NAACCR Committee Guidelines

February 2024



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 first NAACCR Strategic Management Plan (SMP). The current <u>SMP</u> defines the five priority areas: 1) Strategic Planning and 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 (SPA)

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. In addition, investment in strategic partnerships is needed to advance NAACCR's mission. Relationships of mutual benefit must be carefully chosen and built over time. The purpose of this Steering Committee is to support the Board in identifying and advancing both strategic priorities and partnerships.

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

Standardization and registry development continue to be critical to ensuring 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: 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 <u>Standing Rules</u> 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:	Identify, research, and evaluate strategic threats and opportunities, and strengthen and expand relationships with key stakeholders.
Composition:	
Chair/Co- chairs	Appointed by President.
Members	 Executive Director President Past-President or President-Elect Canadian representative NAACCR appointed liaisons to external organizations 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. 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-	Appointed by President.
chairs	
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. Professional Development Steering Committee

Purpose:	Address workforce issues for the surveillance community, skill development,
	and training needs of the NAACCR community.

Composition:	
Chair/Co-	Appointed by President.
chairs	
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. 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 Subgroups Structure and Membership

4.1. Nominating Committee

in the matrix committee		
Purpose:	Secure candidates for the Nominating Committee and 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 from the Professional Development 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)

+.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)

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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

4.5. Strategic Management Plan (SMP) Work Group

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Purpose:	The purpose of the SMP WG is to oversee the regular and ongoing revisions to NAACCR's Strategic Management Plan, including gathering membership and NAACCR staff perspectives on future directions. This WG ensures that the SMP is implemented in accordance with Board directives. An additional charge of this WG is to monitor and communicate progress towards achieving the goals of the SMP to NAACCR's membership. This is an ongoing WG that is not expected to sunset between SMP revisions.
Composition:	
Chair/Co-	Appointed by President.
chairs	
Members	President
	Past-President or President-Elect
	Executive Director
	One additional Board member
	 Any association member appointed by the Chair(s)
	The Chair(s) will seek Canadian representation.
BOD Liaison(s):	No
Voting rights:	Each member may vote.
Alternates:	No

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 Steering Committee.

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. Steering Committee Chair Responsibilities

The Steering Committee Chair responsibilities are grouped under the month for completion; however, responsibilities that are monthly or are not associated with a timeline are listed under the general responsibilities.

Note: the June responsibilities reflect the month that a Steering Committee Chair will begin serving their term as well as the end of a year.

June

- Attend NAACCR Annual Conference.
 - Attend annual Board/Chair in-person meeting.
 - Hold in-person Steering Committee meeting (this serves as the first Steering Committee meeting for the year).
 - Discuss salient issues or changes to Steering Committee Charter and Strategic Management Plan Goals/Objectives.
 - Present Steering Committee highlights during annual business meeting.
 - Attend Steering Committee Chair meeting.
- Review the Steering Committee charter, workplan, and the Strategic Management Plan.
 - Revise Steering Committee charter and/or workplan as needed (Steering Committee goals and objectives).
 - Maintain metrics to measure progress towards reaching objectives.
- Submit an annual status report of Steering Committee activities and progress on completion of goals and objectives, including metrics, challenges and barriers, to the Board.
- Review Steering Committee work groups, task forces, and advisory groups to determine if any should disband and see if any of the chairs want to step down.

July

- Orient new Steering Committee members to goals and objectives, Steering Committee NAACCR Share site, member participation and conduct.
- Confirm Steering Committee meeting schedule with members.
- Review the Steering Committee website including work groups, task forces, and advisory groups descriptions, members, and charters. Report any updates to the staff liaison.

October

• Attend Board/Chair quarterly meeting and report on their respective priority area activities, challenges/barriers, budget requests, Board guidance, etc.

January

- Review and update if needed, the Steering Committee charter, workplan, and the Strategic Management Plan progress.
 - Revise Steering Committee workplan (goals and objectives) as needed.
 - Identify resources needed including funding for special projects.
 - Prepare budget requests, as needed, submit to NAACCR Board by March 31st.
- Advise President/President-Elect of willingness to continue as SC chair.

February

- Submit updated work plan/progress report to Board by February 1.
- Attend Board/Chair in-person meeting (timing is approximate and subject to change).

March

- Submit budget requests to the NAACCR Board by March 31st.
- Advise NAACCR staff liaison if Steering Committee will need meeting space at NAACCR Annual Conference.

April

• Attend Board/Chair quarterly meeting and report on their respective priority area activities, challenges/barriers, budget requests, Board guidance, etc.

May

- Evaluate Steering Committee member participation and confirm recommitment of current members.
 - Ensure that ongoing participation is not exclusionary of other representatives who would like to be active in NAACCR.
 - Appoint new Steering Committee members.
- Prepare annual status report of Steering Committee (including work groups and task forces)
 activities and progress on completion of goals and objectives to the Board by June 1. This
 report should also include metrics, challenges and/or barriers.
- Attend new Steering Committee chair orientation.

General Responsibilities

- Manage meetings.
- Work with staff liaison to develop agenda.
- Facilitate meetings.
- 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.
 - Draft charter for new work groups, task forces, and advisory groups.
 - Identify a chair and recruit volunteers for new works groups, task forces, and advisory groups.
- 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.
- Attend Steering Committee Chairs meeting and submit agenda item to facilitator.
- Provide the Board with at least two months' notice of upcoming documents, products and/or major issues needing review. These documents, products and/or major issues need to be provided to the Board at least one month prior to their scheduled review.
- Prepare an article at least 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 they can appoint a NAACCR representative.

- Collaborate with the Strategic Management Plan Work Group as needed.
- Submit all website updates to the Steering Committee staff liaison.
- Submit suggested social media communications as needed.

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. There is no term limit on representatives serving on a Steering Committee. The specific responsibilities of committee members are to:

- Be actively involved in the cancer surveillance field.
- Regularly attend steering committee/work group/task force 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.
- Review the Steering Committee charter, workplan, and the Strategic Management Plan.
- 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 for approval 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.
- 6.4. NAACCR Staff Liaison Responsibilities (When Staff Support is Available)
 - Serve as non-voting member(s) of Steering Committees and can chair work groups, task forces, and advisory groups. Staff cannot chair a Steering Committee.
 - Provide professional and administrative support to Steering Committees and selected work groups, task forces, and advisory groups, including:
 - Work with Steering Committee chair(s) to develop agendas.
 - Distribute meeting materials to participants.
 - Schedule meetings/teleconferences (solicit dates/times, schedule the meeting, and set-up the logistics for the virtual meeting).
 - Prepare meeting minutes and distribute the draft to the Chair and Steering Committee members.
 - Submit approved Steering Committee minutes to the NAACCR Web and Technology
 Developer to post on the NAACCR Steering Committee website.

- Maintain Steering Committee, work group, and task force rosters and submit website updates to the NAACCR Web and Technology Developer. Changes should also be made to the SHARE site, when needed.
- Maintain Steering Committee charters and goals/objectives (as developed by Steering Committees).
- Maintains documentation of official steering committee votes and decisions.
- Support work groups, task forces, or advisory groups at the discretion of NAACCR management.
- Attend Steering Committee chair meetings.

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 and bring recommendations to the Board.
- Provide guidance to Steering Committee in alignment with the NAACCR Board strategic priorities.
- Ensure goals/objectives align with the Strategic Management Plan.
- Does not vote on official steering committee business.

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 may contact the chair of the committee or the steering committee chair, or use the MAP form.
- 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 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.

- 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.
 - 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 CiNA data-based reports prepared by Steering Committees, workgroups, task forces or outside researchers must be submitted to the SEB before submission for publication. Papers are submitted to the NAACCR Executive Office through DaRT, or directly to the Program Manager of Research and Data Use, for coordination with the SEB. The exception to this is the annual statistical monograph, *Cancer in North America*, which is released directly by the CiNA Editorial Work Group of the Research and Data Use Steering Committee.

8.2. Research and Data Use Recommendations, Primers, and other Documentation Prior to publication, the Research and Data Use (RDU) Steering Committee must approve all RDU work group and taskforce generated documents, and a courtesy copy is provided to the NAACCR Board.

8.3. Standards Registry Operations Documents

The Standardization and Registry Development Steering Committee must approve all documents generated by their work groups, task force, and advisory groups before publication (via NAACCR website or other distribution method).

9. Membership Survey

NAACCR committees may survey the NAACCR membership to gather data for various reasons. All surveys must be submitted to the NAACCR staff coordinator for review and approval prior to distribution to review content, monitor frequency of surveys, and avoid overlap that may place an undue burden on members. Surveys should be conducted using a web-based survey tool (e.g., Alchemer, Survey Monkey, etc.).

Steering Committees must work with their NAACCR staff liaison to draft the survey and complete the survey request form (posted on the <u>NAACCR Chairs Only Share site</u>). All fields in the survey request form must be completed prior to the survey request.

9.1. Steps to Create an Effective Survey

Define the purpose and goal(s)

- •What do you want to find out?
- •How will the survey results be used?

Define the population

- •Who will participate in the survey?
- •How many responses are needed?

Design the survey questions

- •What type of questions will you ask?
- •How will you ask them?

Pretest the survey questions

- •Test survey questions with someone not involved in the development.
- •Determine the estimated time to complete the survey.

Distribute survey with deadline for completion

- •Who will send out the survey?
- Provide an estimated time to complete the survey.
- •Allow sufficient time for completion.

Survey Results

- •Who will receive the survey results?
- Who will complete the analysis?
- •Who will write the report?
- •How will the survey results be shared?
- •Who will share the survey results?