The North American Association of Central Cancer Registries (NAACCR) is highly regarded for its history and tradition of innovation and forward thinking. Working with key partners, it has brought uniformity and standards to cancer surveillance in a singularly progressive approach to disease reporting, developed innovative methods for aggregating high-quality data, and implemented a registry certification program that has ultimately improved cancer surveillance data in North America. Its contributions to cancer surveillance are without question.

Rapid advances in science are now bringing new challenges to cancer surveillance, much as they are doing for the entire cancer and health informatics arenas. NAACCR’s continued success in the face of these challenges will depend in large measure on its ability to carry on its innovative and collaborative approaches.

As recent experiences with the Collaborative Staging conversion have shown, central cancer registries are at a crossroads that may require new roles, definitions, collaborations and an enhanced responsiveness to a dynamic environment. In recognition of the changing environment and the potential for new initiatives, the NAACCR Board engaged Applied Ethics Enterprises LLC (AEE, Red Bank, NJ) to assist the association in reviewing its current status and developing its first comprehensive five-year Strategic Management Plan. AEE will work with the Board and membership to produce a comprehensive, consensus-driven, five-year strategic management plan that acknowledges these new demands and positions NAACCR to advance its mission.

In recognition of the closely-knit and dedicated membership base, as well as the essential collaborative role of the supporting agencies, The Board requested that ongoing progress and updates be communicated on a regular basis. This document summarizes activities through October 2010.

 INITIAL PROCESS

At the NAACCR annual meeting in Quebec City Canada in June 2010, six focus groups were convened, and ten expert interviews were conducted with key representatives of Sponsoring Member Organizations (SMO). Insights into current attitudes and perceptions about the roles and functions of NAACCR were gathered and future directions explored. Each focus group represented a specific category of members and leaders. Following the June meeting, the NAACCR staff was interviewed.
Summarizing the results of the focus groups and interviews involved a process called “SWOT” analysis, assessing the Strengths, Weaknesses, Opportunities and Threats to NAACCR. This analysis is by nature subjective and qualitative, reflecting “a snapshot in time”, which may be sensitive to recent events and fluctuating circumstances. Nonetheless, the analysis can reveal an organizational baseline of internal and external factors important to strategic planning. The focus groups rely upon key agenda items, but participants are free to raise additional issues for discussion. Throughout the process, participants are encouraged to be candid and open. It is important to approach the SWOT as an auditing tool to help the organization move forward in the future.

❖ **Strengths and Opportunities**

“NAACR members are its strength.”

The analysis demonstrates considerable energy, presence in the field, and dedication to the future of the organization. NAACR’s role as a dynamic trend-setter, educator and facilitator of essential collaboration among data organizations and researchers was clearly acknowledged. NAACCR was unanimously viewed as a critical “forum” for consensus building and problem-solving, and the “honest broker” in cancer surveillance. Workgroups have provided significant contributions by providing technical expertise and handling complex and demanding problems. Most important was the recognition of NAACCR’s unique role in developing and maintaining standardization and uniformity within the cancer surveillance community. The dedication and cohesiveness of the “grass roots” members are testimony to the strength of the organization. Members have an unparalleled understanding of, and technical expertise in, the collection, management, and use of data.

These strengths led inevitably to the identification of NAACCR to take a prominent role in responding to emerging needs including 1) rapid developments in science that are leading to more targeted approaches to diagnosis and treatment 2) a focus on automation and new IT technologies and 3) new and innovative approaches for data use. Bolstered by NAACCR’s record of past achievement, and the dedication of volunteers and staff, participants viewed the organization as well positioned to overcome perceived obstacles and continue as a leader in the collaborative venture that is cancer surveillance.

❖ **Weaknesses and Threats**

“It’s not clear whether NAACCR will be a leader or an adopter in the future. It’s a critical question to ask ourselves.”

At the same time, the participants highlighted some important challenges. While historically a collaborative enterprise, NAACCR appears to have less authority than some of its peers. Some participants felt that NAACCR should adopt a more proactive position on certain issues. Furthermore, concerns about the need for NAACCR to obtain new sources of funding and
additional resources were voiced. Respondents felt that greater financial support for much needed staff and expanded initiatives is essential for any future growth. Participants raised concerns over what they described as a prevailing “safe and accustomed” attitude among members even when faced with necessary change. Finally, recognition of the need to promote interest in recruiting, retaining and responding to younger colleagues in the field was viewed as essential.

Internally, NAACCR is a mature organization that, like any comparable organization at this stage in its history, would benefit from a critical self-assessment and review of its governance. New membership recruitment, leadership development, and succession planning were recommended. The addition of more IT expertise and a greater understanding of clinical biomarkers among membership were viewed as critical. Openness to new and accelerating demands for smart technologies to improve consolidation, data streaming and multi-level data linkages was deemed essential.

**FUTURE DIRECTIONS**

“We should build change into our processes and NAACCR is the key for planning and guidance.”

The need for a significant shift in thinking in certain areas was apparent: Specific strategic directions that were suggested included:

- Enhancing and redefining the collaborative relationship with Sponsoring Members Organizations and other major stakeholders;
- Promoting and developing a new generation of leadership among members including identifying new incentives to make the field more attractive to young people;
- Becoming more open to innovative partnerships and gaining expertise in new technologies;
- Retooling the valued certification process to increase relevance to the registries and partnership members;
- Expanding sources for additional funding, including exploring new growth opportunities;
- Adopting new and efficient project management approaches;
- Integrating automation and smart technologies throughout systems;
- Balancing the needs of smaller registries, and needs of partners, with the demands of the marketplace for more technologically advanced methodologies.
“NAACCR’s success, going forward, will require an even greater commitment by the members to this unique and remarkable organization.”

The expectation is that the strategic planning process will be fully completed within the next nine - twelve months. A specific and detailed course of action has been identified which will include: refining the organizational assessment; incorporating strategic thinking; and assuring broad consensus. A Strategic Planning Oversight Committee composed of experienced NAACCR leaders has been established. Their mandate is to provide critical guidance, direction and leadership for the Five Year strategic management planning initiative.

In addition, during the next several months, AEE will conduct a continuous market research analysis and investigate growth opportunities. A management assessment of internal capacities and resources will be undertaken. Alternative funding sources and new business prospects will be explored.

The Strategic Planning process will provide abundant opportunities for membership input and inclusion. An online survey of members will be dedicated to securing opinions on key issues and insights into major trends in order to reach consensus. In addition, participation from relevant stakeholders, including IT experts, clinicians and cancer control professionals, will help to promote a comprehensive examination of the most effective future direction for NAACCR.

Its undeniable success to date is attributable to the unfailing belief in NAACCR by its members. It goes without saying that at this critical juncture, NAACCR’s success, going forward, will require an even greater commitment by the members to this unique and remarkable organization.

OVERSIGHT COMMITTEE MEMBERS

| Chair: Maria J. Schymura, PhD | Maureen MacIntyre, BSN, MHSA |
| Vivien W. Chen, PhD | Jill A. MacKinnon, PhD, CTR |
| Dennis Deapen, DrPH | Les Mery, MSc |
| Mignon Dryden, CTR | Lori Swain, BA, MS |
| Eric B. Durbin, MS | Kevin C. Ward, PhD, MPH |
| Betsy A. Kohler, MPH, CTR | John L. Young Jr., DrPH, CTR |
| NAACCR Staff: Charlie Blackburn, MBA | AEE Staff: Ann Marie Hill, MBA |
NAACCR SWOT ANALYSIS

**STRENGTHS**
- Membership is devoted and supportive.
- Workgroups bring technical expertise, problem solving skills and extensive knowledge of registries.
- Diverse and open membership unites shared knowledge and encourages innovation.
- Standardization & uniformity unique among surveillance community.
- Certification is valued.
- NAACCR is the voice of registry community.
- North American perspective brings benefits.
- NAACCR is a facilitator of change/honest broker.

**WEAKNESSES**
- Ability to influence key decision makers & partners sometimes limited.
- Too much reliance on funding from standard setters.
- Culture & values lead to old thinking & hinder necessary change.
- More vision and less focus on operations are needed to meet future challenges.
- New generation of leaders need to be recruited.
- More IT and clinical expertise needed to move forward.
- Staffing & resources limited given responsibilities.

**OPPORTUNITIES**
- Develop and implement a rational system that adapts to rapid changes and advances in science.
- Develop and implement an electronic reporting system that incorporates automation and efficiencies across all processes.
- Implement change management systems to address cultural stagnation.
- Expand data use opportunities to grow business & add products.
- Expand and enhance strategic partnerships including standard setters and SMOs.

**THREATS**
- Registry culture is safe and linear. It resists change.
- No coordinated governance among standard setters exists.
- Generation gap among experienced and new members exists.
- Younger workforce not interested in careers in the cancer surveillance field.
- Registries vary in skill and capacity making major process changes difficult.

The table above is a composite of all NAACCR focus groups and expert interviews held between 6/1/2010 – 8/01/2010 in Quebec, Canada and Springfield, Illinois.