ask members to resign if they do not regularly attend or participate in meetings and activities.
- Participate actively in meetings by reviewing meeting minutes and reports, providing comments, and contributing to discussion.
- Be knowledgeable about the NAACCR Strategic Management Plan and priority area goals and objectives.
- Assure major goals and objectives are organized and achieved.
- Be actively involved in the development, review and revision process of work products that come out of the work group, task force, or advisory group.
- Review and approve all products submitted by work groups, task forces, and advisory groups.

- Generate and facilitate innovative problem-solving and open communication across multidisciplinary members and groups.
- Contribute to and enhance the work of the Steering Committee, work groups, task forces, and/or advisory groups.
- Assist with developing charters and work plans as well as developing timelines and strategies for completing priority area tasks.
- Identify and facilitate cross collaboration between priority areas when necessary.
- Identify emerging issues within assigned priority areas and through their steering committee, determine if these require integration in future Strategic Management Plan enhancements.
- For Steering Committees, an in-person meeting at the NAACCR Annual Conference of the steering committee is often planned and members are encouraged to attend. This meeting serves as the first Steering Committee meeting for the year.
- There is no term limit on representatives serving on a Steering Committee.

6.4. Staff Support Responsibilities (When Staff Support is Available)
- Staff serve as members of Steering Committees and can chair work groups, task forces, and advisory groups. They cannot hold office or chair a Steering Committee.
- Staff provide professional support and administrative services to the Board of Directors, NAACCR Steering Committees and selected work groups, task forces, and advisory groups. Administrative staff support may be provided for work groups, task forces, or advisory groups at the discretion of the Executive Director.
- Staff schedule meetings/teleconferences (solicit dates/times, schedule the meeting, and set-up the logistics for the virtual meeting).
- Staff distribute meeting materials to participants.
- Staff prepare meeting minutes and distribute the draft to the Chair and Steering Committee members.
- Staff post approved Steering Committee minutes on the NAACCR website.
- Staff maintain a Steering Committee roster.
- Staff maintain Steering Committee charters and goals/objectives (as developed by Steering Committees).

6.5. Board Liaison
- Appointed by the President
- Two Board Liaisons per Steering Committee (senior and junior)
- Promote 2-way communication between Board and Steering Committee
- Relay concerns & bring recommendations to Board
- Provide guidance to Steering Committee
- Ensure goals/objectives align with the Strategic Management Plan
- Does not vote

6.6. Levels of Participation by NAACCR Membership Category
All NAACCR members may participate on steering committees, work groups, task forces or advisory groups.

6.6.1. Full Members
- A Full member may chair steering committees, work groups, task forces, and advisory groups.

6.6.2.   Sponsoring Member Organization (SMO) Representative
- A SMO representative regularly communicates information to his/her organization's leadership from the steering committee, work group, task force, or advisory group on which he/she serves, and vice versa.
- SMO representatives may chair steering committees, work groups, task forces, and advisory groups.

6.6.3.   Individual Members
- Individual Members are not eligible to chair a steering committee.
- Individual Members may chair work groups, task forces, and advisory groups.

6.6.4.   Sustaining Member Organization Representative
- Representatives from sustaining members may chair steering committees, work groups, task forces, and advisory groups.

6.6.5.   International Membership
- International members are not eligible to chair a steering committee.
- International members may chair work groups, task forces, and advisory groups.

7.   Process to Join Committees

- Steering committee, work group, task force, or advisory group participation is open to all members of NAACCR. One representative from each member organization may serve as a voting member at a time. The chair has the responsibility of ensuring that the representativeness and size is appropriate for the tasks required of that committee.
- Persons interested in serving on a work group, task force, or advisory group should contact the chair of the committee or the steering committee chair.
- Persons interested in serving on a steering committee should contact the steering committee chair or President. The steering committee chair may ask proposed members to complete an application if needed.

8.   Document Approval Process

All documents need to be reviewed and approved before they are released to the membership or the public via the NAACCR website and other distribution methods. The process is dependent on the type of document. Steering committees must approve all documents prepared by work groups, task forces, or advisory groups.

Process for Steering Committee Document Approval (effective August 1, 2020)

The NAACCR Board recently decided to delegate approval of most documents to Steering Committees. Steering Committees will be able to provide final approval for most types of documents/products. ***The only exception is membership surveys. Surveys will still require Board approval before they can be deployed to members.***
- Each Steering Committee may develop their own specific process for review which may be different for each document to be reviewed. Suggested options:
    - Two Steering Committee members are assigned to review products in depth (a primary reviewer and a secondary reviewer). These two reviewers will document their feedback

and bring a recommendation back to the Steering Committee on whether to release as is, release with minor revisions, or revise and resubmit.

- o Request cross-committee review. One Steering Committee might ask another to review a product, particularly when there's common interest in the content.
- At times, a Steering Committee may want a Board review before a product is released. Make this request through your Board liaison and the Board will review and provide feedback at the earliest possible date.
- If needed, make a request to the Board for a review from a professional editor. If NAACCR has the funds for this service, this may be an option.

Once a document is approved by the Steering Committee for release, make certain that your Board liaison is aware of the approval and the estimated release date. The Board liaison will inform the Board of the new resource and its anticipated availability to the membership.

8.1. Research papers, reports, manuscripts

All research manuscripts or reports prepared by Steering Committees, workgroups, task forces or advisory groups must be submitted to the SEB before submission for publication or presentation at any meeting, other than the NAACCR annual meeting. Papers are submitted to the NAACCR Executive Office for coordination with the SEB. The exception to this is the annual statistical monograph, *Cancer in North America*, which is released directly by the Research and Data Use Steering Committee.

8.2. Standards Volumes.

The Standardization and Registry Development Steering Committee must approve all documents before publication that relate to cancer registry standards.

8.3. Recommendations for Registry Operations or Procedures

The Standardization and Registry Development Steering must approve all documents before publication that relate to cancer registry operations or procedures as either guidelines, recommendations, or as a resource (e.g., handbooks or manuals).

9. Revision Control

Revision Date	Section	Revision Notes
6/2021	1	Priority Area 1: renamed Strategic Alliances to Strategic Planning and Alliances; updated description.
6/2021	3.1	Updated name of SC and purpose. Revised Chair/Co-Chair, Board liaison and Alternates to be consistent with the Standing Rules (revised 8/19/20).
6/2021	3.2	Revised Purpose to be consistent with the Standing Rules (revised 8/19/20).
6/2021	3.3	Revised Purpose to be consistent with the Standing Rules (revised 8/19/20).
6/2021	3.4	Revised Purpose to be consistent with the Standing Rules (revised 8/19/20).
6/2021	3.5	Revised Purpose to be consistent with the Standing Rules (revised 8/19/20).
6/2021	4.1	Revised Chair, Membership and Voting Rights to be consistent with the Standing Rules (revised 8/19/20).
6/2021	4.2	Revised Purpose to be consistent with the Standing Rules (revised 8/19/20).
6/2021	6.2	Added bullet on document review process and a bullet on SC voting.
6/2021	6.3	Modified bullet on document review process.
6/2021	6.4	Modified bullet regarding meeting logistics.
6/2021	6.6	Changed title of this section from Responsibilities by NAACCR Membership Category.
6/2021	6.1	Added Full Members as 6.6.1 which moved others down one.
6/2021	6.6.4	Added International membership.
6/2021	8	Modified last sentence in first paragraph regarding document review and added Process for Steering Committee Document Approval.
6/2021	8.2	Modified paragraph regarding document review.
6/2021	8.3	Modified paragraph regarding document review.
8/2021	3.1	Revised Members to include President and modified wording in last bullet.