



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.

NAACCR is an association of more than 100 sponsoring, sustaining, and full members representing 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 National Cancer Institute (NCI); 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 under the NAACCR umbrella to ensure the promotion and development of high-quality, population-based cancer registries across North America.

Central registries play an essential role in our understanding of cancer, its diagnosis, treatment, and prevention by ensuring that accurate and timely cancer 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 a certification process, 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 proposed plan was developed to articulate the five major areas essential to the mission of NAACCR in light of a rapidly changing technical and professional environment within which it operates. These priority areas include: (1) strategic alliances, (2) standardization and registry development, (3) research and data use, (4) communications, and (5) professional development. Major goals, measurable objectives, key strategies, expected outcomes, and timelines were set for each priority area.

The SMP defined the work to be undertaken during the next 5 years and called for an adaptable and nimble approach to manage change effectively. After careful consideration, a matrix-style structure was crafted and designed to foster communication, provide flexibility and adaptability, promote

innovation, and utilize resources judiciously. 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 within their priority assignment. 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 fully completed by June 2013.

Quickly thereafter, the Steering Committees began to address needs, solve problems and advance towards the successful completion of priority area goals. Monitoring and member feedback loops were introduced in an effort to improve communication across the organization. More than 36 workgroups and 15 task forces focused on completing their duties. A sense of forward momentum and a comfort level with the new system emerged over time.

Board and Priority Area Accomplishments

Since implementation of the SMP, both the Board and the Steering Committees forged ahead realizing a number of accomplishments and successes. Progress was made on major priority area goals and several new endeavors were 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:

- Developed a matrix-style committee structure designed to be flexible and nimble.
- Recruited Steering Committee leadership and key members.
- Enhanced membership on the Board by seeking new representatives from diverse backgrounds.
- Expanded financial resources through strategic grantsmanship.
- Identified and funded new staff positions to support research and the Virtual Pooled Registry (VPR).
- Co-hosted the International Association of Cancer Registries (IACR) Annual Conference in Ottawa in conjunction with the NAACCR Annual Conference.
- Played 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.
- Provided consultation and support to international registries throughout the Caribbean.
- Established protocols and conducted pilot studies to establish a Virtual Pooled Registry Cancer Linkage System (VPR-CLS) for cohort matching to all cancer registries.
- Obtained cooperation from 45 central cancer registries to participate in the Camp LeJeune pilot test of the VPR-CLS, and obtained matches at every test site within a record timeframe.

- Guided the design of C-Change's Geographic Intervention Project.
- Achieved an 80% participation rate in NAACCR Interstate Data Exchange (44 of 55 potential central registries).



Steering Committee Activities & Accomplishments



Standardization & Registry Development

- Implemented a change management process.
- Monitored national health information technology (IT) initiatives and submitted comments on national initiatives including:
 - the HL-7 ballot process for the Implementation Guide for Ambulatory Reporting;
 - the Meaningful Use Stage 3 Proposed Rule; and,
 - the American Society for Clinical Oncology (ASCO) Treatment Summary and Survivorship Care Plan.
- Assisted CDC with Meaningful Use implementation.
- Advised on the transition from Collaborative Stage.
- 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.
- Presented 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 the:
 - 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.
- Introduced Cancer in North America Volume Four: Cancer Survival including population-based survival data for the United States and Canada.
- Initiated the (VPR-CLS), facilitating record linkages across multiple registries.
- Improved the speed and accuracy of the NAACCR geocoder, and developed the capacity to geocode Puerto Rico.
- Launched the Epidemiology Training Videos, including 19 webinars aimed at researchers and analysts.
- 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.
- 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 through the Scientific Editorial Board.



Communications

- Created and distributed a video explaining NAACCR and cancer surveillance for public use.
- Distributed the NAACCR Video Toolkit promotion to all central cancer registries.
- Highlighted the value of cancer surveillance research to external stakeholders.
- Launched the NAACCRReview Blog.
- Developed a Communication Plan and Best Practices for Communications.
- Worked with two communications interns.
- Expanded and enhanced NAACCR's social media presence.
- Began planning for the overhaul of the NAACCR website.
- Developed and implemented the Workspace Collaboration Tool on NAACCR Causeway.
- Showcased World Cancer Day, Annual Report to the Nation, and CINA releases.



Professional Development

- Developed a survey course called “Understanding Population Based Central Cancer Registries.”
- Launched Epi Moments in collaboration with the Research and Data Use Steering Committee to enhance the understanding of epidemiologic relevance to data collection.
- Planned and initiated a learning management system.
- Coordinated a journal club showcasing research publications relevant to the cancer surveillance community in collaboration with the Research and Data Use Steering Committee.
- Facilitated scientific webinars for epidemiologists in association with the Research and Data Use Steering Committee.
- Provided extensive Certified Tumor Registrar (CTR) training.
- Continued the development of a comprehensive educational plan for NAACCR.
- 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 to discuss ways to collaborate efficiently on initiatives of mutual interest.
 - Serves 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.
 - Maintains 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 problems or issues that have emerged. The NAACCR Annual Conference brings together members with interests 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 as needed. Throughout this effort, Steering Committees and the Board have made adjustments and updates 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 as required to ensure NAACCR has continued commitment to advancing central cancer registries and contributing to the cancer surveillance field.

On 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 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 successful meeting, Steering Committees worked to update each priority area. Continuation of key functions and activities, revision or deletion of some objectives and new goals and objectives were recommended. Crosscutting areas and priority area plans are provided in the next section.

NAACCR Advancing to the Next Level

If NAACCR is to advance its core values, embrace new strategies, and seize emerging opportunities, it must be prepared to adapt to change and move forward. During the January meeting, a number of

critical crosscutting issues were identified that may require new structures to focus NAACCR's substantial and diverse talent to advance NAACCR, including:

- Some of NAACCR's mission-critical projects entail dynamic and integrated collaborations that cross priority areas. Matrix organizations require mechanisms designed to build connections across specialties and enhance cross-fertilization. Although the current structure is working well across some priority areas, enhancements designed to foster communication, collaboration, and excellence are required.
- 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 the success of the SMP.
- Priority Area Networks (PANs) have been underutilized, and the need to reassess how to engage members more successfully to share ideas and strategies, explore innovative solutions, and collaboratively learn within as well as across priority areas are critical.
- A fair 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 areas that would benefit from increased collaboration.
- Efforts to inform membership to assure transparency and expand feedback loops must continue.
- Strong leaders are necessary to manage the Steering Committees and key work groups. Recruitment for key positions is crucial. Member engagement, especially among those newer to NAACCR, remains challenging 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 to address these crosscutting issues:

1. The Board should re-establish the NAACCR SMP Work Group to promote horizontal integration that enhances internal communication and cross-fertilization among Steering Committees and moves the NAACCR organizational structure to the next level of productivity.
2. Steps to assure work distribution balance across PANs (especially for the Standardization & Registry Development Steering Committee) need to be taken at the Board and Steering Committee levels.
3. The NAACCR SMP Work Group should conduct a process review of the PANs to find strategies and best practices to engage members.
4. An assessment tool to guide the lifespan of working groups and committees should be implemented across all Steering Committees to reduce risk of mission drift and assure high-functioning committees.

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:
 - Conduct market research on best strategies to raise awareness of NAACCR
 - Initiate focus groups of key stakeholders and interested public
 - Seek member feedback
 - Develop marketing materials such as a professional quality annual report, research findings, and promotional brochures
 - Expand and target NAACCR's social media campaign to key stakeholders and interested public
 - Solidify NAACCR's brand by providing consistent messaging across all levels
 - Leverage existing member connections to key organizations and audiences at the national, state, and local levels.
 - Prepare 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.
 - Provide a sounding board for member concerns and recommendations through new feedback channels (such as member surveys)
 - Seek 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, 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 the challenges of the future. 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 the NAACCR 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 centralized 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 cancer 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: Facilitate the development and availability of state- and province-specific relative survival data.

Objective 4: Maintain and enhance tools to inform researchers about state- and province-specific research experience, interests, and processes to initiate research.

Objective 5: Increase accessibility to NAACCR's CINA products by periodically evaluating data access policies and processes.

Objective 6: 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 unifying 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.

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: Move NAACCR's use of web-based and technology-driven communication systems forward to improve information sharing, and promote adoption of best practices. 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 products more widely available and minimize duplicative efforts.

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 well into the future.

In addition, an aging workforce looking to retire in the next decade will create demand for a strong 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 registries 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 reliable supply of NAACCR leaders.



THE NAACCR WOW Initiatives

As part of its first SMP, 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 should involve a complex problem within the cancer surveillance community that requires innovative and collaborative solutions that cross all priority areas and bring together outside partners. In 2012, NAACCR identified the VPR as its first **WOW** project:

1. **Virtual Pooled Registry:** The creation of a resource to support multi-state or nation-wide 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, clinical trials, and U.S. Food and Drug Administration (FDA) required post-marketing surveillance. Not only will the VPR 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 templated IRB application is being developed to streamline IRB processes.

NEW!! In this new SMP, several other innovative initiatives are also being developed concurrently. 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. In addition, we are building a mentorship and twinning program to assist registries in other parts of the world to measure the burden of cancer and develop effective cancer control plans and 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. Platinum level Registry Certification:** A proposal to consider and evaluate a new level of recognition for central cancer registries that meet the highest standards to be determined by NAACCR members, such as data sharing, de-duplicating between states, and other criteria that improve the overall quality of North American data and data use.

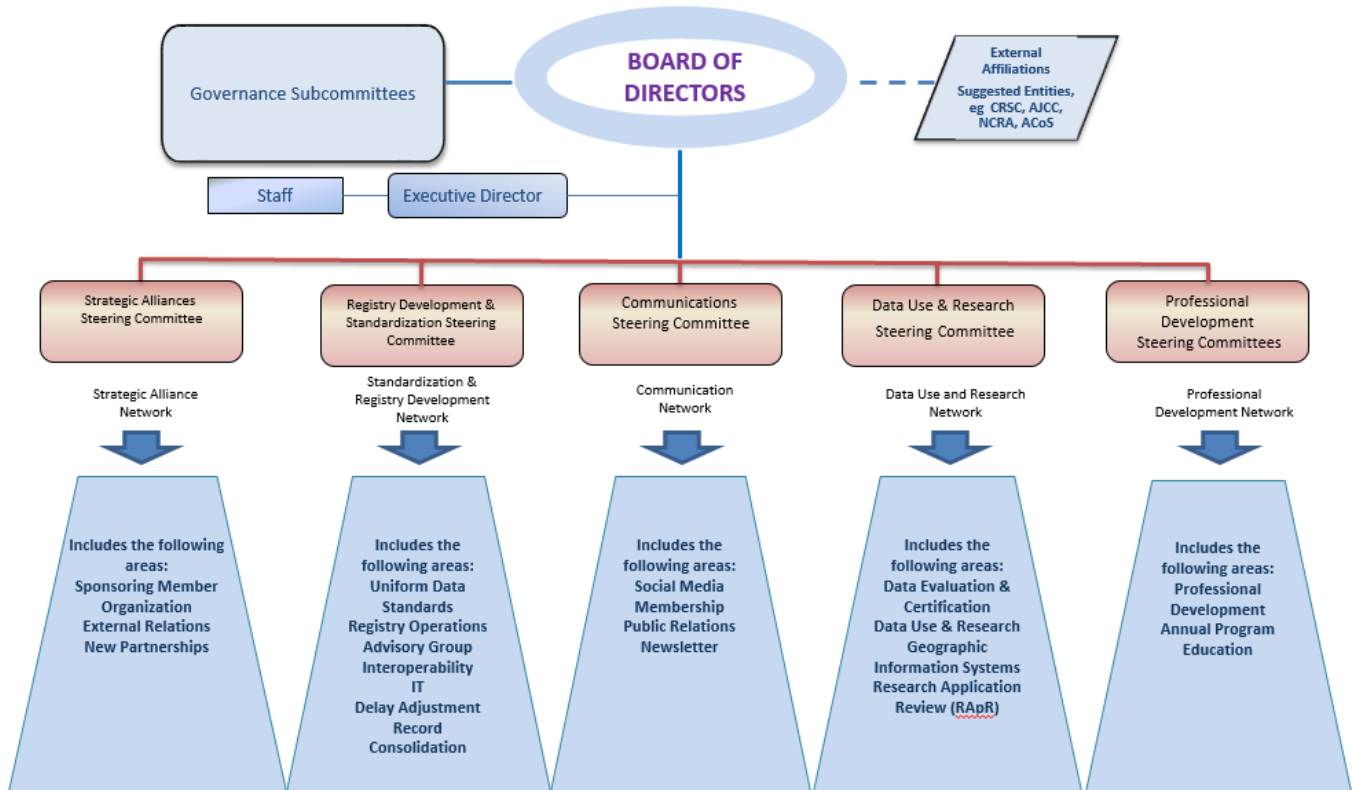
Strategic Management Plan: Conclusions

In a rapidly changing environment with significant challenges and opportunities, progress must continue or it may escape us. To succeed in such an environment calls for its own combination of retaining core values and embracing new strategies that neutralize the challenges and exploit the opportunities. Recognizing this state of affairs, NAACCR and its members have worked diligently over the past 5 years to lay a foundation sufficient to move forward while remaining focused on its mission. This new SMP maintains core principles, yet builds new capacity and positions NAACCR ready to adapt as necessary. A new and flexible committee structure is in place. Refinements are being made to address the need to handle overarching issues in a way that encourages multidisciplinary solutions. Finally, this SMP is expected to ensure that NAACCR is equipped in every reasonable respect to meet whatever demands, and to exploit whatever possibilities the future presents.

Appendix

NAACCR COMMITTEES and WORKGROUP STRUCTURE

NAACCR Committee Organization Chart



Organizational Structure

The responsibilities of a Steering Committee include the following:

- Leads and develops its priority area.
- Plans, interprets, and sets overall direction for priority area.
- Develops annual and long-term work plans.
- Assures that major goals, objectives, and tasks are organized and achieved.
- Develops 'Terms of Reference' for associated committees, workgroups, and task forces.
- Works with committees, working groups, or task forces as needed.
- Identifies the best people and facilitates processes for collaborative projects and tasks.
- Assures that the member interests align with various tasks and activities.
- Controls scope and manages approved resources.

- Generates and facilitates innovative problem-solving and open communication across multidisciplinary members and groups.
- Encourages relationship building across networks.
- 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 annually to 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 data assessment or pathology data standards. Working groups usually have a defined scope, 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 abstract review, confidentiality, and volume III.
- Advisory Group: A long-standing group of volunteers that meets regularly and plays strong supportive roles by building relationships, expanding the reach of the organization, and identifying opportunities for growth and development.

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

CTR – Certified Tumor Registrar

DSTU - Draft Standard for Trial Use

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 - Internal Review Board
IT – Information Technology
MU - Meaningful Use
NCI – National Cancer Institute
NCRA- National Cancer Registrar’s Association
PAN - Priority Area Networks
RapR - Research Application Review
SC - Steering Committee
SMO – Sponsoring Member Organization
SMP - Strategic Management Plan
S&RD – Standardization and Registry Development
SWOT – Strengths, weaknesses, opportunities and threats
TF – Task Force
TNM- Tumor Nodes Metastasis staging system
VPR-CLS Virtual Pooled Registry Cancer Linkage System
WG – Work Group
WHO – World Health Organization
XML- Extensible Markup Language