Strategic Management Plan

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

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

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

The SMP defined the work to be undertaken from 2011-2016, which required an adaptable and nimble approach to manage change effectively. Steering Committees were created to lead the overall planning, implementation, and monitoring of their assigned priority area and for keeping the organization informed of emerging issues. Working groups, advisory groups, and task forces were created around specific tasks with timelines and expected outcomes. A committee structure that aligned with the mission and goals of NAACCR was slowly rolled out and completed in June 2013.

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

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: Working together to make every cancer count.

NAACCR SMP

Board and Priority Area Accomplishments (2011-2016)

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

Crosscutting Board Accomplishments and NAACCR Initiatives

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

- Developing a matrix-style committee structure designed to be flexible and nimble.

- Recruiting Steering Committee leadership and key members.

- Enhancing membership on the Board by seeking new representatives from diverse backgrounds.

- Expanding financial resources through strategic grantsmanship.

- Co-hosting the International Association of Cancer Registries (IACR) Annual Conference in Ottawa in conjunction with the 2014 NAACCR Annual Conference.

- Playing a key role as an international partner in the establishment of the Caribbean Hub of the Global Initiative for Cancer Registration with IARC, NCI, and CDC; and providing consultation and support to international registries throughout the Caribbean.

- Establishing protocols and conducting pilot studies to establish the Virtual Pooled Registry-Cancer Linkage System (VPR-CLS) for cohort matching to all cancer registries; and, obtaining cooperation from 45 central cancer registries to participate in the Camp LeJeune pilot test of the VPR-CLS.

- Guiding the design of C-Change's Geographic Intervention Project.

- Achieving an 80% participation rate in NAACCR Interstate Data Exchange (41 of 55 potential central registries).

- Identifying and funding new staff positions to support research and the VPR-CLS; and identified other avenues for filling gaps in resources needed to carry out the SMP (i.e., interns, federal funding announcements).

Steering Committee Activities & Accomplishments

Standardization & Registry Development

- Implemented a change management process.

- Monitored national health information technology (IT) initiatives and submitted comments on national initiatives including:
  — the HL-7 ballot process for the Implementation Guide for Ambulatory Reporting;
  — the Meaningful Use (MU) Stage 3 Proposed Rule; and,
  — the American Society for Clinical Oncology (ASCO) Treatment Summary and Survivorship Care Plan.

- Assisted CDC with MU implementation.

- Advised on the transition from Collaborative Stage to directly coded T, N, and M staging guidelines.

- Defined an XML-based data exchange standard and produced an XML conversion tool to convert an existing flat file to the XML standard.

- Recommended changes to Standards Volume II Data Dictionary to accommodate electronic health record reporting.

- Completed a comparison of the NAACCR Standards Volume V and the HL7 Version 2.5.1 Implementation Guide, Electronic Laboratory Reporting to Public Health, Release 2, Draft Standard for Trial Use.

- Facilitated discussions around future needs and direction for NAACCR through the Registry of the Future sessions at the NAACCR Annual Conferences and NAACCR Webinars.

- Defined an approach for creating a web-based venue and clearinghouse for tools and other products that may be shared among NAACCR members.

- Included 12-month data in the NAACCR Call for Data.

- Published and released several guidelines, including:
  - Discharge and Claims Data Best Practices Guide;
  - Data Item Consolidation Manual and TNM Consolidation Guidelines;
  - Revised Death Clearance Manual;
  - Standards Volumes I and II on an annual basis;
  - Volume V supplement; and,
  - ICD-O-3 Implementation Guidelines.

- Expanded the Cancer Control Indicators Task Force, identifying core indicators for use in cancer control, to create a report with state/province rankings on these indicators.

- Reviewed new proposals and manuscripts for Institutional Review Board (IRB) compliance through the IRB Workgroup.

- Hosted an information webinar and submitted comments to the Department of Health and Human Services' Notice of Proposed Rule Making (NPRM) for the Federal Policy for the Protection of Human Subjects (aka: "Common Rule").

- Reviewed and approved numerous applications for CINA data use by NAACCR members through the Research Application Review (RapR) Workgroup.

- Reviewed publications that used CINA data.

Research & Data Use

- Published Cancer in North America (CINA) Monographs annually, and marked the 25th Edition of this publication series.

- Introduced Stage Data to Cancer in North America in the Incidence Volume in 2013.

- Introduced Cancer in North America Volume Four: Cancer Survival in the United States and Canada in 2016.

- Initiated the Virtual Pooled Registry-Cancer Linkage System (VPR-CLS), facilitating record linkages across multiple registries.

- Improved the speed and accuracy of the Automated Geospatial Geocoding Interface Environment (AGGIE) system, and developed the capacity to geocode Puerto Rico.

- Launched the Training Videos, including 19 webinars aimed at researchers and analysts, and continued to host pre-conference workshops and other training sessions for cancer researchers and registry staff.

Communications

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

- Proposed a Communication Plan and Best Practices for Communications.

- Worked with two communications interns to implement communications strategies.

- Began planning for the NAACCR website redesign.

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- Developed and implemented the Workspace Collaboration Tool on NAACCR Causeway (see https://naaccr.causewaynow.com/site/login).

- Created infrastructure and processes for timely release of publications and other NAACCR accomplishments through press releases and social media outlets.

- Implemented live streaming for the first time at the NAACCR 2016 Annual Conference.

Professional Development

- Planned and initiated a learning management system (LMS) to provide educational opportunities in a more flexible and efficient way.

- Developed a survey course called "Understanding Population Based Central Cancer Registries," which will be free and available to all NAACCR members through the LMS by December, 2016.

- In collaboration with the Research and Data Use Steering Committee, enhanced the understanding of epidemiologic relevance to data collection by expanding webinar offerings through Cancer Surveillance Webinars, journal club presentation, and NAACCReview (http://news.naaccr.org/). Go to http://naaccr.org/EducationandTraining/TownHallWebinars.aspx for recorded webinars.

- Continued to provide extensive Certified Tumor Registrar (CTR) training through NAACCR's monthly webinar series and CTR-prep course.

- Through strong partnerships with subject matter experts, began the development of a comprehensive educational plan for NAACCR to ensure that central cancer registry staff are well equipped with the knowledge and skills needed for the changing informatics, research, and clinical data used in cancer care and surveillance.

- Developed a concept map on data collection from the educational plan.

Strategic Alliances

- The Strategic Alliances Steering Committee has collaborated with the following key organizations over the past 5 years:

  – Co-Sponsored the 2015 Annual Conference with IACR.

  – Collaborated with ACS, NCI, and CDC on Annual Reports to the Nation.

  – Guided the design of C-Change's Geographic Intervention Project.

  – Held face-to-face meetings with several key partners, including the CDC, NCI, ACS, and others to discuss ways to collaborate efficiently on initiatives of mutual interest.

  – Served as active member of the following leadership groups: National Coordinating Council for Cancer Surveillance, Comprehensive Cancer Control National Partnership, International Comprehensive Cancer Control Partnership, IACR, Union for International Cancer Control, C-Change.

  – Maintained liaisons with and/or actively participates on committees of the following key organizations: American Joint Commission on Cancer, American College of Surgeons, American Public Health Association, American Lung Association, Council of State and Territorial Epidemiologists, College of American Pathologists, Joint Public Health Informatics Taskforce, HL7 Anatomic Pathology Workgroup, National Cancer Registrars Association, Population Association of America, various state cancer registry associations, various academic institutions and universities.

Monitoring and Review

Steering Committees monitor progress towards reaching goals on an ongoing basis as one of their key responsibilities. Progress on objectives and strategic steps are assessed at every Steering Committee meeting. In addition, Board Liaisons work with Steering Committees to bridge any gaps or address emerging issues that might arise. The Board and Steering Committee Chairs meet annually to conduct an in-depth assessment of the SMP

and address challenges and barriers that impact progress. The NAACCR Annual Conference has also served as a venue for communicating progress in each of the five priority areas, and meetings have been held to report on progress and discuss concerns. At the same time, additional member focus groups have been organized to capture more critical feedback. Throughout this effort, Steering Committees and the Board have made adjustments and updates to the SMP when necessary.

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

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

- A review of progress on the current SMP was undertaken by Steering Committees;

- Board members reviewed NAACCR's contributions to its vision and mission;

- A key stakeholder survey was completed to obtain feedback on both the benefits and costs of the SMP and the committee restructuring; and

- An updated analysis of NAACCR strengths, weaknesses, opportunities and threats (SWOT) was outlined.

At the meeting:

- Progress in each priority area was assessed and an intensive evaluation of goals and objectives was undertaken;

- Process evaluations were completed and changes considered; and,

- Crosscutting issues were considered and strategies to address them were proposed.

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

NAACCR Advancing to the Next Level

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

- Some of NAACCR's mission-critical projects entail dynamic and integrated collaborations that cross priority areas, requiring mechanisms designed to build connections across specialties and enhance cross-fertilization of ideas. Although the current structure is working well across some priority areas, the need for enhancements designed to foster communication, collaboration, and excellence remain.

- The scope of work for the Standardization and Registry Development Steering Committee may not be sustainable under the current structure and may require a judicious realignment to assure NAACCR's success in meeting the goals and objectives of the SMP.

- Priority Area Networks (PANs) have been underutilized, and the need to reassess how to effectively engage members to share ideas and strategies, explore innovative solutions, and collaboratively learn within as well as across priority areas is critical.

- An effective approach to sunsetting work groups and task forces needs to be implemented upon completion of objectives.

- Internal communication within and across Steering Committees needs significant strengthening to improve efficiencies, and more importantly, to identify activities that would benefit from increased collaboration.

- Efforts to inform membership to assure transparency and expand feedback loops must be deliberate, consistent, and timely.

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

After careful consideration, the following steps were recommended:

1. The Board should re-establish the NAACCR SMP Work Group to follow-up on these recommendations and evaluate progress.

2. Evaluation of work distribution across priority areas, especially for the Standardization & Registry Development Steering Committee, needs to take place at the Board and Steering Committee levels.

3. The NAACCR SMP Work Group should review best practices and recommend several strategies to engage members.

4. An assessment tool to guide the lifespan of working groups and task forces should be implemented across all Steering Committees to reduce risk of mission drift and assure high-functioning, successful work groups and task forces.

5. A formal mechanism to apprise the Communications Steering Committee of important actions and newsworthy developments within priority areas should be established.

6. Town Hall meetings, greater use of social media, and member assessment surveys should be used on an ongoing basis to provide transparency and capture member feedback.

7. Member engagement, recruitment, and leadership development require significant attention by the Board, Steering Committees, and all Registry Directors. New approaches to reduce burnout and improve succession planning should be included. Adapting best practices and model programs from successful non-profit associations should be considered.

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

1. A marketing plan is needed to raise awareness of the valuable role that NAACCR plays in the cancer surveillance community and improve its branding to its key stakeholders and other pertinent constituents. Specific strategies include:

   - Conducting market research on best strategies to raise awareness of NAACCR
     – Initiating focus groups of key stakeholders and interested public
     – Seeking member feedback

   - Developing marketing materials such as a professional quality annual report, research findings, and promotional brochures

   - Expanding and targeting NAACCR's social media campaign to key stakeholders and interested public

   - Solidifying NAACCR's brand by providing consistent messaging across all levels

   - Leveraging existing member connections to key organizations and audiences at the national, state, and local levels.

   - Preparing a tool to guide central registries at state and local levels in marketing their value.

2. The Sponsoring Member Organization (SMO) communication efforts should be expanded to improve the dialogue with standard setters, members, and key constituents on topics important to the surveillance community.

   - Providing a sounding board for member concerns and recommendations through new feedback channels (such as member surveys)

   - Seeking ways to assure a smoother transition when standards are changed.

3. A coordinated approach aimed at building strategic alliances with current and new stakeholders should be initiated across the NAACCR membership.

   - A database of NAACCR members who have relationships with current or potential strategic stakeholders at the state and local level should be created to leverage connections.

   - Materials and training to help volunteers reach out to various organizations should be developed.

   - A NAACCR campaign to inform and educate leaders from the cancer surveillance, clinical care, research, and cancer control communities should be implemented.

Strategic Management Plan Goals & Objectives, 2016-2021

Priority Area 1: Strategic Alliances

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Priority Area 3: Research and Data Use

Rationale: The fundamental value of centralized cancer registries is the high-quality data that allows innovative research, reliable cancer surveillance and improved cancer control. The Research and Data Use Steering Committee plays a vital role in assuring promotion and access to registry data in a systematic and user-friendly way. Significant advances in technology and science offer new opportunities and challenges for cancer surveillance. Data analytics and "Big Data" are presenting new ways to analyze both structured and unstructured data to provide new insights and directions in our understanding of cancer. It is essential that NAACCR keeps pace with

these developments by making certain that central registries are positioned to make the fullest possible contribution to future research in epidemiology, cancer prevention and control, and, in particular, clinical outcomes.

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

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

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

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

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

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

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

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

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

Priority Area 4: Communications and Policy Development

Rationale: Communicating a unifyied understanding of purpose to members, outside stakeholders, and the public is the critical role performed by the Communication Steering Committee. Keeping members informed of advances in the field, reporting progress towards reaching

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

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

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

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

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

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

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

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

Objective 3: Enhance NAACCR's use of web-based and technology-driven communication systems to improve

information sharing, and promote adoption of best practices, and develop a more global distribution list for outward communication.

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

Priority Area 5: Professional Development

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

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

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

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

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

NAACCR SMP

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

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

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

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

The NAACCR WOW Initiatives

As part of its first SMP from 2011-2016, the *WOW* project was originally proposed to challenge the cancer surveillance community to take on a big-picture problem that would have a transformative impact on the field. *WOW* projects are complex problems within the cancer surveillance community that require innovative and collaborative solutions that cross all priority areas and bring together outside partners. In 2012, NAACCR identified the VPR-CLS as its first *WOW* project:

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

as a universal IRB for VPR-CLS eligible studies. In addition, a template IRB application is being developed to streamline the IRB process.

NEW!! In this new SMP, several other innovative initiatives are also being developed. These include:
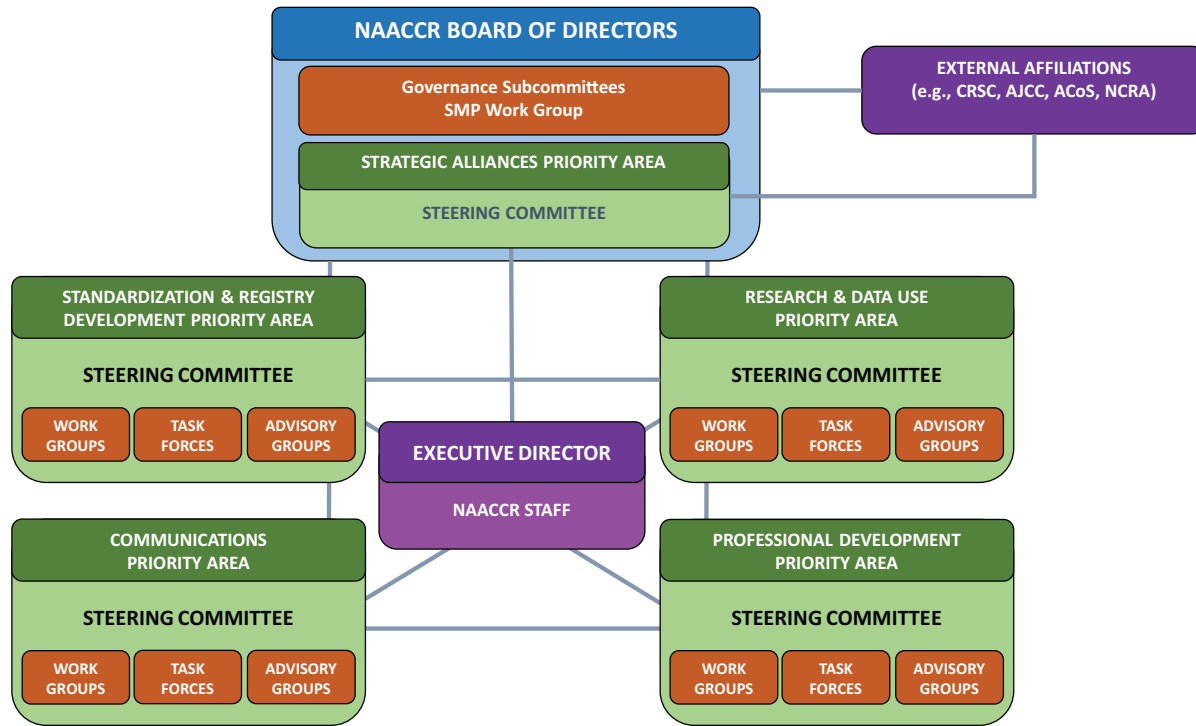
2. **Technical Assistance for International Cancer Registries:** NAACCR has been an active partner in establishing and supporting the Caribbean Hub for the Global Initiative for Cancer Registration, sponsored by the World Health Organization (WHO) and IARC. In addition, NAACCR has established an international membership category, and is working to provide education, training, and other resources through portal access on our website. We are also building a mentorship and training program through twinning to assist registries in other parts of the world in their effort to measure the burden of cancer and develop effective cancer control programs.

3. **Registry of the Future Expert Leadership Panel:** An expert leadership conference that brings some of the world's top leaders in cancer surveillance together to vision the cancer registry of the future using critical thinking and innovative problem solving techniques.

4. **Review Registry Certification:** Explore the need for modifications to current Gold and Silver certification levels, or the addition of a new level of certification. Criteria to be considered may include data sharing, de-duplication between states, and other activities that improve the overall quality of North American data and data use.

Strategic Management Plan: Conclusions

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

Appendix

NAACCR Committees and Workgroup Structure

NAACCR BOARD OF DIRECTORS

Governance Subcommittees
SMP Work Group

STRATEGIC ALLIANCES PRIORITY AREA

STEERING COMMITTEE

EXTERNAL AFFILIATIONS
(e.g., CRSC, AJCC, ACoS, NCRA)

STANDARDIZATION & REGISTRY
DEVELOPMENT PRIORITY AREA

STEERING COMMITTEE

WORK GROUPS · TASK FORCES · ADVISORY GROUPS

RESEARCH & DATA USE
PRIORITY AREA

STEERING COMMITTEE

WORK GROUPS · TASK FORCES · ADVISORY GROUPS

EXECUTIVE DIRECTOR

NAACCR STAFF

COMMUNICATIONS
PRIORITY AREA

STEERING COMMITTEE

WORK GROUPS · TASK FORCES · ADVISORY GROUPS

PROFESSIONAL DEVELOPMENT
PRIORITY AREA

STEERING COMMITTEE

WORK GROUPS · TASK FORCES · ADVISORY GROUPS

Organizational Structure

The responsibilities of a Steering Committee include the following:

- Leads and develops its priority area.

- Plans, interprets, and sets overall direction for the priority area.

- Develops annual and long-term work plans.

- Assures that major goals, objectives, and tasks are organized and achieved.

- Assists with developing timelines and strategies for work groups and task forces.

- Works with working groups and or task forces as needed.

- Identifies talent and subject matter experts and facilitates collaboration.

- Assures that the member interests align with various tasks and activities for the completion of SMP goals and objectives.

- Controls scope and manages approved resources.

- Generates and facilitates innovative problem-solving and open communication across multidisciplinary members and groups.

- Encourages relationship building across priority areas.

- Monitors progress and tracks timelines.

- Identifies emerging issues within assigned priority areas and advises the Board if these require integration in future SMP enhancements.

NAACCR SMP

- Reports regularly to the Board and NAACCR members.

- Serves as a sounding board for new ideas and opportunities for growth.

- Assesses the need for changes to any SMP priority area.

Definitions

- **Committee:** A group of team members who *accept responsibility for major goals and objectives*. Committees tend to be ongoing and with no identified endpoints or anticipated termination.

- **Working Group:** A group of experts brought together to accomplish *a measurable objective*, a major project, or a defined activity such as Edits Work Group, Physician Reporting Work Group, CINA Editorial Review Work Group, and the Research Application Review Work Group. Working groups usually have a defined scope and are technically focused with specific recurring or *ongoing deliverables*.

- **Task Force:** A group of team members with complementary skills brought together to accomplish a defined and specific task in a *set period*. Task Forces are often *need-based or event-driven* and then disbanded upon completion of work. Examples of possible task forces include ELR Messaging Comparison Task Force, Primary Payer Crosswalk Task Force, NAACCR Geocoder Task Force, and the Website Redesign Task Force .

- **Advisory Group:** A group of volunteers that plays a strong supportive role to the Steering Committee by identifying opportunities for growth and development, and serving as a sounding-board for specific initiatives being vetted by the Steering Committee.

Abbreviations

ACS – American Cancer Society

ASCO – American Society of Clinical Oncology

CDC – Centers for Disease Control and Prevention

CINA – Cancer in North America

CoC – Commission on Cancer

CPAC – Canadian Partnership Against Cancer

CTR – Certified Tumor Registrar

FDA – Food and Drug Administration

HL7 – Health Level 7

IACR – International Association of Cancer Registries

IARC – International Association for Research on Cancer

ICD-O-3 – International Classification of Diseases for Oncology 3

IRB – Institutional Review Board

IT – Information Technology

LMS – Learning Management System

MU – Meaningful Use

NAACCR – North American Association of Central Cancer Registries

NCI – National Cancer Institute

NCRA – National Cancer Registrar's Association

RapR – Research Application Review

SMO – Sponsoring Member Organization

SMP – Strategic Management Plan

S&RD – Standardization and Registry Development

StatsCan – Statistics Canada

SWOT – Strengths, weaknesses, opportunities and threats

TNM – Tumor Nodes Metastasis staging system

VPR-CLS – Virtual Pooled Registry Cancer Linkage System

WHO – World Health Organization

XML – Extensible Markup Language