Strategic Management Plan

North American Association of Central Cancer Registries

Blueprint for Action

2011 - 2016

NAACCR: Working Together to make every cancer count

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Report prepared by ***Applied Ethics Enterprises, LLC***
Red Bank, New Jersey
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June 22, 2011

Dear Colleagues,

It is my pleasure to submit the 2011-2016 North American Association of Central Cancer Registries' (NAACCR) Strategic Management Plan (SMP). When we began this initiative last year during the Annual Conference in Quebec, we recognized that advances in science and information technology placed cancer surveillance at a crossroad that would require NAACCR to work in new ways. So, for the first time, NAACCR engaged in a comprehensive and consensus-driven strategic management process that reached out and involved almost everyone in our organization. It was truly amazing to see the level of commitment from so many of you. As a result, I believe we have a forward-looking blueprint for action that acknowledges the challenges ahead but preserves our core values and mission.

I want to express my sincere thanks to the Board, whose vision and commitment to this process helped assure its success; the Oversight Committee, composed of some of our most experienced and knowledgeable members, who worked tenaciously to assure that key priority areas, major goals and objectives reflected the values, needs and interests of NAACCR; the Chairs, committees and workgroups who all pitched in by laying out a detailed action plan for all of our objectives; the SMOs who came together to offer their insights and support; and finally, I want to thank all of our members who helped with focus groups, interviews and surveys. Your insights and opinions have driven this plan, and we simply could not have been successful without you.

This SMP is designed to focus on critical needs, take advantage of emerging opportunities and chart a course that will advance NAACCR into the future. It maintains our core mission of standardization, registry improvement, data use and research and professional development, while moving us in new directions such as building strategic alliances, enhancing communication and initiating new policy. The SMP is designed to be a living document with the flexibility to adapt to a changing environment.

It is clear that there is much work ahead for all of us. However, if there is one thing I learned in leading this endeavor, it's that NAACCR's real strength lies with its members. We are a family that supports each other and NAACCR even in times of extreme challenges. This dedication is the driving force that makes us unique. It is for this reason that I am confident that with this plan to guide us, and ***working together, we will make every cancer count.***

Sincerely yours,

Maria Schymura,
President

Executive Summary

The North American Central Cancer Registries, (hereafter NAACCR) has a consistent history of responding to the complex needs of cancer registries, since its inception in 1987. Now, new challenges are emerging with rapid developments in science and technology. In response to this circumstance, NAACCR undertook a comprehensive strategic planning initiative in 2010 to develop a robust blueprint for the future.

The process included a SWOT analysis, management assessment, membership survey and Board interviews. An oversight committee, consisting of leaders from central cancer registries and the cancer surveillance community, provided critical guidance in developing the following proposed 5-year strategic plan. The NAACCR Board met in February, 2011 to review and approve a draft of priorities, goals and measurable objectives to be developed in detail. From that draft, came a detailed action plan consisting of SMART (specific, measurable, attainable, realistic and timely) goals, tactics, assigned responsibilities, measurable outcomes, evaluation components, financial assessment and timelines. To carry out the plan, the oversight committee worked closely with working group chairs and their membership to draft the SMART goals and objectives, specific to each working group, which the chairs reviewed and approved at their meeting in April 2011.

To ensure transparency and inclusiveness, a consensus building process was set up and consisted in periodic progress reports, educational programs and negotiations with key constituents. A webpage was established to post updates and collect input. All feed-back was carefully reviewed by the oversight committee.

The proposed strategic management plan is organized around five (5) priority areas, each with its own carefully developed rationale: 1) strategic alliances; 2) standardization and registry development; 3) research and data use; 4) communications and policy development; 5) professional development.

For each priority area, a major goal, measurable objectives, key strategies, expected outcomes, and timelines are set, with those responsible for their achievement also identified. Thus, for example, the major goal for strategic alliances is to strengthen relationships with sponsoring member organizations (SMOs) and existing partners, while establishing new alliances to further promote the mission of NAACCR. The NAACCR Board, senior staff and the SMO members will be responsible for this priority area. A key strategy will be to improve SMO quarterly meetings by employing collaborative problem solving approaches to important challenges as they emerge in the cancer surveillance field. One expected outcome is a change in the format of the quarterly meetings, which will be implemented in the next six months.

The proposed plan is designed to re-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. The plan represents a vote of confidence in NAACCR and its continued central role in the cancer surveillance community. The Board unanimously approved the major goals and objectives on June 19, 2011, at its Board meeting. An implementation plan, now in development, will guide the SMP forward by monitoring progress, providing evaluation and assuring continuous member feedback.

The North American Association of Central Cancer Registries

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.

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American Cancer Society
American College of Surgeons
American Joint Committee on Cancer
Canadian Partnership Against Cancer
Centers for Disease Control and Prevention's National Program of Cancer Registries
College of American Pathologists
National Cancer Institute
National Cancer Registrars Association
Public Health Agency of Canada

SECTION I: Background and SMP Process

NAACCR Overview

Established in 1987, NAACCR, Inc. is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America dedicated to enhancing the quality and use of cancer registry data. All central cancer registries in the United States and Canada are members and a variety of other membership levels is available. 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.

While NAACCR has always recognized and responded to the complex and comprehensive needs of cancer registries throughout the past 24 years, new challenges are emerging as science and technology advance that will require the concerted and assertive action of the cancer surveillance community. In recognition of this dynamic state of affairs, NAACCR launched a major strategic planning initiative in 2010 designed to develop a farsighted and innovative blueprint for the future. Although NAACCR has been goal directed, it has never developed a wide-ranging strategic management plan that includes an across the board evaluation of NAACCR's goals and objectives and organizational structure. This process incorporates all areas of the association including, but not limited to: finance and administration, education, certification, staffing, governance, membership, fundraising, annual conference, advocacy. Also included are NAACCR's role in research, and the future of cancer surveillance.

Vision

"Working together to make every cancer count."

The unique quality that NAACCR brings to cancer surveillance is its capacity to promote collaboration among all the players in the field in a way that assures quality, innovation, and progress. So the Board in identifying its vision included '*working together*' as a unifying term to represent the breadth and expertise that NAACCR members bring to cancer surveillance. '*Making every cancer count*' is a concept that has broad meaning. Clearly, as an organization, NAACCR is focused on accuracy and comprehensiveness in its reporting and standards, so this is a natural fit. At the same time, its data count when used for research, cancer control and clinical outcomes. Most importantly, it wants every person diagnosed with cancer to understand that central cancer registries are doing all that they can to make a difference to patients' lives. Finally, NAACCR wants the public to know that its work is relevant and integral to the fundamental understanding of cancer. Central cancer registries strive to reduce the burden of cancer for all by supporting control and prevention activities in communities throughout North America.

Mission

NAACCR 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.

Organizational Values

NAACCR as an organization:

- Strives for the highest quality of data through standardization and uniformity
- Recognizes that data must be used by researchers and policy makers to reduce the burden of cancer
- Serves as a collaborative umbrella for the surveillance community
- Promotes volunteerism and service to the profession
- Supports central registries at all levels of development
- Fosters open and diverse membership

History and Background

NAACCR was created to establish and maintain standards for cancer surveillance, provide training and education, and promote data use across all central registries in the United States and Canada. All central cancer registries in North America participate in the organization as full voting members. Individual and sustaining memberships, for those with an interest in cancer surveillance, are also available. These members bring different expertise and perspectives to NAACCR as they represent a variety of fields and interests. There are currently more than 400 active individuals participating in NAACCR, representing a wide range of multidisciplinary arenas. Since its founding, NAACCR has also been supported by a number of cancer organizations in the United States and Canada. These professional organizations, with a focus on cancer surveillance, comprise a special level of membership called Sponsoring Member Organizations (SMOs).

Quite early on, NAACCR established a complex system of committees and workgroups to solve technically challenging problems and assure uniformity and best practices across the entire surveillance system. Federal surveillance entities, the American College of Surgeon's Commission on Cancer (CoC), the American Joint Committee on Cancer (AJCC) and central registries recognized the value of having an independent association providing a forum for the development of consensus standards rather than developing parallel, possibly incompatible, systems across the domain.

Now in its 24th year, NAACCR is a mature organization that has accomplished the greater part of its original goal of assuring standardization across registries. It now faces the challenge of adapting standards in the context of changing medical and informatics environments, and deciding what other directions might be undertaken to assure that central cancer registries flourish in the future.

Strategic Management Process

A comprehensive approach to strategic planning was undertaken by NAACCR beginning in June 2010. The process incorporated a variety of planning techniques to help NAACCR prioritize core areas, identify major goals, set measurable objectives and establish benchmarks of success. In parallel, an action plan was also developed with significant input from NAACCR committees and workgroups to provide detailed tactics, assign specific responsibilities, identify evaluation procedures and set timelines for completion of each SMP goal and objective. Consensus building and feedback loops were included throughout this process. Specific steps included:

A. Market Research and Environmental Scan:

SWOT analysis: A major first step in the strategic planning process was the completion of an in-depth SWOT (Strengths, Weaknesses, Opportunities and Threats) Analysis that was used extensively in the

identification of key strategic directions for NAACCR during the next 5 years. A SWOT analysis is a snapshot of a company or agency's internal organization and management as well as an evaluation of the external environment that may influence its operations and their outcomes. It is the first stage of planning and identifies key issues that should be considered in any strategic management process. NAACCR members and major stakeholders participated in 6 focus groups and 15 expert interviews as part of this critical activity.

Management Assessment: An intensive assessment of NAACCR's internal management and operations was provided in each of the following areas: Finance and Administration, Governance and Organizational Structure, Program/Education Development, Growth Opportunities and New Markets, and Resource Enhancement and Strategic Partnerships and Affiliations. This analysis is intended to guide NAACCR's capacity to expand in new directions and to help inform the Board about necessary infrastructure and staffing needs in the future.

Membership Survey: An online survey of the full membership was planned, implemented, and analyzed to complement the SWOT findings at the annual meeting held in June 2010 in Quebec, Canada. Major trends and important issues from the Quebec focus groups/expert interviews served as basis for broad based input on major topics. This step assured a more comprehensive evaluation of NAACCR and helped build consensus around future directions throughout the organization.

Board Interviews: All Board members, many SMO representatives, and key experts were interviewed and findings incorporated into overall findings.

B. Plan Development Leadership and Oversight

SMP Oversight Committee: The NAACCR SMP Oversight Committee consisted of experienced leaders representing central cancer registries and experts from the cancer surveillance community. The group provided critical guidance, direction and leadership to the 5-year strategic management planning initiative. The charge of the group included:

1. Review, evaluation and interpretation of market analysis, SWOTs, and internal management assessment of NAACCR's organization and structure.

2. Assessment and appraisal of findings of membership/stakeholders surveys and feedback as required.

3. Guidance, facilitation and oversight of the development of a draft 5-year SMP aimed at securing NAACCR's future viability and development. Steps in this process included setting new directions and priority areas, identifying major long term goals and developing measurable objectives for these goals.

4. As a result of these intensive deliberations, the Oversight committee identified 5 critical directions as priorities for NAACCR over the next 5 years. These included *Strategic Alliances* incorporating the need to expand and strengthen existing and new strategic partnerships to better address NAACCR's mission; *Standardization and Registry Development*, recognizing that a new flexibility will need to be built into this core function; *Research and Data Use*, focusing renewed energy on improving access and quality of data; *Communications and Policy*; modernizing communication so it's open, accurate and timely while addressing the need to

serve as the voice of NAACCR members on important issues involving central cancer registries and *Professional Development*, assuring those in the field that they have the skill set necessary to function in the future while energizing the field so improved recruitment of new people is easier.

Board Approval of Draft Goals: The Board met on February 3-4, 2011, for two intensive days of discussion and review of the draft priorities, major goals and some suggested measurable objectives, to approve them for detailed development.

Committee and Workgroup: The next steps in the SMP development included the creation of a detailed action plan that breaks down broader goals into SMART (Specific, Measurable, Attainable, Realistic, and Timely) objectives, tactics, assigned responsibilities, measurable outcomes, evaluation components, financial assessment and timeliness. Because of their expertise and significant skill set, Committee and Workgroup Chairs in close collaboration with their members were assigned this critical responsibility. After preparing SMART objectives for each committee, Chairs met in Atlanta on April 4, 2011, to carefully review and approve draft major goals and objectives.

Feedback Loops and Membership Input: A consensus building process was put in place, using a series of reports, educational programs and negotiations with key members and stakeholders. A webpage on the NAACCR website was provided to post updates and collect input. The Major Goals and Objectives were posted for full review and comment by the entire NAACCR community. All feedback was carefully considered by Oversight Committee members.

Board Approval

In light of this exhaustive and deliberative process, involving the entire NAACCR Community, the Board unanimously approved the plan at the annual conference held in Louisville, Kentucky, in June 2011. The Board views the plan as a living document that will be fine-tuned as circumstances or needs change. It takes full responsibility for the realization of the plan and will set forth a carefully crafted implementation plan that assigns responsibilities, sets deliverables and measurable endpoints, monitors progress and establishes a comprehensive cross cutting evaluation for the plan.

NAACCR Strategic Management Plan

Blueprint for Action: 2011-1016

SECTION 2: Plan Details

The NAACCR Strategic Management Plan

The NAACCR strategic management plan consists of five major priority areas that are broken down into major goals and objectives. Each objective is further refined by assigned responsible parties, strategic actions, expected outcomes and anticipated timelines. These items are described below. The plan focuses on bigger picture items and builds in flexibility. In addition, a Board directed implementation plan to launch in July, 2011, will serve to assure progress in reaching major goals and objectives by bringing together committee specific SMART goals and tactics with operational procedures, monitoring and feedback.

Priority Area 1: Strategic Alliances

Rationale: The need to strengthen and expand relationships with key stakeholders, especially sponsoring member organizations, ranked high in the SWOT analysis and was identified as a major priority area by the Oversight Committee. Reshaping SMO meetings and interactions to focus on productive, issues-driven agendas and collaborative problem solving was a specific strategy suggested to 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 partnerships with IT and electronic medical record companies, chronic disease surveillance organizations, pharmaceutical and biotechnology companies and broader oncology groups was viewed as a way of supplementing expertise and developing possible new funding streams. In a rapidly and radically changing environment, pursuing new alliances and rethinking existing strategic alliances and their operation are a major priority for NAACCR.

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 SMOs by facilitating open communications and purposeful actions.

Responsible Parties: NAACCR Board, Senior Staff, SMOs

Key Strategies:

1. Work towards mutually productive relationships and transparency among SMO members by clearly defining roles and responsibilities.
2. Improve SMO quarterly meetings by employing collaborative problem solving approaches to important challenges in the cancer surveillance field.
3. Develop operational procedures and improve communication channels among SMO members.
4. Identify areas of mutual interest where specific SMO organizations and NAACCR can focus on projects or activities of special interest to that particular SMO.
5. Evaluate and improve the process.

Expected Outcomes: Roles and responsibilities of SMOs and NAACCR are clarified. SMO members work collaboratively to deal with at least one major challenge in the field on an annual basis. SMO projects completed with NAACR's support. Improved communication among SMO members and NAACCR occurs.

Timeline: Roles defined, meeting redesign and implementation within 6 months. Within Year 1, address 1 major challenge and evaluate process for improvement. Within 2 years, full implementation.

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

Responsible Parties: Board, Executive Director, SMO Chair and members.

Key Strategies:

1. Work with existing partners to promote the importance of cancer surveillance across North America.
2. Leverage relationships with existing partners by identifying areas of mutual interest and collaborating on activities that benefit everyone.
3. Expand relationships with Canadian partners in areas of mutual benefit.
4. Explore innovative new relationships with key organizations in disease surveillance, informatics and oncology.
5. Explore collaborations with biotechnology and pharmaceutical industries.

Expected Outcomes: Stronger relationships and more collaborative activities among existing partners takes place. New partnerships with key organizations initiated. Collaborations with biotechnology and pharmaceutical companies explored.

Timeline: 1-2 years to strengthen partnerships with existing organizations. 1.5-3 years with key organizations. 1.5-5 years with biotechnology and pharmaceutical companies.

Priority Area 2: Standardization and Registry Development

Rationale: The core function of NAACCR is to support and strengthen central registry standardization and development. The SWOT analysis indicated that this mission-critical role must move forward so that central registries are adequately prepared to adapt rapidly and successfully to changing developments in cancer surveillance, including IT and technology breakthroughs, advances in clinical outcomes and treatments, survivorship issues, and adoption of electronic health records, characterized by an environment of technologically-driven change present everywhere. In such an environment, NAACCR cannot afford, if it is to remain true to its core function, to conduct business as usual but rather must embrace change.

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

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

Responsible Parties: Interoperability Committee, and various SMOs

Key Strategies:

1. Develop criteria for central and hospital cancer registry software systems capable of receiving and processing electronic reports from multiple reporting sources.
2. Explore the conversion of NAACCR cancer abstract data items identified to be consistent and semantically interoperable with other national standards and, if appropriate, develop implementation plans.
3. Explore the capabilities of the SNOMED-CT (**S**ystematized **No**menclature of **Med**icine -- **C**linical **T**erms) terminology to capture cancer information at the appropriate level of granularity to map directly into the AJCC staging classification system.

Expected Outcomes: Some NAACCR member registries will begin interfacing with electronic health records.

Timeline: Ongoing

Objective 2: Stay engaged and remain current with national/international efforts regarding electronic health records and enhance efforts to include cancer in the "meaningful use" case for public health reporting.

Responsible Parties: Interoperability Committee, SMOs and others

Key Strategies:

1. Seek and maintain NAACCR representation on the relevant national committees.
2. Monitor the activities of national health information technology initiatives.
3. Respond to public comment periods when germane to cancer surveillance.
4. Monitor the development of and endorse, as appropriate, implementation guides for the transmission of synoptic consultation and treatment reports.

Expected Outcomes: NAACCR's interest will be represented at critical national levels for oncology related EHR information.

Timeline: Ongoing

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.

Responsible Parties: Interoperability Committee, Registry Operations Committee, Uniform Data Standards Committee, Information and Technology Committee

Key Strategies

1. Maintain Standards volumes and implementation guidelines utilizing a software solution.
2. Provide a forum for evaluating the feasibility of collecting new data items and/or rules, vetting proposed changes and eliminating obsolete/unused items.
3. Ensure that cancer registries are able to routinely receive and process electronic, interoperable, cancer pathology reports - including those in text and synoptic formats.
4. Continue to develop NAACCR XML as an alternative for the Volume II column-delimited format.

Expected Outcomes: Agreed upon method for posting and vetting changes to data collection is in place. Standards documents and implementation guidelines meet NAACCR member needs. The process for maintaining standards volumes is streamlined. Pathology laboratories adopt the NAACCR Volume V standard. Some registries will receive and transmit cancer abstracts in XML format.

Timeline: Ongoing

Objective 2: Develop standards/best practices for incorporating information from administrative and other data sources into the central cancer registry database to improve completeness and enhance registry data.

Responsible Parties: Interoperability Committee, Registry Operations Committee, Uniform Data Standards Committee, Geographic Information System Committee

Key Strategies:

1. Identify and assess potentially useful data sources for augmenting cancer surveillance systems.
2. Develop guidelines for use of each type of relevant data source.
3. Offer feedback loops for member input and comment.

Expected Outcomes: Registry data augmented from other data sources.

Timeline: Ongoing through 5 years

Objective 3: Develop methods to simplify the death clearance process and make it more efficient and cost-effective.

Responsible Parties: Death Clearance Workgroup

Key Strategies:

1. Identify, review, and evaluate the different components of the death clearance process.
2. Recommend the most efficient and cost effective system for membership consideration.
3. Provide feedback loops and ongoing evaluation for further improvement.

Expected Outcomes: Death clearance is simplified.

Timeline: 2 - 3 years

Objective 4: Facilitate automation of record consolidation by developing general principles and consolidation guidelines.

Responsible Parties: Registry Operations Committee and various SMOs

Key Strategies:

1. Identify, review, and evaluate previous work on establishing consolidation guidelines.
2. Assess and develop consolidation guidelines and rules for automation of record consolidation.
3. Inform membership of recommendations and provide feedback loops, *beta* testing and revisions as necessary.

Expected Outcomes: Guiding principles for record consolidation improve the automation process.

Timeline: 3 -5 years

Objective 5: Update white papers on confidentiality to assure that confidentiality guidelines and standards reflect current best practice recommendations and emerging issues relevant to registries.

Responsible Parties: Data Use and Research Committee, Uniform Data Standards Committee

Key Strategies:

1. Develop updated and referenced white papers on specific confidentiality topics.
2. Routinely review and assess registry standards on confidentiality and make recommendations for change when appropriate.
3. Identify opportunities to promote uniformity across registries with special attention to practices that ease the data access issues currently encountered by researchers conducting multi-registry research projects.

Expected Outcomes: Confidentiality guidelines established and maintained.

Timeline: 2 - 3 years

Goal 3: Facilitate sharing of technical resources and tools among NAACCR member organizations.

Objective 1: Provide opportunities for mentorship in cancer registry operations to strengthen cancer registries and their personnel throughout North America.

Responsible Parties: NAACCR staff, mentors, cancer surveillance experts

Key Strategies:

1. Support travel to mentoring registries.
2. Identify appropriate registries to provide mentoring by area of expertise.

Expected Outcomes: Central cancer registries are strengthened.

Timeline: Ongoing

Objective 2: Provide a venue and act as a clearinghouse for sharing open source software products, SAS or other programs, algorithms, tools, and/or templates to make products more widely available and minimize duplicative efforts.

Responsible Parties: Information Technology and IT related committees

Key Strategies:

1. Develop a clearinghouse management plan including categories of content, annotation requirements, and posting-criteria.
2. Create a well organized web-based delivery system.
3. Publicize content and provide opportunities for feedback to improve quality and enhance the value to members.

Expected Outcomes: Resources are shared among members and duplication of effort is reduced.

Timeline: 2 years

Objective 3: Meet the geographic information needs of the NAACCR membership, including maintenance of relevant data items, acquisition and assessment of census data, and development of software tools and educational materials related to spatial analysis.

Responsible Parties: Geographic Information System Committee

Key Strategies:

1. Develop best practices and create a series of interactive training materials for registry analysts including geocoding, small area incidence calculations and spatial analysis.
2. Evaluate issues related to the use of the American Community Survey data including its compatibility to the 2000 Summary File.
3. Foster use of novel spatial analytics methods by sponsoring a GIS student presentation at the NAACCR conference.

Expected Outcomes: Central registry spatial analysis capacity is increased.

Timeline: 1-3 years

Goal 4: Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public.

Objective 1: Maintain and systematically evaluate updates to the existing certification process for population-based registries with a focus on using certification to help drive data quality, timeliness, and completeness.

Responsible Parties Data Evaluation and Certification Committee

Key Strategies:

1. Continue to examine and refine the NAACCR completeness estimate and explore alternative methods for estimating completeness for Canadian territories.
2. Use results from the Call for Data quality assessment to inform possible modifications to the certification criteria.
3. Obtain membership feedback and publicize intention to expand certification criteria prior to implementing new criteria.

Expected Outcomes: Improved data quality and completeness and a sound certification methodology.

Timeline: Continuous over 5 years

Objective 2: Improve the timeliness of registry data by requesting incidence data submission at 12 months after the end of the diagnosis year.

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees

Key Strategies:

1. Plan, organize and implement 12 month incidence Call for Data.
2. Assess quality of data.
3. Create a high quality "fitness for use" category in certification.

Expected Outcomes: High quality 12-month incidence data are available.

Timeline: 2 years

Objective 3: Establish "fitness for use" guidelines to improve data quality/completeness for specific purposes such as cancer control, survival, outcomes evaluation, comparative effectiveness research, and spatial analysis.

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees

Key Strategies:

1. Identify and assess fitness for use measures pertaining to stage, treatment, survival and other data needed for specific purposes.
2. Test measures against NAACCR Call for Data datasets to determine current distributions.
3. Obtain member feedback regarding proposed measures and revise as needed.
4. Incorporate "fitness for use" metrics in *EDITS* as applicable.
5. Publish "fitness for use" guidelines for Cancer in North America (CINA hereafter) data sets to inform researchers.

Expected Outcomes: Research value of CINA data sets is improved.

Timeline: 2 - 3 years to establish and then continuous over 5 years

Objective 4: Foster increased collaboration between Central Cancer Registries, reporting facilities, and local tumor registrar associations by identifying ways in which Central Cancer Registries can be of service to reporting facilities.

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees

Key Strategies:

1. Assess needs of reporting facilities and local tumor registrars for reports, services or other ways in which Central Cancer Registries might be helpful.
2. Develop, organize and provide templates that might address needs on NAACCR website.
3. Continue the NAACCR Process Improvement Program.
4. Highlight success stories and model programs on NAACCR website.

Expected Outcomes: Relationships with reporting facilities and local tumor registrar's associations are improved.

Timeline: 1-3 years

Objective 5: Identify the hallmarks of registries with high quality/complete/timely data, and develop best practice guidelines based on identified measures.

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees

Key Strategies:

1. Develop criteria for determining the best-performing registries for different functions.
2. Determine factors that are the most critical to success for each function.
3. Provide information on proposed best practices as developed through NAACCR's website.

Expected Outcomes: Best practice guidelines for key registry functions provided on NAACCR website. Adoption of best practices across central registries is expanded.

Timeline: 2 - 3 years; will follow completion of objectives 2 and 3 (12 month data and fitness for use.)

Objective 6: Develop software tools for use by central cancer registries that will generate comprehensive data assessment reports that registries can use to periodically evaluate the quality and completeness of their data.

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees, Data Assessment Work Group

Key Strategies:

1. Identify, review, and evaluate the tools/reports currently available through SEER, NPCR, Commission on Cancer (CoC hereafter), and central registries.
2. Develop specifications for desired content components; metrics for each type of profile; appropriate benchmark or target values for each metric; programming language and desired format.
3. Share specifications with NAACCR membership to obtain additional feedback.
4. Revise specifications, beta test and make tools available to registries.

Expected Outcomes: Registries use these tools to correct data before submission. Quality of submitted data is improved.

Timeline: 2 years; start date to be determined by available funding

Priority Area: Research and Data Use

Rationale: The SWOT analysis indicated that NAACCR members believe that the expanded use of data for research, cancer prevention and control, and clinical outcomes is important. The need to improve access to pooled data across states and provinces for research was recognized by key leaders in the SWOT analysis as a critical strategic direction for NAACCR. Canadian members also voiced strong support for making data more user-friendly for the cancer control community, emphasizing the need to improve data-driven outcomes and expand the use of metrics in general. In addition, there was a clear recognition that post marketing surveillance is an emerging area that might offer opportunities for central registries to work with a larger pool of partners, including pharmaceutical and biotechnology companies. As research methodologies are changing, the development and use of data will also have to change to make the fullest possible contribution to North America's future research agenda 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, and surveillance.

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

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees and CINA Editorial Subcommittee

Key Strategies:

1. Review all CINA products annually to evaluate if consumer needs are being met, including the need for additional data elements and completeness of data.
2. Revise and update all CINA products based on findings. Initiate expansion of CINA publication to include selected stage, survival and treatment information.
3. Encourage analytical assessments of stage, treatment, and survival/vital status data using CINA Deluxe and incorporate data quality findings into considerations for future publications and advise to researchers.
4. Explore the possibility of developing state and province-specific cancer control profiles and evaluation measures, using population-based data.

Expected Outcomes: CINA and CINA Deluxe are continuously timely and comprehensive.

Timeline: Ongoing with first changes in 1-2 years

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

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees

Key Strategies:

1. Evaluate legal and liability issues.
2. Identify ways to reduce IRB burden and barriers.
3. Develop the methodology for creating the datasets for linkage including encrypted and enhanced publically available data.
4. Develop a secure process using unique identifiers to provide linked data to researchers through a neutral third party.
5. Test, evaluate and revise process as needed.

6. Consider a fee-based service to research community.

Expected Outcomes: Increased number of multi-state linkage studies.

Timeline: 4 - 5 years

Objective 3: Facilitate the development and availability of state and province-specific relative survival data.

Responsible Parties: Survival Analysis Work Group of the Data Use and Research Committee and the SMOs.

Key Strategies:

1. Develop "fitness for use" criteria for aggregating survival data from multiple state and provincial registries.
2. Identify *EDITs* for variables related to survival and resource needs related for robust survival analyses.
3. Work with SMOs to obtain state and province-specific life-tables.
4. Generate state and province-specific 5-year relative survival estimates by race, gender, and cancer site for inclusion in the CINA annual report.

Expected Outcomes: Cancer survival estimates on a wider population than are currently available will be provided by NAACCR.

Timeline: 4-5 years

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

Responsible Parties: Data Use and Research Committee

Key Strategies:

1. Work with researchers and experienced central registries to identify key data elements and limitations, critical data access requirements and best communication practices.
2. Develop a web-based communication portal on the NAACCR website for the above information with query capabilities for researchers.
3. Establish a mechanism for registries to update registry-specific information and set a requirement to review on an annual basis.

Expected Outcomes: Increased access to registry data, a more thorough understanding of strengths, weaknesses and appropriate uses of registry data are provided.

Timeline: 1-2 years

Objective 5: Increase accessibility to NAACCR's Cancer in North America (CINA) products by periodically evaluating data access policies and processes.

Responsible Parties: Data Use and Research Committee

Key Strategies:

1. Review and revise current data request and registry consent procedures to identify improvements and streamlining.
2. Pilot test the proposed templates, review form and information sheet.
3. Revise and implement documentation.

4. Develop an online tool for proposal submissions and communication between applicants and reviewers.
5. Develop a comprehensive plan for disseminating information regarding CINA data request procedures to NAACCR members and the broader cancer surveillance and research community.

Expected Outcomes: Timelier processing of data requests; and an increase in the number of data requests occur. Registries and researchers will use the data more and promote importance of cancer registry data for cancer prevention and control.

Timeline: 2-3 years

Objective 6: Strengthen NAACCR's internal capacity to support research activities.

Responsible Parties: Board and Executive Director

Key Strategies:

1. Assess current staffing capacity to meet research work demands.
2. Based on findings, make staffing recommendations.
3. Identify and procure funding for any required new staff.

Expected Outcomes: Facilitation of more research activities using central registry data occurs. Interface with scientific community on ongoing basis is strengthened. Improved procedures for data use and research are in place.

Timeline: 1-2 years

Priority Area 4: Communications and Policy Development

Rationale: The SWOT analysis and member survey indicated a strong need for NAACCR to develop and strengthen its communications and policy programs. Specifically, internal communication systems should expand rapidly into social marketing arenas and should include more survey and consensus building activities. Opportunities to capture member opinions and perspectives in order to share information with the broader cancer surveillance community were recommended as a way of bringing a greater awareness of NAACCR member interests to wider audiences. As an association representing the interests of central cancer registries, NAACCR needs to 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.

Responsible Parties: Communications Committee and NAACCR staff

Key Strategies:

1. Plan and implement surveys, polls, and focus groups on key issues for central cancer registries.
2. Create on-going member feedback loops and other web-based communications mechanisms, such as electronic suggestion boxes for on-going membership input.
3. Promote active and frequent input into issues of concern at meetings, through email, and other web access.

4. Identify a process to share findings and information with members and key stakeholders.

Expected Outcomes: Member concerns are voiced and shared with NAACCR and key stakeholders within the cancer surveillance community. Improved member morale occurs.

Timeline: 1-2 years

Objective 2: Develop position papers and policy statements, as appropriate, that support registries, cancer surveillance, and the NAACCR mission.

Responsible Parties: NAACCR Board

Key Strategies:

1. Develop procedures and guidelines for NAACCR policy activities at national levels.
2. Identify key policy concerns and issues affecting central registries.
3. Form ad hoc working groups to assess and develop NAACCR policy statements and position papers on an as needed basis.
4. Use membership feedback loops and surveys to determine support. Provide policies on website and as requested.

Expected Outcomes: Policy statements for key issues involving central registries are available.

Timeline: Ongoing

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

Responsible Parties: NAACCR Board, appropriate key committees depending upon issue and membership.

Key Strategies:

1. Identify and collaborate with key organizations in cancer and surveillance communities to partner with NAACCR on important issues of concern to members.
2. Share NAACCR policy and position statements with partners and through website, FaceBook and twitter.
3. Offer expert comment on key policy issues of concern to central registries as needed.

Expected Outcomes: NAACCR's policies and positions used to help guide national course of action.

Timeline: 1 - 3 years

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

Objective 1: Develop a resource on the NAACCR website where members may post informational items that may be of value to other NAACCR members.

Responsible Parties: NAACCR staff, NAACCR members

Key Strategies:

1. Develop a web-page for sharing innovative ideas, tools, suggested efficiencies, and helpful hints for members by members.
2. Encourage members to share tools and make suggestions for the web-page.

Expected Outcomes: Innovations are shared easily among members. Communication among members is improved.

Timeline: < 1 year

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.

Responsible Parties: NAACCR staff, NAACCR members

Key Strategies:

1. Develop a web-page or blog for requests for help by members.
2. Promote member responses to all requests for help.
3. Encourage members to participate in exchanging ideas and solutions.

Expected Outcomes: Members get help from each other. Communication among members is improved.

Timeline: < 1 year

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.

Responsible Parties: NAACCR staff

Key Strategies:

1. Identify tools to facilitate rapid, accessible and effective delivery of information through internet listservs, web postings, and mechanisms such as "FaceBook" and Twitter, among others as appropriate.
2. Encourage members to participate in new forms of communication.

Expected Outcomes: Greater use of NAACCR website enhances member communication.

Timeline: Ongoing

Priority Area 5: Professional Development

Rationale: The cancer arena is changing as new technologies and advances in fundamental research inform the thinking and practices of the clinical and surveillance communities. Developments in computer-based technologies, genomics, bioinformatics, and molecular epidemiology are combining to push for change in the way registries function. New skill development will be necessary and will require extensive technical training in the immediate future.

In addition, demographics point to a generation gap between experienced and younger registry professionals across North America. The SWOT analysis indicated that recruitment/retention problems with younger workers are increasing for most central registries. In a similar vein, assuring that a strong pool of future leaders is available for central registries means that training in management, leadership, and strategic thinking is a priority for the SMP as laid out here. It appears that workforce issues for the surveillance community are substantial and go beyond the scope of any single agency to resolve. NAACCR needs to work collaboratively with other key agencies to address this serious concern. The ultimate goal of this management plan is to sustain a NAACCR that is equipped in every reasonable logistic and strategic respect to meet whatever the demands, to exploit whatever the possibilities, the future presents.

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

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.

Responsible Parties: Education Committee, SMOs, partners

Key Strategies:

1. Identify and partner with key organizations with a vested interest in retention of personnel working in cancer surveillance.
2. Examine opportunities to build career ladders within central cancer registries.
3. Encourage cross-training of personnel.

Expected Outcomes: Partnerships with other organizations are initiated and strategies are identified to enhance career opportunities for central registry personnel.

Timeline: 2 years

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

Responsible Parties: Education Committee, SMO's, partners

Key Strategies:

1. Identify and partner with key organizations with a vested interest in recruitment of personnel working in cancer surveillance.
2. Explore related fields to see if joint ventures or collaborative approaches might be adapted for central registry personnel.
3. Identify innovative ways of attracting new people into the cancer surveillance field, such as internships, flexible work hours, and retraining programs.

Expected Outcomes: Partnerships with other organizations are initiated.

Timeline: 2 years

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.

Responsible Parties: Education Committee, with area specific workgroups such as IT.

Key Strategies:

1. Continue webinar series, Central Tumor Registry prep workshops, and the annual conference, including pre-and post-conference workshops.
2. Identify, plan, and implement new workshops/webinars in areas of interest to members.

Expected Outcomes: Education and training of members continues.

Timeline: Ongoing

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.

Responsible Parties: Education Committee with support from IT and other

Key Strategies:

1. Identify training available in database management, information security, health information exchange/transfer, knowledge of cancer reporting requirements, reporting sources, file formats, coding schemas, and business needs.
2. Determine best method to disseminate IT training, in-person workshops, live and/or recorded webinars, on-demand electronic training modules.

Expected Outcomes: IT and other related skills improved among members.

Timeline: 2 years

Objective 3: Create a comprehensive training program, including 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.

Responsible Parties: New workgroup required

Key Strategies:

1. Define core competencies required to manage central cancer registries.
2. Inventory teaching tools/courses/syllabi already existing among the surveillance community members.
3. Develop a syllabus for a possible certification program for management level central registry staff.

Expected Outcomes: Core competencies and leadership skills are improved among members.

Timeline: 1 year for planning and 2-4 years for implementation

Strategic Management Plan: Conclusions

In a rapidly changing environment with significant challenges and opportunities, to stand still is to fall behind. To succeed in such an environment calls for its own combination of retaining core values and embracing compatible new strategies that neutralize the challenges and exploit the opportunities. Recognizing this state of affairs, NAACCR and its members have undergone a systematic, year-long process of strategic planning that has left no stone unturned in the effort to assure a NAACCR that is stronger now, after this journey, than it was before. During the process, core values were revisited and confirmed, internal and external challenges to the institution were measured, and the range of opportunities was carefully assessed. The result is that now, as it ventures into this brave new world around it, NAACCR has both compass and map to negotiate its future with even greater success.

NAACCR Strategic Management Plan 2011-2016

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.

Goal 1: Prepare for the cancer surveillance system of the future

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

Standardization & Registry Development

Goal 3: Facilitate sharing of technical resources & tools.

Goal 4: Increase the value and relevancy of central registries to the cancer control community, clinicians, researchers and the public.

Goal: Strengthen relationships with Sponsoring Member Organizations and existing partners, while establishing new alliances with key organizations.

Strategic Alliances

NAACCR
North American Association of Central Cancer Registries

Research & Data Use

Goal: Develop efficient, centralized processes to improve access to cancer registry data for cancer linkages, research and surveillance.

Goal 1: Serve as the voice for NAACCR members.

Goal 2: Promote the sharing of expertise, knowledge, procedures, and best practices among NAACCR .

Communication & Policy

Professional Development

Goal 1: Partner with other professional organizations to address recruitment and retention

Goal 2: Develop a comprehensive training program for professional personnel in NAACCR to excel in the changing cancer surveillance environment.

NAACCR: Working Together to make every cancer count.