2014 Annual Business Meeting

Ottawa, Ontario

Tuesday, June 24, 2014

Meeting Highlights

- Meeting Agenda
- Committee Reports
- Fiscal Status

2014 Business Meeting Agenda

1. Call to Order, President's Welcome, and Report (pg.1) — Jill MacKinnon
    a. Call for New Business from the Membership

2. **ACTION: Approval of Minutes From 2013 Meeting** (pg.2) — Jill MacKinnon

3. Election Results and Destruction of Ballots (pg.4) — Bobbi Matt
    a. **ACTION: Destruction of Ballots**

4. Highlights and Accomplishments — Betsy Kohler

5. Progress on Strategic Management Plan (pg.5) — Jill MacKinnon

6. Steering Committee Updates and Committee Reports (pg.9) — Committee Chairs

7. Chair Recognition — Jill MacKinnon

8. Outgoing Board Member Recognition — Jill MacKinnon

9. Financial Status Report
    a. Balance Sheet as of 2/28/14 (pg.24) — Susan Gershman
    b. Financial Trends as of 2013 Audit (pg.25) — Susan Gershman
    c. Presentation of Support of All Kinds 2013-2014 (pg.28) — Susan Gershman

10. Nominations for Nominating Committee — Jill MacKinnon
    a. Nominating Committee 2014-2015
    b. **ACTION: Appoint Nominating Committee Chair**

11. Items from the Floor — Jill MacKinnon

12. Adjournment — Jill MacKinnon

Appendix of Documents

- Registry Certification (pg.31)
- Bylaws (pg.34)
- Standing Rules (pg.42)
- Organizational Charts (pg.46)
- NAACCR Executive Office Contact List (pg.49)

NAACCR Annual Business Meeting Minutes

Austin, Texas, United States
June 12, 2013

1. **Call to Order, President's Welcome, and Report** — **Maureen MacIntyre**
   Written materials were offered to those attending as they entered the meeting. A quorum was determined by a count of the attending voting delegates. The meeting was brought to order at 2:43 PM local time. A Call for New Business from the Membership was made but no new business was brought forward.

2. **Approval of Minutes From 2012 Meeting** — **Maureen MacIntyre**
   The minutes from the 2012 Annual Conference could be found on page 3 of the agenda. A motion was made to approve the minutes. One delegate abstained but the motion was carried by a majority vote.

3. **Election Results and Destruction of Ballots** — **Dennis Deapen**
   Dennis Deapen, the chair of the 2012-2013 Nominating Committee, presented the results of this year's election. Susan Gershman was re-elected as the Treasurer. Three new Representatives-at-Large were elected: Eric Durbin of the Kentucky Cancer Registry, Winny Roshala of the Cancer Registry of Greater California, and Chuck Wiggins of the New Mexico Tumor Registry.
   a. **ACTION: Destruction of Ballots**
      A movement was made and seconded to destroy the ballots. None were opposed and the motion was carried. The ballots were destroyed.

4. **Highlights and Accomplishments** — **Betsy Kohler**
   Betsy highlighted several accomplishments of the organization from the past year.

5. **Status of Committee Restructuring and Progress on Strategic Management Plan (verbal)** — **Maureen MacIntyre**
   Maureen described several of the steps that were taken to move the restructuring forward and outlined the required steps still to be taken in the process. These include evaluation, focus groups, and creating a feedback loop. The organization intends to keep the plan dynamic to grow with its continually-changing needs.

6. **Steering Committee Updates and Committee Reports** — **Committee Chairs**
   The committee reports could be found in the agenda on page 6. Several Steering Committee and work group chairs gave brief overviews of their groups' activities throughout the year.

7. **Chair Recognition** — **Maureen MacIntyre**
   All chairs of current and previous committees were recognized by the board. The organization wishes to thank all of the leaders of previous and current groups as we move forward with our transition to a new structure.

8. **Financial Status Report**
   a. **Balance Sheet as of 2/28/13** — **Susan Gershman**
      Susan Gershman, Treasurer, reviewed several highlights of the NAACCR balance sheet, which could be found in the agenda on page 24.

   b. **Financial Trends as of 2012 Audit** — **Susan Gershman**
      More information about the financial trends of the organization could be found in the agenda on pages 25-27.

   c. **Presentation of Support of All Kinds 2012-2013** — **Susan Gershman**

Susan presented a list of organizations which provided major support to the organization in 2012 and 2013. This list could be found on pages 28 and 29 of the agenda.

9. Nominations for Nominating Committee

a. Nominating Committee 2013-2014 **Maureen MacIntyre**

Maureen called for nominations from the floor for the 2013-2014 Nominating Committee. The following individuals were nominated and accepted: Susan-Bolick, Nancy Lozan, Heather Stewart-Panko, Bobbi Matt, Dennis Deapen, and Tina Clarke. An election was held to elect the four members of the committee. The four elected were: Susan Bolick, Dennis Deapen, Tina Clarke, and Bobbi Matt.

b. Appoint Nominating Committee Chair **Maureen MacIntyre**

Maureen appointed Dennis Deapen as the chair and he agreed to serve in this role.

10. New Items from the Floor **Maureen MacIntyre**

Maureen asked if any additional items were to be discussed from the floor and none were brought forward.

11. Adjournment **Maureen MacIntyre**

The meeting was adjourned at 3:28 PM local time.

Election Results: 2014

The NAACCR elections were held in the spring of 2014. Open seats included President-Elect, two Representative-at-Large positions, and the Sponsoring Member Organizations Representative.

President-Elect is Charles Wiggins, PhD, from the New Mexico Tumor Registry.

The new Representatives-at-Large are Christopher Johnson, MPH, from the Cancer Data Registry of Idaho and Francis Boscoe, PhD, from the New York State Cancer Registry.

The new Sponsoring Member Organizations Representative is Lori Swain, BA, MS, from the National Cancer Registrars Association.

The Committee thanks all of the candidates who were nominated this year and the member registries for their participation.

ACTION REQUIRED FOR VOTE: The destruction of the ballots.

Strategic Management Plan Spring 2014 Update

What is the purpose of the Steering Committees?
The Steering Committees lead each of NAACCR's five priority areas - Strategic Alliances, Standardization & Registry Development, Research & Data Use, Communications, and Professional Development. To encourage related groups to work collaboratively and more effectively on cancer surveillance issues, existing groups were combined under each priority area to reduce duplication of effort and bring new focus and energy.

How do the Steering Committees function?
Steering Committees determine what additional structures such as work groups and task forces are needed under each priority area to ensure work is carried out. Additionally, each Steering Committee is supported by a priority area network or PAN of interested members to assure success in meeting Strategic Management Plan goals.

How have the Steering Committees progressed?
The following is an overview of their progress. Please click the Steering Committee name for additional information about the respective Steering Committees including a list of all active work/task groups. The table below is organized into Goals, Objectives and Activities as depicted below.

- **Goal**
  - ➢ Objective
    - **Activities**
    - ✓ Active/ongoing
    - ❖ Planned
    - • Complete

Standardization and Registry Development Steering Committee

- **Prepare for the cancer surveillance system of the future – a system that is more timely and adaptable to change.**
  - ➢ Explore how cancer surveillance systems will interface with electronic health records and continue to assess semantic interoperability issues.
    - ✓ **EHR Reporting and NAACCR Volume II Harmonization Task Force**
    - ✓ **Primary Payer Crosswalk Task Force**
  - ➢ Stay engaged/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.
    - ❖ **Health IT Advisory Group**
    - ✓ **Physicians Reporting WG**
  - ➢ Develop a vision and an action plan for the cancer surveillance community to prepare for the cancer surveillance system of the future. The vision and plan should address registry operations, data standards, and data use needs for cancer surveillance in the next ten years.
    - ✓ **Cancer Surveillance of the Future Task Force**

- **Provide consensus standards and best practices for the collection and processing of cancer and patient information.**
  - ➢ 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.
    - ✓ **EDITS Work Group**
    - • **Volume V Supplement Task Force**
    - ✓ **UDS Work Group**
  - ➢ 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.

- ✓ Discharge Data Best Practices Task Force
- ✓ Registry Operations Advisory Group (ROAG)

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

- ✓ Death Clearance Task Force

➢ Facilitate automation of record consolidation by developing general principles and consolidation guidelines.

- ❖ Data Item Consolidation Task Force

- **Provide opportunities for mentorship in cancer registry operations to strengthen cancer registries and their personnel throughout North America.**

➢ 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

Research and Data Use Steering Committee

- **Develop efficient, centralized processes to improve access to North American population-based cancer registry data for cancer linkages, research and surveillance.**

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

- ✓ CINA Call for Data WG
- ✓ CINA Editorial WG

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

- ✓ Virtual Pooled Linkage Task Force (in progress)

➢ Facilitate the development and availability of state and province-specific relative survival data.

- ✓ Survival Analysis Task Force

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

- ✓ RDU Steering Committee
- ✓ Research Webinar WG
- ✓ Journal Club

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

- ✓ Research Application Review WG
- ✓ Data Quality Profile Templates TF (complete)

- **Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public.**

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

- ❖ Registry Certification Work Group

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

- ❖ 12 Month Data Task Force

➢ 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.

- ✓ Fitness for Use Task Force (July 2014)

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

- ✓ Data Analysis Handbook for Researchers
- ✓ Comprehensive Cancer Control Score Card Task Force

- **Facilitate sharing of technical resources and tools among NAACCR member organizations.**

- 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.
  - ✓ **2010 Census Data Task Force**
  - ✓ **NAACCR Geocoder WG (ongoing)**
  - ✓ **Census Tract Poverty Evaluation TF (complete)**

Communications Steering Committee

- Serve as the voice for NAACCR members on key issues involving central cancer registries.
- Use modern methods such as internet-based technologies to capture and share member views, opinions, and perspectives on important registry issues.
  - ✓ **Social Media WG**
- Develop position papers and policy statements, as appropriate, that support registries, cancer surveillance, and the NAACCR mission.
  - ✓ **News releases**
  - ✓ **NAACCR post conference workshops**
  - ✓ **NAACCR explainer (promotional) web video (Early 2014)**
  - ✓ **Draft proposal for the development of an overall communication plan**
- Serve as the voice for NAACCR members on key issues involving central cancer registries
  - ✓ **The Narrative WG**
- Promote the sharing of expertise, knowledge, procedures, and best practices among NAACCR members to ensure efficiency and reduce redundancy of effort.
- Develop a resource on the NAACCR website where members may post informational items that may be of value to other NAACCR members.
  - ✓ **Update NetLink as necessary**
- 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
  - ❖ **Develop an informational resource on the NAACCR website**
- Move NAACCR's use of web-based and technology-driven communication systems forward to improve information sharing, and promote adoption of best practices.
  - ✓ **Social media contest at NAACCR Annual meeting**
  - ✓ **Review/update NAACCR website**

Professional Development Steering Committee

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

- **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.**
  - Continue to provide educational venues to assist development of registry personnel in scientific, operational, technological, management, and data use issues.
    - ✓ **CTR-based webinars**
    - ✓ **Pre conference workshops**
    - ✓ **Surveillance webinars**

❖ **Develop comprehensive training plan**

- 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.
- 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.

Strategic Alliances Steering Committee

- **Strengthen relationships with SMOs and existing partners, while establishing new alliances with key organizations to promote the NAACCR mission.**
  - Cultivate productive working relationships with SMOs by facilitating open communications and purposeful actions.
  - Enhance existing relationships and build new strategic alliances that benefit cancer registries and support the NAACCR mission.

NAACCR
North American Association of Central Cancer Registries

Committee / Group Annual Report

Report Type: Steering Committee **Report Period or Year:** 2013-2014

Name (Steering/Standing Committee, Subcommittee, Workgroup, etc.): Communications Steering Committee
Parent Committee (if Subcommittee, Workgroup, or Task Force Report):
Chair Name: Roberta Koscielny **Co-Chair Name:** Annette Hurlbut

PURPOSE / GOALS

Develop and strengthen internal and external NAACCR communications and bring a greater awareness of NAACCR member interests to wider audiences.

ACHIEVEMENTS AND ACTIVITIES OVER THE PAST YEAR

The Communications Steering Committee has maintained its membership and continues to be a vibrant voice for NAACCR members and a sounding board for NAACCR staff regarding communication initiatives.

The Narrative Working Group, led by Annette Hurlbut, Elekta Impac Software, regularly engages WG members to work collaboratively and improve the reader experience through story/column ideas and format changes for The Narrative. An unflagging editor, Ms. Hurlbut was an invaluable asset during the new production procedures. Four quarterly issues have been produced this year.

The Social Media Working Group, led by Dan Curran, C/NET Solutions of the Public Health Institute, has done a tremendous job of managing the organization's social media presence. To highlight social media and to bolster user confidence and uptake, Mr. Curran developed and presented a how-to Twitter webinar this spring. It was very well attended. NAACCR intern Bhavika Kothary provided research support for the webinar and was also a presenter. The Social Media WG also now offers Twitter support (the "Twitter Reporter") to registries who want to share information but may not have access to the social media platform through their own agencies.

As well, both WGs work in partnership with NAACCR to develop content and move NAACCR's use of web-based and tech-driven communication systems forward.

The CSC worked cooperatively to write, edit and produce a web-based "explainer video" - an animated, professionally voiced video highlighting the organization's work for a public audience. The debut is planned for the 2014 annual conference.

The CSC organized and planned the annual NAACCR conference giveaway items. The Social Media Working Group also developed a campaign for members to promote the conference using social media. Additionally, CSC members will be attending the Communications booth along with NAACCR staff to interact with members, promote Twitter participation, and recruit writers and Narrative contributors.

FUTURE PLANS

The Communications Steering Committee started small and worked within the Committee to develop materials to promote the 2014 conference, including reaching out to other organizations to publicize the event. Now, the CSC aims to develop a communications plan framework to further promote NAACCR to internal and external audiences.

ACKNOWLEDGEMENTS

The Communications Steering Committee is an outstanding collection of energetic people dedicated to improving how NAACCR members communicate with each other and sharing the work the organization does with the world.

Definitely an amazing team!

Committee / Group Annual Report

Report Type: Steering Committee **Report Period or Year:** 2013-2014

Name (Steering/Standing Committee, Subcommittee, Workgroup, etc.): Professional Development Steering Committee
Parent Committee (if Subcommittee, Workgroup, or Task Force Report):
Chair Name: Deirdre Rogers **Co-Chair Name:**

PURPOSE / GOALS

Develop a Comprehensive Training Program to provide registry professionals with the knowledge and skills to operate a high quality cancer surveillance program.

ACHIEVEMENTS AND ACTIVITIES OVER THE PAST YEAR

Objective 1: Expand training modules using existing resources, volunteer member faculty and talks captured from the annual conference.
1. NAACCR Surveillance Webinars focus on methodological issues in cancer surveillance. The first installment, "Measuring the Burden of Cancer", was held on Wednesday, March 5th, 2014. It was conducted by Chuck Wiggins, Ph.D., Director and Principal Investigator for the New Mexico Tumor Registry.
2. The NAACCR Journal Club is presenting a series of webinars. The first meeting of the Journal club on Friday, February 21, 2014 was the presentation, "Investigating Suspected Cancer Clusters and Responding to Community Concerns", led by Dr. Lauren Lewis, M.D., M.P.H., from the Health Studies Branch at the CDC's National Center for Environmental Health.

Objective 2: Design and organize a comprehensive training curriculum that focuses on core professional skills, competencies and best practices for cancer surveillance professionals.
1. The PDSC is working on implementation of a comprehensive education and training plan for NAACCR that strengthens the professional development of its members and the cancer surveillance community overall. The plan includes core competency areas for cancer registry and surveillance. Task forces for each core competency area will be formed. Before forming the core competency task forces, the PDSC will develop an education and training outline for the data collection core competency area that can be used as a template for the task forces developing the other core competency plans. PDSC members are currently working on a spreadsheet to document education needed, resources available, and gaps in education for the data collection core competency. Once this process is done, task forces for other core competency areas will be formed.
2. Core Competency Areas for Central Cancer Registries
a. The Fundamentals of Surveillance
b. Data Collection
c. Quality Assurance
d. Data Management
e. IT/Databases
f. Statistics/Analysis/GIS
g. Education and Training
h. Communications
i. Management
3. Core competency area task forces will need to:
a. Determine the topics to include
b. Identify the audience
c. Identify basic, intermediate, and advanced skills for the topic areas
d. Identify and assess educational resources that are available for the topic areas
e. Identify educational gaps for the topic areas and how to address those.

FUTURE PLANS

Complete objectives 1 and 2.

Objective 3: Identify, assess and acquire training delivery platforms that support the comprehensive training program.
Status: Activity on this objective has been deferred to a future date, after objective 2 has been accomplished.

Objective 4: Identify outside funding resources to support the comprehensive training program through planning and implementation stages of development.
Status: Activity on this objective has been deferred to a future date, after objective 2 has been accomplished.

ACKNOWLEDGEMENTS

Professional Development Steering Committee members: Deirdre Rogers (chair), Michelle Esterly, Steve Peace, Kevin Ward, Melanie Williams; board of directors representatives - Frances Ross, Jill MacKinnon; NAACCR staff - Jim Hofferkamp, Betsy Kohler, Shannon Vann

Committee / Group Annual Report

Report Type: Steering Committee **Report Period or Year:** July 2013 - June014

Name (Steering/Standing Committee, Subcommittee, Workgroup, etc.): Research and Data Use Steering Committee
Parent Committee (if Subcommittee, Workgroup, or Task Force Report):
Chair Name: Hannah Weir **Co-Chair Name:** Frank Boscoe

PURPOSE / GOALS

The Research and Data Use Steering Committee help co-ordinate the work of various work groups and task forces facilitating and promoting the use of NAACCR member data.

ACHIEVEMENTS AND ACTIVITIES OVER THE PAST YEAR

1. CINA Call for Data WG: CINA published online May, 2014
2. Virtual Pooled Linkage TF: conducted test linkage with Idaho and cohort study
3. Survival Analysis TF: several members contributed paper to a survival monograph to be published in the Journal of the National Cancer Institute.
   "Evaluation of NAACCR Cancer in North America Data for Use in Population-Based Cancer Survival Studies." Weir, Johnson, et al.
   "The Impact of State-Specific Life Tables on Relative Survival" – Stroup, Cho, Scoppa, Weir, Mariotto
4. 5 publications shared within RDU PAN, posted on NetLink:
5 Web-based, query system for researchers implemented on NAACCR website.
6. Research Webinar WG: 5/5/2014: "Measuring the Burden of Cancer"
7. 3 Journal Club: 2/21/14: Investigating suspected cancer clusters and responding to community concerns; 4/11/14: Twenty five year follow-up for breast cancer incidence and mortality of the Canadian National Breast Screening Study: randomized screening trial.; 4/15/14: Annual report to the Nation Status of Cancer 1975-2010, featuring prevalence of comorbidity and impact on survival among \ persons with lung, colorectal, breast, or prostate cancer
8. Research Application Review WG: 3 applications for CINA Deluxe reviewed, all materials updated.
9. Provided standard area-based SES measures from ACS by tract data via GIS Resource page. Provided updated FIPS codes for US Census 2010 for call for data edits\
10. Census Tract Poverty Evaluation TF: paper published by Boscoe et al. Cancer 2014.
11. 2000 Census Tract TF: provided standard area-based SES measures from ACS by tract data via GIS Resource page and povided updated FIPS codes for US Census 2010 for call for data edits

FUTURE PLANS

New Activities:

12 Month Data TF: improve the timeliness of registry data by requesting incidence data submission at 12 months after the end of the diagnosis year. (Frank Boscoe)

Case completeness TF: to investigate methods for ascertaining completeness in Hispanic populations (Kevin Ward)

Comprehensive Cancer Control Score Card TF: to compile cancer control indicators (Recinda Sherman)
Evaluation of Consent Process WG: to look at ways that certain kinds of consent could be moved from "active" (Maria Schymura)

Data Analysis Handbook for Researchers TF: develop a handbook (Recinda Sherman)

ACKNOWLEDGEMENTS

CINA Call-for-data and Editorial WG: Glenn Copeland
Virtual Pooled Linkage TF: Dennis Deapen
Research Webinar WG: Chuck Wiggens
Research Application Review WG: Xiaocheng Wu
Scientific Editorial Board WG: Myles Cockburn
Survival Analysis TF: co-chairs Chris Johnson Deb Hurley
Data Quality Profile Templates TF: Kevin Henry
NAACCR staff: Jim Hoffenkamp, Recinda sherman

				DQP templates for use by registries		registries (complete)

Priority Area 3: Research and Data Use (continued)	Priority Level[1] (S or L) (I or W)	Responsible Working Group(s) or Task Force(s)[2]	Working Group or Task Force Lead	Expected Deliverables	Progress to Date by major task	Timeline for completion
Goal 1: Develop efficient, centralized processes to improve access to North American population-based cancer registry data for cancer linkages, research and surveillance.						
Objective 6: Strengthen NAACCR's internal capacity to support research activities.	N/A for RDU	BOARD/NAACCR Responsibility	N/A for RDU	N/A for RDU	N/A for RDU	N/A for RDU
Goal 2: Facilitate sharing of technical resources and tools among NAACCR member organizations (From Priority Area 2: Standardization and Registry Development, Goal 3) ----NEW R&DU GOAL BASED ON PREVIOUSLY IDENTIFIED OBJECTIVES FROM S&RD GOAL----						

[1] Short Term (S) or Long Term (L) and Important Need (I) or Less Important Want (W) – As defined at the Miami Meeting (Jan 2013) or updated since Miami Meeting

[2] Also indicate if working collaboratively with members of another Priority Area group

Objective 1: 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. ***[Formerly, Priority Area 2, Goal 3, Objective 3]***	S/I	2010 Census Data Task Force NAACCR Geocoder Work Group Census Tract Poverty	Recinda Sherman Dan Goldberg Frank Boscoe	Provide updated Census (decennially) and ACS data (annually) to GIS Resource Page; Provide technical assistance on census and ACS variables. Maintain the NAACCR geocoder	Provided standard area-based SES measures from ACS by tract data via GIS Resource page. Provided updated FIPS codes for US Census 2010 for call for data edits Ongoing Paper published:	On-going, annual Ongoing Complete

16

Priority Area 3: Research and Data Use (continued)	**Priority Level[1] (S or L) (I or W)**	**Responsible Working Group(s) or Task Force(s)[2]**	**Working Group or Task Force Lead**	**Expected Deliverables**	**Progress to Date by major task**	**Timeline for completion**
Goal 3: Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public. (Previously Priority Area 2, Goal #4 in Standardization and Registry Development. Moved to Research & Data Use at Miami Meeting). ----NEW R&DU GOAL BASED ON PREVIOUSLY IDENTIFIED OBJECTIVES FROM S&RD GOAL----						
Objective 1: Maintain and systematically evaluate updates to the existing certification process for population-based registries with a	S/I	Registry Certification Work Group	Kevin Ward		New TF lead identified June 2014, TF members will	Ongoing

[1] Short Term (S) or Long Term (L) and Important Need (I) or Less Important Want (W) – As defined at the Miami Meeting (Jan 2013) or updated since Miami Meeting

[2] Also indicate if working collaboratively with members of another Priority Area group

focus on using certification to help drive data quality, timeliness, and completeness.		Case Completeness Task Force			begin meeting June 2014.	
Objective 2: Improve the timeliness of registry data by requesting incidence data submission at 12 months after the end of the diagnosis year.	L/W	12 Month Data Task Force	Frank Boscoe	Assessment how recent 12 month delay compares with historical 23 month delay (i.e., the current 12 month delay may be comparable to the 23 month delay 10 years ago). Compare data from historic submissions – delay-adjustment or projections not needed.	None	Future RDU call, at which point we can decide where to go next

Priority Area 3: Research and Data Use (continued)	**Priority Level[1] (S or L) (I or W)**	**Responsible Working Group(s) or Task Force(s)[2]**	**Working Group or Task Force Lead**	**Expected Deliverables**	**Progress to Date by major task**	**Timeline for completion**
Goal 3: Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public. (Previously Priority Area 2, Goal #4 in Standardization and Registry Development. Moved to Research & Data Use at Miami Meeting). ----NEW R&DU GOAL BASED ON PREVIOUSLY IDENTIFIED OBJECTIVES FROM S&RD GOAL----						

[1] Short Term (S) or Long Term (L) and Important Need (I) or Less Important Want (W) – As defined at the Miami Meeting (Jan 2013) or updated since Miami Meeting

[2] Also indicate if working collaboratively with members of another Priority Area group

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.	S/W	Fitness for Use Task Force Survival Analysis Task Force	Brad Wohler Mei-Chin Hsieh Chris Johnson	Evaluating the data quality on the derived AJCC stage based on 6th and 7th edition Recommendations around use of NAACCR data in survival studies	Need update JNCI Publication (in Press): "Evaluation of NAACCR Cancer In North America Data for Use in Population-based Cancer Survival Studies" (Weir et al.)	 Complete

Priority Area 3: Research and Data Use (continued)	**Priority Level[1] (S or L) (I or W)**	**Responsible Working Group(s) or Task Force(s)[2]**	**Working Group or Task Force Lead**	**Expected Deliverables**	**Progress to Date by major task**	**Timeline for completion**
Goal 3: Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public. (Previously Priority Area 2, Goal #4 in Standardization and Registry Development. Moved to Research & Data Use at Miami Meeting). ----NEW R&DU GOAL BASED ON PREVIOUSLY IDENTIFIED OBJECTIVES FROM S&RD GOAL----						

[1] Short Term (S) or Long Term (L) and Important Need (I) or Less Important Want (W) – As defined at the Miami Meeting (Jan 2013) or updated since Miami Meeting

[2] Also indicate if working collaboratively with members of another Priority Area group

Objective 5: Identify the hallmarks of registries with high quality/complete/timely data, and develop best practice guidelines based on identified measures.	None	Collaboration between S&RD and R&DU Data Analysis Handbook for Researchers Task Force Comprehensive Cancer Control Score Card Task Force	SRD & RDU SC ?? ??	Coordinate activities of task forces/work groups Handbook for researchers Develop score card of cancer control related indicators	 Call for volunteers via PAN (no response) Obtaining CDC and Canadian representation, reviewing CPAC systems indicator reports	Ongoing

19

[1] Short Term (S) or Long Term (L) and Important Need (I) or Less Important Want (W) – As defined at the Miami Meeting (Jan 2013) or updated since Miami Meeting

[2] Also indicate if working collaboratively with members of another Priority Area group

Priority Area 3: Research and Data Use (continued)	**Priority Level[1] (S or L) (I or W)**	**Responsible Working Group(s) or Task Force(s)[2]**	**Working Group or Task Force Lead**	**Expected Deliverables**	**Progress to Date by major task**	**Timeline for completion**
Goal 3: Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public. (Previously Priority Area 2, Goal #4 in Standardization and Registry Development. Moved to Research & Data Use at Miami Meeting). ----NEW R&DU GOAL BASED ON PREVIOUSLY IDENTIFIED OBJECTIVES FROM S&RD GOAL----						
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.	N/A	IMS, RDU SC Charles Wiggins	Andy Lake Charles Wiggins	Currently registry managers get somewhat comprehensive reports from IMS when CINA editorial committee reviews registry data for inclusion in CINA.	Routine data evaluation reports submitted annually. C Wiggins shared NM cancer registry reports used to evaluate regional completeness. Will develop venue to invite registries to showcase special registry reports to share with NAACCR community.	Annually.

20

[1] Short Term (S) or Long Term (L) and Important Need (I) or Less Important Want (W) – As defined at the Miami Meeting (Jan 2013) or updated since Miami Meeting

[2] Also indicate if working collaboratively with members of another Priority Area group

Priority Area 3: Research and Data Use (continued)	Priority Level[1] (S or L) (I or W)	Responsible Working Group(s) or Task Force(s)[2]	Working Group or Task Force Lead	Expected Deliverables	Progress to Date by major task	Timeline for completion
Goal 4. Provide consensus standards and best practices for the collection and processing of cancer and patient information. (Previously Priority Area 2, Goal 2 in Standardization and Registry Development. Moved to Research & Data Use). ----NEW R&DU GOAL BASED ON PREVIOUSLY IDENTIFIED OBJECTIVES FROM S&RD GOAL----						
Objective 1: Update white papers on confidentiality to assure that confidentiality guidelines and standards reflect current best practice recommendation and emerging issues relevant to registries.	L/W	None	None	White paper	None	None

[1] Short Term (S) or Long Term (L) and Important Need (I) or Less Important Want (W) – As defined at the Miami Meeting (Jan 2013) or updated since Miami Meeting

[2] Also indicate if working collaboratively with members of another Priority Area group

Committee / Group Annual Report

Report Type: Steering Committee **Report Period or Year:** 2013-2014

Name (Steering/Standing Committee, Subcommittee, Workgroup, etc.)**:** Standardization & Registry Dvlpmt Steering Committee

Parent Committee (if Subcommittee, Workgroup, or Task Force Report)**:**

Chair Name: Dave Stinchcomb **Co-Chair Name:**

PURPOSE / GOALS

Monitor and guide NAACCR activities for the SMP Standardization & Registry Development priority area. The main SMP goals include preparing for the registry of the future, maintaining and enhancing NAACCR's standards and best practices, and sharing technical resources and tools.

ACHIEVEMENTS AND ACTIVITIES OVER THE PAST YEAR

Completed conversion to the new committee structure.

Helped registries prepared for the new Cancer Reporting element in the Stage 2 Meaningful Use through the activities of the Physician Reporting Work Group.

Completed Guidelines for ICD-O-3 Update Implementation (Effective January 1, 2014).

Assisted with Collaborative Staging transition planning by evaluating alternatives for SSF data structures.

Released Standards Volume V Supplement (January 2014).

Released Standards Volume V Summary Table for HL7 Version 2.3.1 (January 2014).

Released Standards Volume II Version 14 (Effective January 1, 2014).

Released Version 14 Edits Metafile.

Convened the EHR Reporting and Volume II Harmonization TF to evaluate the need for addition/revision of data elements in Standards Volume II as a result of the electronic health record reporting.

Finalizing the Discharge Data Best Practices.

Finalizing the Death Clearance Manual.

Finalizing the Data Item Consolidation document.

Submitted comments on national health IT issues for NAACCR.

FUTURE PLANS

Continue Stage 2 Meaningful Use implementation.

Monitor and prepare for Stage 3 Meaningful Use.

Continue to assist with the CS transition process.

Convene a group to articulate a clear vision for the Registry of the Future.

Pursue opportunities to implement a more robust data exchange format (XML).

Activate the Health IT Advisory Group.

ACKNOWLEDGEMENTS

The S&RD Steering Committee has been fortunate to have strong support and assistance from our two Board representatives: Eric Durbin and Winny Roshala, and three NAACCR staff members: Lori Havener, Jim Hofferkamp, and Shannon Vann.

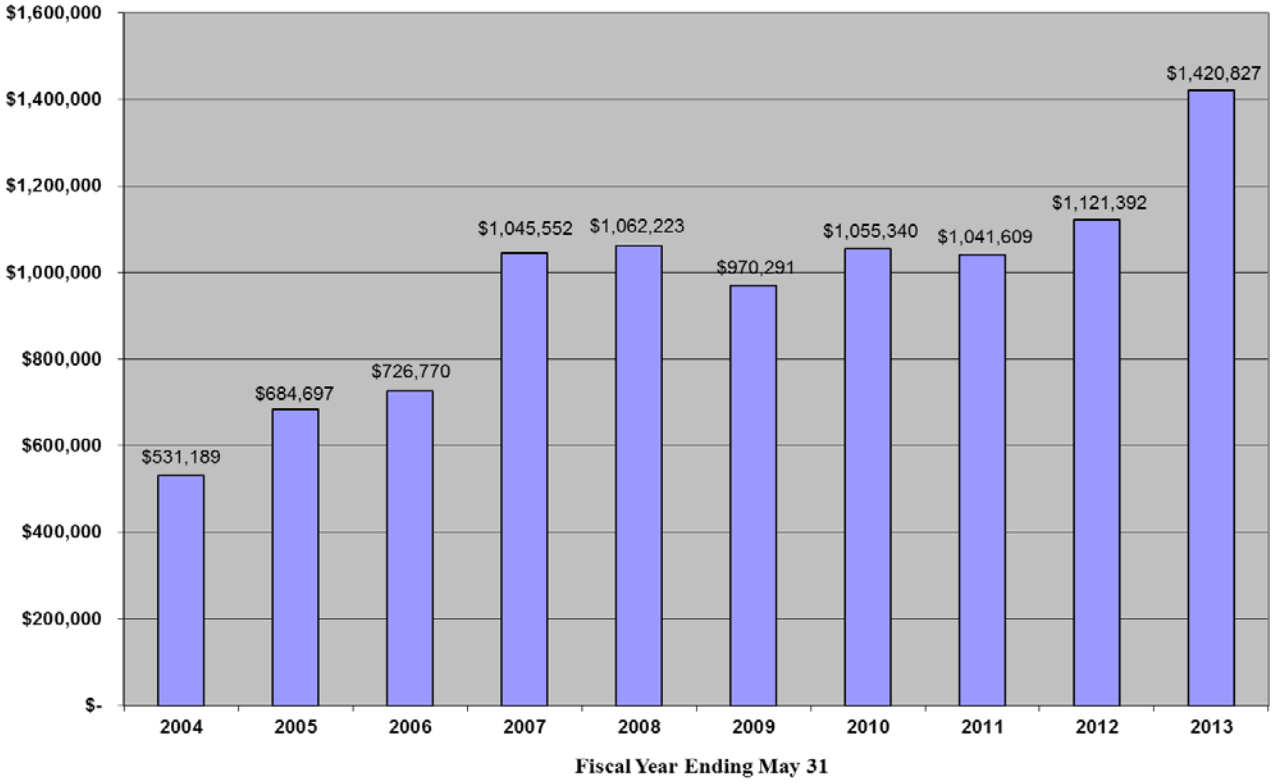
Financial Status Report and General Updates

NAACCR, Inc.

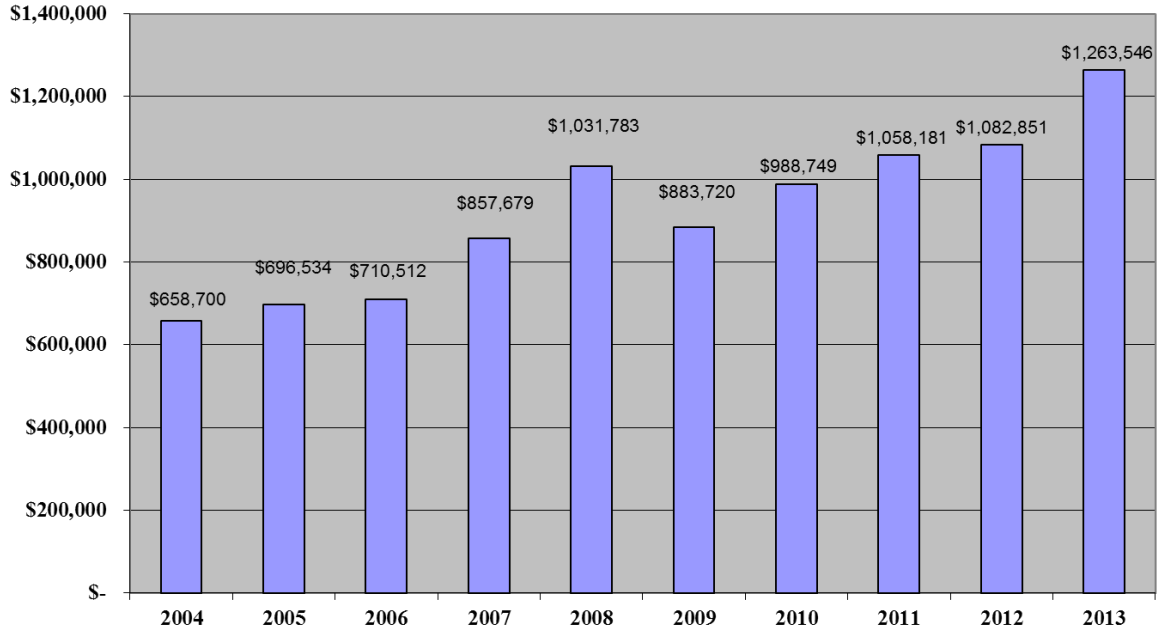
Balance Sheet
All Funds
As of February 28, 2014

		Previous Month	Current Month
Assets			
Cash			
	BOS Checking/Savings Account	387,007.14	405,593.17
	Flex Spending Account	1,865.85	5,829.99
Investments			
	Certificates of Deposit	211,758.25	211,758.25
	Merrill Lynch Portfolio	801,146.08	829,327.57
	Subtotal Cash & Investments	1,401,777.32	1,452,508.98
Receivables			
	Accounts Receivable	1,800.00	1,500.00
	Indirect Funds Receivable	47,265.81	34,398.68
	Grants Receivable	173,900.14	141,384.72
	Subtotal Receivables	222,965.95	177,283.40
Prepaids			
	Prepaid Insurance	6,326.44	6,326.44
	Other Prepaids	24,917.46	37,854.16
Other			
	Total Equipment	144,545.54	144,545.54
	Accumulated Depreciation	(133,692.91)	(134,474.39)
Total Assets		**1,666,839.80**	**1,684,044.13**
Liabilities			
Current			
	Accounts Payable	50,809.90	43,536.44
	Accrued Liabilities	74,677.91	73,087.21
	Deferred Revenue	216,361.78	221,900.18
Total Liabilities		**341,849.59**	**338,523.83**
Net Assets			
	Unrestricted Net Assets	1,258,701.88	1,258,701.88
	Temporarily Restricted Net Assets	4,552.50	4,552.50
	Change in Net Assets	61,735.83	82,265.92
Total Net Assets		**1,324,990.21**	**1,345,520.30**
Total Liabilities and Net Assets		**1,666,839.80**	**1,684,044.13**

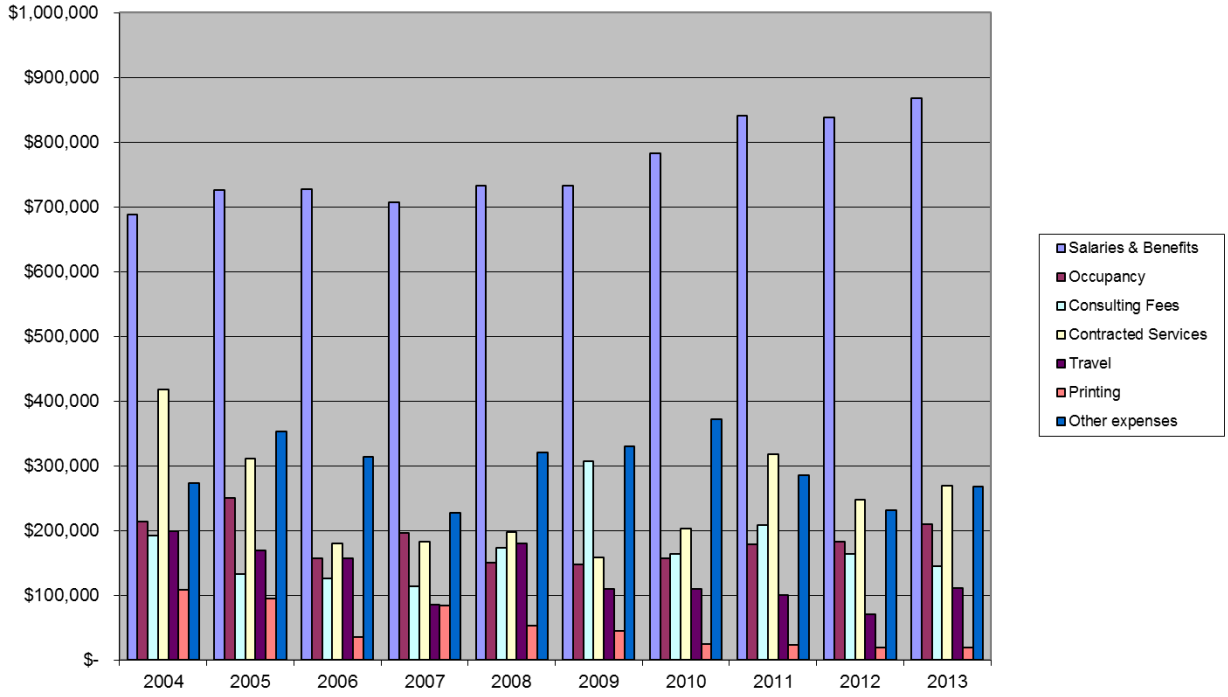
NAACCR
Cash and Investments



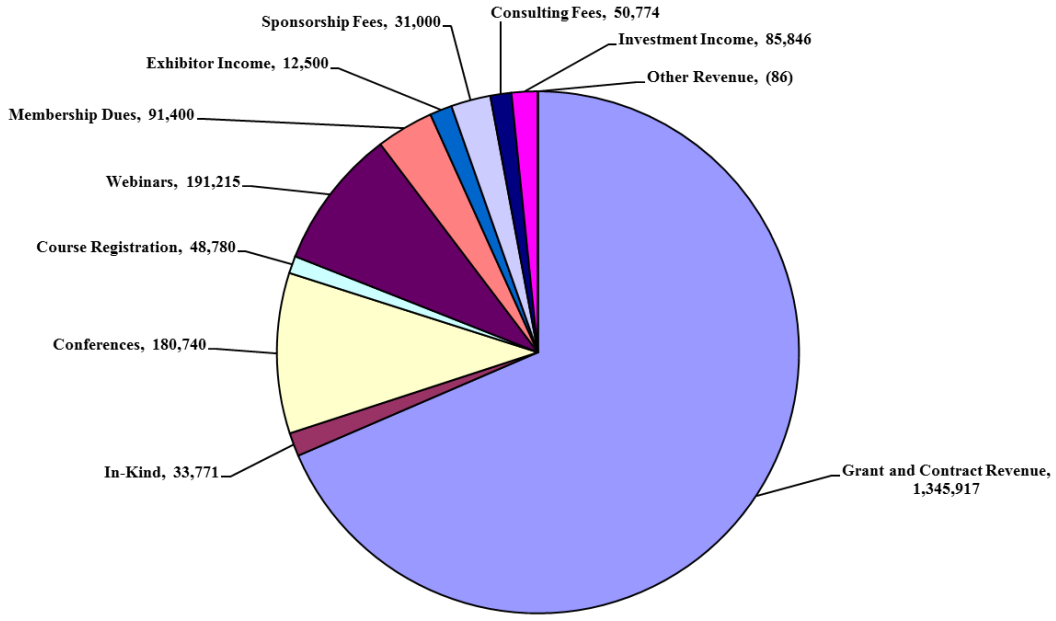
NAACCR
Net Assets

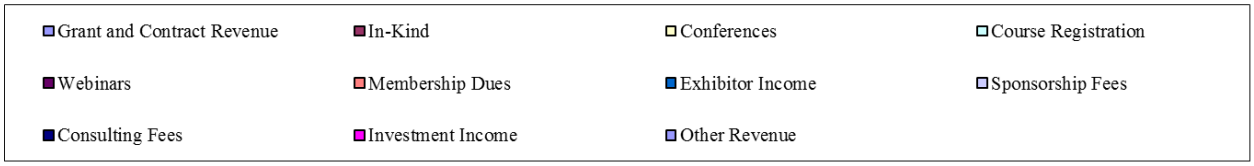


NAACCR
Expenditures

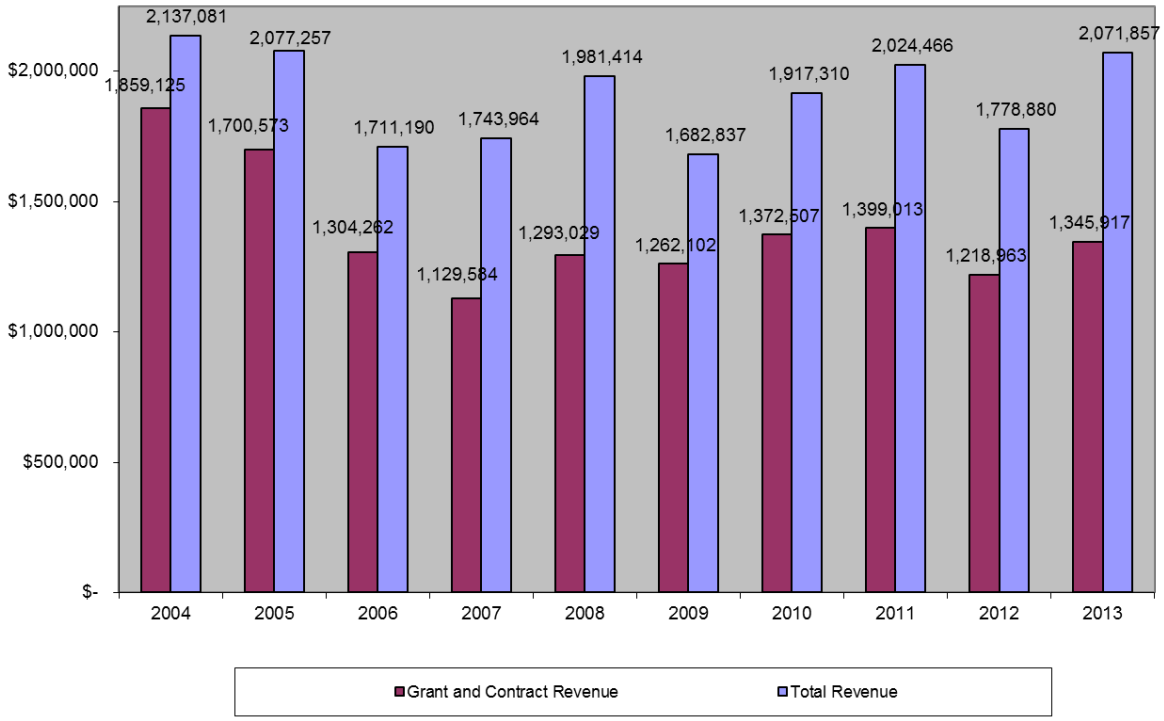


NAACCR
Revenue for the Year Ending May 31, 2013

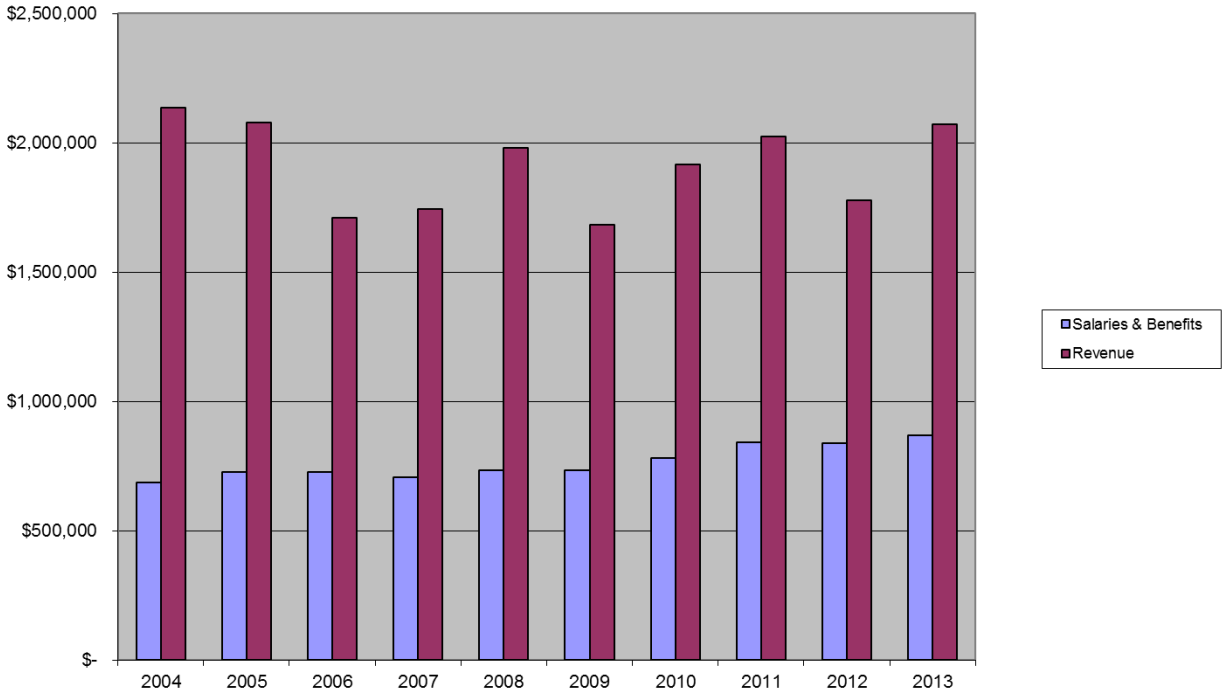




NAACCR
Grant & Contract Revenues vs Total Revenues



NAACCR
Total Revenue and Salaries Expense



Support of All Kinds

Support of All Kinds from Sponsoring Organizations for 2013-2014

American Cancer Society - ACS
- Sponsor with Distinction ($20,000) with dues
- Grant for Enhancing Cancer Registries for Research ($119,103 in Yr 1)
- Diamond Sponsor and Exhibitor at 2014 NAACCR & IACR Annual Conferences
- Phone bridge for teleconference calls
- Support to NAACCR Committees

American College of Surgeons - ACoS
- Sponsor with Distinction ($10,000) with dues
- Bronze sponsor of Annual Conference (CoC)
- Phone bridge for teleconference calls
- Support to NAACCR Committees

American Joint Committee on Cancer - AJCC
- Sponsor with Distinction ($10,000) with dues
- Support to NAACCR Committees

Canadian Cancer Registry
- Dues
- Support to NAACCR Committees

Canadian Partnership Against Cancer – CPAC
- Dues
- Diamond Sponsor and Exhibitor at 2014 NAACCR & IACR Annual Conferences
- Support to NAACCR Committees

Centers for Disease Control & Prevention - CDC
- Cooperative agreement to support NAACCR infrastructure ($379,998 in Yr 1)
- CDC phone bridge for conference calls. Assignment of three CDC teleconference bridge lines.
- Dues
- Support to NAACCR Committees

Continued On Next Page

College of American Pathologists - CAP

- Dues
- Support to NAACCR Committees

National Cancer Institute - NCI

- Contract for Technical Assistance for Cancer Surveillance (5-year $3.4 million)
- Conference grant to support the Annual Conference
- Phone bridge for teleconference calls of the Board and Program Committee
- Exhibitor at Annual Conference
- Dues
- Support to NAACCR Committees

National Cancer Registrars Association - NCRA

- Liaison support to several NAACCR committees
- Exhibitor at Annual Conference
- Dues
- Support to NAACCR Committees

Public Health Agency of Canada - PHAC

- Dues
- Support to NAACCR Committees

Appendix of Documents

Registry Certification

Gold

Alabama
Alaska
Greater California
California
Greater Bay
Colorado
Connecticut
Delaware
District Of Columbia
Florida
Georgia
Atlanta
Hawaii
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Detroit
Mississippi
Missouri
Montana

Nebraska
New Hampshire
New York
North Carolina
North Dakota
Oregon
Pennsylvania
Rhode Island
South Dakota
Tennessee
Utah
Vermont
Washington
Seattle
West Virginia
Wisconsin
Wyoming
Alberta
Manitoba
New Brunswick
Newfoundland and Labrador
Northwest Territory
Prince Edward Island
Saskatchewan
Yukon

Registry Certification

Silver

Arizona
Los Angeles
New Jersey
New Mexico
Ohio
Oklahoma
South Carolina
Texas
Virginia
British Columbia
Nova Scotia

North American Association of Central Cancer Registries, Inc. (NAACCR)

BYLAWS

ARTICLE I. Scope and Purpose

The North American Association of Central Cancer Registries, Inc. (NAACCR), the “Association” 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.

ARTICLE II. Membership

Section 1. Classification of Membership

The four classes of membership shall be:
A. Full: Full member organizations are central registries, which are, or have the potential to become, population-based registries.

B. Individual: Individual members are those persons who are not currently working in a member organization who have demonstrated career and professional commitments and interests that are consistent with or complementary to those of NAACCR. Candidates for Individual Membership must be able to demonstrate involvement or activity in one or more of the following areas: cancer epidemiology, patient care, cancer control, cancer registration, professional education, research, and biostatistics. Each candidate must make a commitment to support NAACCR through active participation in the activities of the Association. Individual members shall be entitled to participate and vote as a member of committees, subcommittees or work groups. Individual members may chair subcommittees or work groups. Individual members may not chair a committee, vote on matters brought before the Membership at the Annual Meeting, nor vote for or hold an elected position in the Association.

C. Sponsoring: Sponsoring member organizations are national professional or national governmental organizations primarily involved in any of the following areas: cancer epidemiology, patient care, cancer control, cancer registration, professional education, research, or biostatistics. Each sponsoring member organization shall be entitled to one vote on each matter submitted to membership vote. No action taken by the Association shall be construed as committing any sponsoring member organization to a prescribed course of action. Each sponsoring member organization may designate one or more representatives from such organization to participate in the Association's affairs on behalf of such organization. Representatives of sponsoring member

organizations may be a member of and chair a committee. Only one representative of a sponsoring member organization shall be entitled to cast that organization's vote.

D. Sustaining: Sustaining member organizations are organizations interested in promoting the purposes of the Association. No action taken by the Association shall be construed as committing any sustaining member organization to a prescribed course of action. Each sustaining member organization may designate one or more representatives from such organization to participate in the Association's affairs on behalf of such organization. Sustaining member organizations shall not be entitled to vote, and their representatives shall not be entitled to hold office. Representatives from sustaining member organizations may be a member of and chair a committee.

Section 2. Application for Membership

Application for membership shall be submitted in a manner prescribed by the Board of Directors.

Section 3. Resignation

Any member may resign by submitting a resignation in writing to the Executive Director.

Section 4. Application for Continuing Membership
Each member shall submit an application for continuing membership every three years. This application for continuing membership shall be submitted in a manner prescribed by the Board of Directors.

ARTICLE III. Officers

Section 1. Officers
The Officers of the Association shall be:

A. President
B. President-Elect
C. Six Representatives-at-Large
D. Sponsoring Member Representative
E. Treasurer
F. Immediate Past President

Section 2. Eligibility
An individual who has been a representative in the Association of a full member organization for one year prior to nomination shall be eligible to hold the following offices: President, President-Elect, Representative-at-Large, and Treasurer. To be eligible for the office of President-Elect, a representative must, prior to the election, have served for one year as a member of the Board of Directors or as a chair of a NAACCR committee. To be eligible for Representative-at-Large or Treasurer, an individual must, prior to the election, have served as a member of a NAACCR committee. One Sponsoring Member Representative from among the sponsoring member organizations shall be elected by the sponsoring member organizations to serve on the Board of Directors.

Section 3. Term of Office
The term of office for President, Representatives-at-Large, Sponsoring Member Representative, and Treasurer shall be two years or until a successor is elected. Individuals in these positions may serve a second consecutive two-year term, if re-elected, not to exceed a total of four consecutive years in the same position. The limit of four consecutive years may be exceeded when consecutive terms are served in different board positions. The term of office for President-Elect and Immediate Past President shall be one year. The Representatives-at-Large shall be elected on a rotating basis. Officers shall assume office at the conclusion of the Annual Meeting of the members at which they are elected.

Section 4. Vacancies
A. All vacancies, except the office of the President and the Sponsoring Member Representative, may be filled for the unexpired term by appointment by the President with the approval of the Board of Directors.

B. A vacancy in the office of President shall be filled for the remainder of the term of office by vote of the Board of Directors.

C. A vacancy in the office of the Sponsoring Member Representative shall be filled for the remainder of the term by a special vote of the Sponsoring Members.

D. A vacancy in the office of President-Elect shall be filled by a special election of the voting members. A vacancy occurring within sixty (60) days prior to assuming the Presidency shall be filled by a vote of the voting members at the next Annual Business Meeting.

Section 5. Nominations and Election
A. Subject to the approval of the Board of Directors, the Nominating Committee shall develop rules and regulations for the conduct of the nomination and election of officers.

B. Elections shall be by ballot. The Nominating Committee shall be responsible for the preparation of the ballot. The Executive Director, or his/her designee, shall mail the ballot pursuant to the rules and regulations of the Nominating Committee including reasonable deadlines for the return of ballots.

C. Election shall be decided by plurality vote of the votes cast. In case of a tie for any NAACCR Board position, a runoff election will be held. If there is a tie in the runoff election, the election will be determined by lot conducted by the Board of Directors.

D. Election of the Sponsoring Member Representative will be by special vote of the Sponsoring Members.

Section 6. Duties of Officers
A. President: The President shall function as the Chief Executive Officer of the Association. Unless specified otherwise, the President shall appoint all committee chairpersons. The President or his/her designee shall be a member, ex-officio, of each committee. The President's ex-officio status is without vote.

B. President-Elect: The President-Elect shall succeed to the office of President at the conclusion of his/her term of office. The President-Elect may appoint the Committee Chairpersons for his/her term of office prior to assuming the Office of President.

C. Representatives-at-Large: The Representatives-at-Large shall serve as primary liaison officers with cancer registries and facilitate the exchange of information and the organization of projects.

D. Sponsoring Member Representative: The Sponsoring Member Representative shall serve as primary liaison with sponsoring members to provide a formal mechanism for inter-organizational activities.

E. Treasurer: The Treasurer shall be responsible for overseeing the receipt and disbursement of all funds, establishing the budget for unrestricted funds, and managing all funds of NAACCR.

F. Immediate Past President: The Immediate Past President shall assist in the business of the Association.

ARTICLE IV. Meetings of the Membership

Section 1. Meetings
A. The Annual Business Meeting of the members of the Association shall be held in conjunction with the Annual Conference. The time and place of the meeting shall be determined by the Board of Directors.

B. Special meetings may be called by the Board of Directors.

Section 2. Notification
The official call and notice of any meeting shall be sent at least 30 days prior to the scheduled meeting, and shall include the agenda and a description of each matter requiring special consideration or action.

Section 3. Quorum
A quorum for any meeting of members shall be a majority of the members registered at the meeting. In the absence of a quorum, no action can be taken by the members at a called meeting .

Section 4. Action
A. Action by the members shall require the affirmative vote of a majority of the members entitled to vote who are present at a meeting at which a quorum has been established.

B. No action can be taken by the members at a special meeting except as to matters described in the notice of the special meeting.

C. When voting on general matters or as a member of a committee either as an NAACCR representative or a representative of another organization, members and NAACCR staff must recuse themselves from discussion and voting if the voting issue places them in a conflict of interest.

ARTICLE V. Board of Directors

Section 1. Composition
The Board of Directors shall be composed of the elected officers of the Association and the Executive Director.

Section 2. Duties
The Board of Directors shall:
A. Act for the Association between scheduled meetings of the membership, be responsible for the management of the business and professional affairs of the Association, and take other actions as required to implement the stated purposes of the Association.

B. Define the duties of the officers in a manner consistent with the Bylaws.

C. Create and dissolve committees.

Section 3. Meeting of the Board of Directors
A. The Board of Directors shall meet just prior to the Annual Business Meeting of the Association and at such times as deemed advisable during the year on call of the President and majority of the Board.

B. A quorum shall be a majority of the members of the Board of Directors.

C. Action by the Board of Directors shall be by resolution adopted by the affirmative vote of a majority of the members of the Board present at a meeting at which a quorum is present. Presence at a meeting may be in person or by telephone, provided that each member present is able to hear all other members present.

Section 4. Minutes and Notification of Action Taken
A. All action taken by the Board of Directors shall be recorded in the minutes of the Board.

B. Minutes of the Board of Directors shall be available to the membership of the Association upon request.

ARTICLE VI. Committees

Section 1. Committees
The Association will maintain a Nominating Committee. As deemed necessary, additional Committees may be created by the membership or Board of Directors to carry on the affairs of the Association. The composition, size, and duties of the committees shall be set forth in the Standing Rules.

Section 2. Eligibility
Any full, sponsoring, or sustaining member representative in good standing for one full year prior to appointment shall be eligible to be appointed as Chairperson of a Committee.

Section 3. Vacancies
Vacancies in committee chairs and presidential appointments shall be filled by appointment by the President. All other vacancies on a committee shall be filled by the Committee Chairperson.

ARTICLE VII. NAACCR Staff

Section 1. Executive Director
The Board may appoint an Executive Director who shall perform all duties as designated by the Board. The Executive Director shall serve on the Board of Directors as an ex officio member without vote. The Executive Director cannot hold office or chair a committee. The Executive Director may serve as a member of committees and may chair ad hoc committees, work groups, and subcommittees. The Executive Director, or his/her designee, shall be responsible for the preparation of a record of all proceedings, and for the general correspondence of the Association.

Section 2. Staff
A. NAACCR staff cannot hold office or chair a committee. They may serve as a member of committees and may chair ad hoc committees, work groups, and subcommittees.

B. The Staff will be responsible for the custody of the organizational records and of all proceedings of the Association.

ARTICLE VIII. Executive Office

Section 1. Organizational Records
The organizational records and proceedings of the Association will be located at the Executive Office.

Section 2. Office Location
The Executive Office will be designated by the Board.

ARTICLE IX. Financial Administration

Section 1. Fiscal Agent
The Board will designate the fiscal agent.

Section 2. Fiscal Year
The fiscal year of the Association shall be determined and established by the Board of Directors.

Section 3. Annual Dues
A. Annual dues shall be paid in the amounts determined and established by the Board of Directors.

B. Dues shall be payable by December 31st of each fiscal year.

C. Sponsoring Members provide fiscal support to the Association at a level and type (direct, in-kind, or combination) to be determined by the Board of Directors. Sponsoring members will define their type of fiscal commitment to the Treasurer on the first day of each fiscal year and will be declared delinquent if not defined by December 31st of each fiscal year.

Section 4. Audit
The financial records of the Association shall be audited each year in the manner determined and established by the Board of Directors.

ARTICLE X. Parliamentary Authority
The rules contained in the current edition of Robert's Rules of Order, Newly Revised, shall govern the Association in all cases to which they are applicable and in which they are consistent with these Bylaws, special rules of order, and any Standing Rules the Association may adopt.

ARTICLE XI. Amendment to the Bylaws

Section 1. Proposed Amendments
Amendment to these Bylaws may be proposed by the Board of Directors or any Committee. Any voting member may propose amendments provided such amendments are accompanied by written endorsement of at least five (5) additional voting members.

Section 2. Amendment Submissions(s)
Proposed amendments to these Bylaws shall be submitted in the prescribed form to the Chair of the Bylaws Committee at least ninety (90) days prior to the Annual Business Meeting.

Section 3. Voting on Amendments
A two-thirds (2/3) vote of the voting members present at the Annual Business Meeting of the Membership at which a quorum has been established shall be required to adopt any amendment. Unless stated otherwise, the amendments shall become effective upon adoption.

Section 4. Notification of Amendments to the Membership
A copy of the proposed amendments shall be sent to the voting members at least thirty (30) days prior to the Annual Business Meeting.

ARTICLE XII. Dissolution of the Association
Voluntary dissolution of the Association may be effective only by consent evidenced by written and signed ballots of three-fourths (3/4) of all voting members. Notice of the intent to dissolve the Association must be mailed to each voting member at least four (4) weeks prior to the date set for the ballots to be counted. Ballots for this purpose shall be enclosed with the notice of intent.

(Approved by vote of membership, Annual Conference 4/28/92)
(Amended by vote of membership, Annual Conference 4/93)
(Amended by vote of membership, Annual Conference 4/27/94)
(Amended by vote of membership, Annual Conference 4/20/95)
(Amended by vote of membership, Annual Conference 4/02/97)
(Amended by vote of membership, Annual Conference 4/22/98)
(Amended by vote of membership, Annual Conference 4/07/99)

(Amended by vote of membership, Annual Conference 4/19/00)
(Amended by vote of membership, Annual Conference 06/06/01)
(Amended by vote of membership, Annual Conference 06/12/02)
(Amended by vote of membership, Annual Conference 06/11/03)
(Amended by vote of membership, Annual Conference 06/08/05)
(Amended by vote of membership, Annual Conference 06/23/2010)
(Amended by vote of membership, Annual Conference 06/06/2012)

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES, INC. (NAACCR)

STANDING RULES

I. Standing Rules

A. Unless specified otherwise, the Board of Directors shall establish and amend the Standing Rules necessary to carry on the business of NAACCR.

B. The Board of Directors shall notify the membership of any changes to the Standing Rules in the official NAACCR publication following such changes. Standing Rules shall be published and made available to the membership.

C. Any Standing Rule adopted by the Board of Directors may be rescinded by a two-thirds (2/3) vote of the voting membership at an Annual Business Meeting.

D. All committee meetings of NAACCR held at the annual meeting are open for observation to all members of NAACCR.

II. Bylaws Committee

A. This committee shall consist of three (3) members. The President shall appoint one (1) of the three (3) members to act as the Chair. The President shall also appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

B. The committee receives and reviews all proposed amendments to the Bylaws. The committee shall be responsible for distributing proposed amendments to the membership at least thirty (30) days prior to action being taken at the annual business meeting.

III. Communications Committee

A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations, Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

B. The committee shall be responsible for the NAACCR newsletters, press releases, press conferences, and oversight and direction of the content of the NAACCR website.

IV. Data Evaluation and Certification [DEC] Committee

A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations, Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

B. The committee shall evaluate member data submissions on an annual basis and determine and evaluate parameters to identify and assess high quality data for various data uses, including objective certification standards.

V. Data Use and Research [DUR] Committee

A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations, Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

B. The committee shall gather, review, and consider data from member organizations for publication. Insofar as resources are available, the committee shall prepare a publication of cancer incidence and mortality data. It is responsible for identifying issues related to the release of various types of data by central cancer registries and providing recommendations and guidelines on these issues, including confidentiality; oversees the NAACCR Research Program; develops a research agenda for the organization; and conducts abstract review for the scientific program of the Annual Conference.

VI. Education Committee

A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

B. The committee shall determine the educational needs of the Association and shall propose methods of meeting those needs including but not limited to the offering of short-term training courses.

VII. Information and Technology Committee

A. This committee shall consist of a chair, one (1) representative from at least three (3) full

members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

B. The committee shall be responsible for developing the standard format for data exchange among members and for developing standards to ensure the security and accuracy of transmitted data.

VIII. Nominating Committee

A. The Nominating Committee shall consist of three (3) members nominated and elected by the voting Membership at the annual business meeting. The President shall appoint the Chair from the three elected candidates. The President also shall appoint a Board of Directors liaison to the committee. No member of this committee may designate an alternate with voting powers to participate in any meeting for which the appointed member is absent.

B. The Nominating Committee shall secure candidates for the office of President-Elect, Treasurer, and Representative-at-Large as appropriate, and shall prepare a ballot to be distributed to the membership. The committee shall receive the completed ballots, tally the votes, and present the results of the election to the membership at the annual business meeting. The Nominating Committee shall also secure candidates from the Sponsoring Member Organizations for the position of Sponsoring Member Organization Representative to the NAACCR Board of Directors, and prepares a ballot to be disseminated to the Sponsoring Member Organizations. The Nominating Committee shall receive the completed ballots, tally the votes, and present the results of the election to the Board of Directors.

IX. **Program Committee**

A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations. Each sponsoring organization shall appoint its representative. The President also shall appoint a Board of Directors liaison to the committee. The President shall appoint the Chair, who should be a member of the host registry for the Annual Conference. The standing committee should also include the previous year's chair, a representative of the host registry for the upcoming year, and a member from both the Education and Communications Committees. The President shall also appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

B. The committee shall be responsible for the program for the Annual Conference and working with the conference planner to set guidelines for meeting logistics and locations.

X. Registry Operations Committee

A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations, Each sponsoring organization shall appoint its representative. The President shall appoint the Chair

from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting..

B. The committee shall provide a forum for discussion of methodological issues as they apply to the policies, procedures and operations of a central cancer registry and shall provide suggested models and developing standards for the policies, procedures, and operations of central cancer registries. The committee shall facilitate the peer-to-peer exchange of information on methods, procedures, and policies among registries.

XI. Uniform Data Standards Committee

A. This committee shall consist of a chair, one (1) representative from at least three (3) full members, and one (1) representative from relevant sponsoring organizations, Each sponsoring organization shall appoint its representative. The President shall appoint the Chair from members of the organization. The President also shall appoint a Board of Directors liaison to the committee. Each committee representative is entitled to vote on committee actions. A committee representative, when unavailable or absent for any reason, may designate an alternate to participate in a committee meeting. The alternate may vote on any business conducted during this meeting.

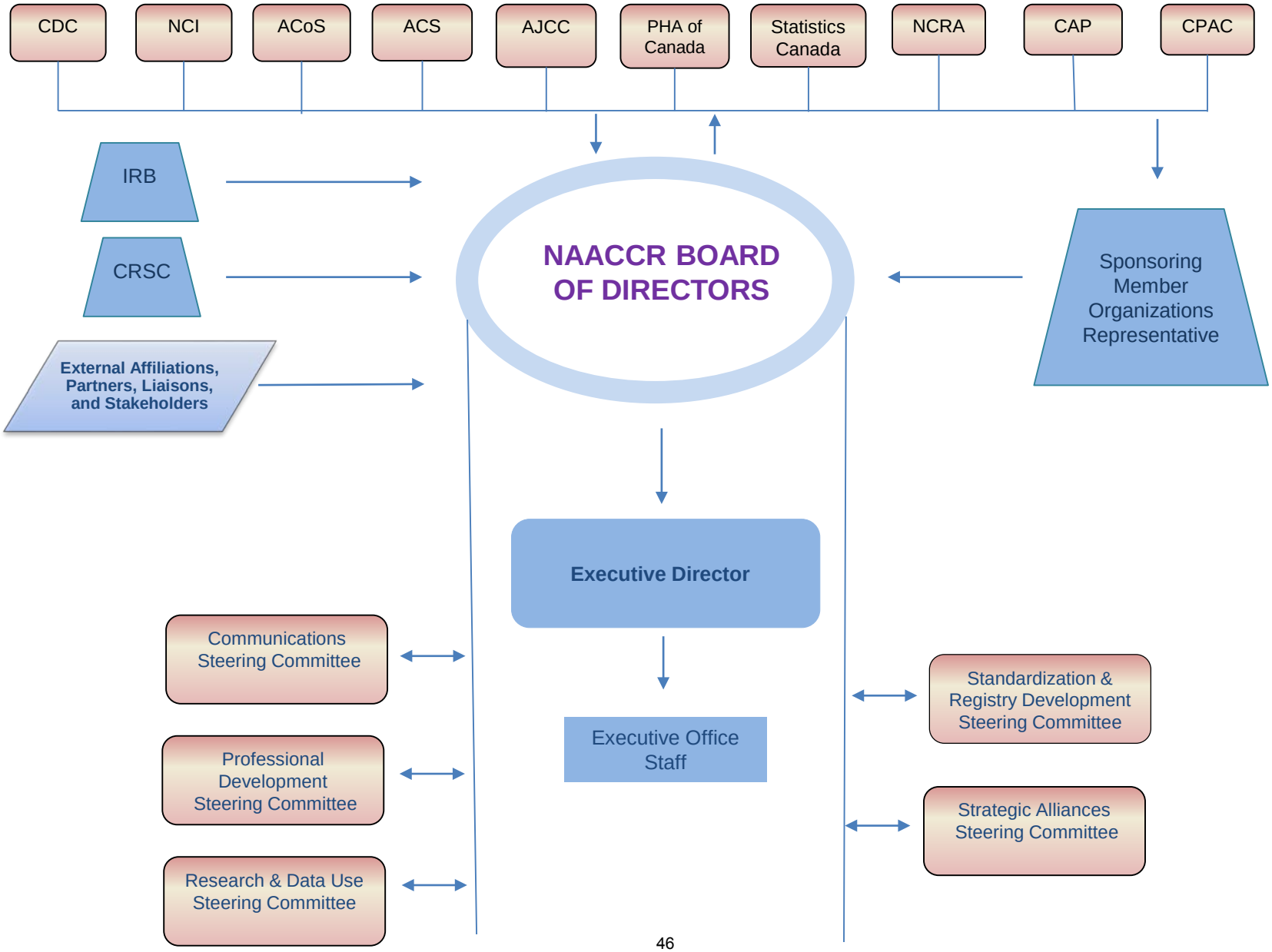
B. The Committee shall provide a formal mechanism to review and recommend proposed changes in data codes and/or the addition of new items submitted by NAACCR members to ensure that data remain comparable among central registries. Further, the committee shall provide a formal mechanism for reviewing and recommending edits of NAACCR approved data items.

XII. Fiscal Year

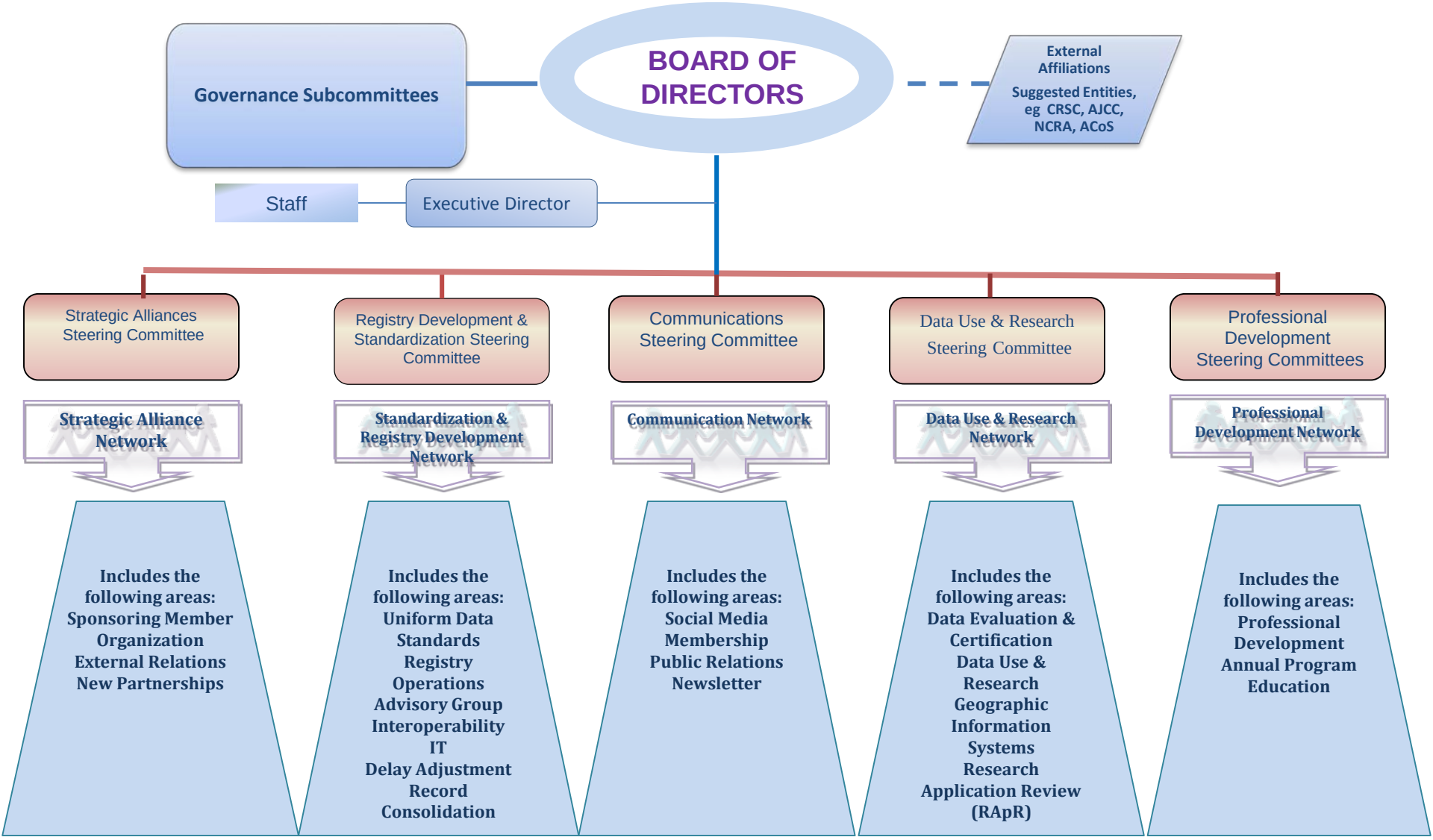
A. The Board of Directors sets the fiscal year.

Approved by Board: 5/15/96
Revised: 3/31/97
Revised: 6/5/97
Revised: 6/17/98
Revised 4/05/99
Revised 11/17/99
Revised 05/17/00
Revised 04/12/2002
Revised 06/09/2005
Revised 06/19/2011

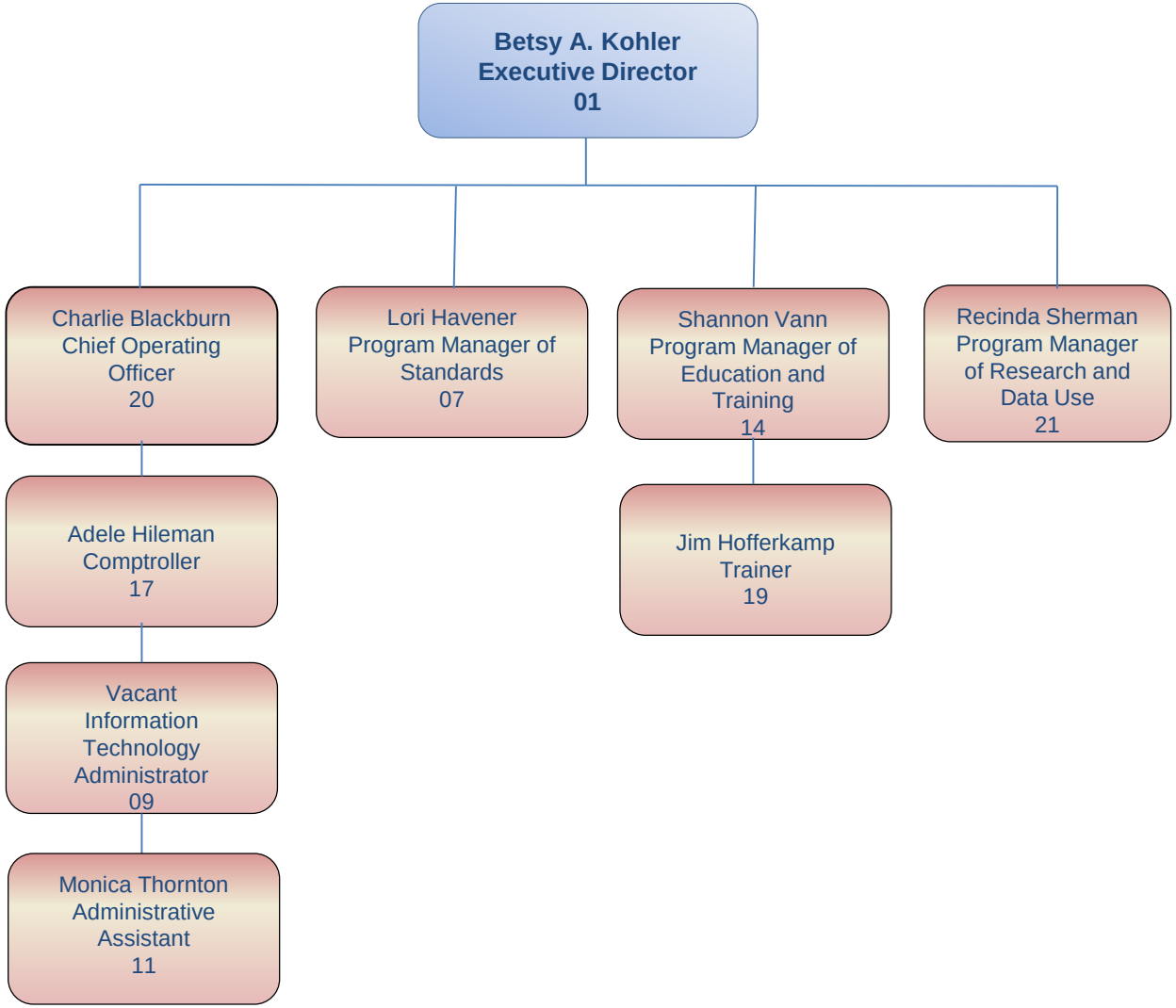
NAACCR Organizational Relationship 2013-2014



NAACCR Committee Organization Chart



NAACCR Executive Office Organizational Chart



2014 NAACCR Executive Office Staff Contact Information

Betsy Kohler, MPH, CTR
Executive Director
Phone: (217) 698-0800 ext. 2
E-Mail: bkohler@naaccr.org

Charlie Blackburn, MBA
Chief Operating Officer
Phone: (217) 698-0800 ext. 4
E-Mail: cblackburn@naaccr.org

Lori Havener, CTR
Program Manager of Standards
Phone: (217) 698-0800 ext. 3
E-Mail: lhavener@naaccr.org

Adele Hileman
Comptroller
Phone: (217) 698-0800 ext. 7
E-Mail: ahileman@naaccr.org

Jim Hofferkamp, BA, CTR
Trainer
Phone: (217) 698-0800 ext. 5
E-Mail: jhofferkamp@naaccr.org

Recinda Sherman, MPH, PhD, CTR
Manager of Data Use and Research
Phone: (217) 698-0800 ext. 6
E-Mail: rsherman@naaccr.org

Monica Thornton
Administrative Assistant
Phone: (217) 698-0800 ext. 1
E-Mail: mthornton@naaccr.org

Shannon Vann, CTR
Program Manager of Education and Training
Phone: (217) 698-0800 ext. 9
E-Mail: svann@naaccr.org