

**North American  
Association of Central  
Cancer Registries  
(NAACCR)**

Susan T. Gershman  
President

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**Outline**

- I. NAACCR Organizational Structure
- II. Data Standards
- III. Education and Training
- IV. Certification
- V. Data Use

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**I. NAACCR  
Organizational Structure**

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### NAACCR Mission

- 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.

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### NAACCR Membership Categories

- Full (Central Cancer Registries)
- Sponsoring
- Sustaining
- Individual

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### Sustaining Membership Category Benefits

- Having organization's name published in NAACCR's lists, such as the Membership Directory
- Receiving reduced registration rates to attend the Annual Conference
- Serving on NAACCR committees
- Receiving copies of NAACCR's standard reports, updated *Standard Volumes* and *Cancer Incidence in North America*
- Participating in the NAACCR Member Award Recognition Program

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## NAACCR Governance

- Board of Directors
  - President
  - President-Elect or Immediate Past President
  - Six Representatives-At-Large
  - Representative, Sponsoring Member Organizations
  - Treasurer
  - Executive Director (*ex officio*)



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## NAACCR Standing Committees

- Bylaws
- Communications
- Data Evaluation and Certification
- Data Use and Research
- Education
- Information and Technology
- Nominating
- Program
- Registry Operations
- Uniform Data Standards

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## Other NAACCR Committees

- *Ad Hoc* Committees
  - GIS
  - Interoperability
- Other Special Committees
  - Cancer Registration Steering Committee
  - Institutional Review Board
  - Scientific Editorial Board
- Liaisons
  - American College of Surgeons
  - American Joint Committee on Cancer

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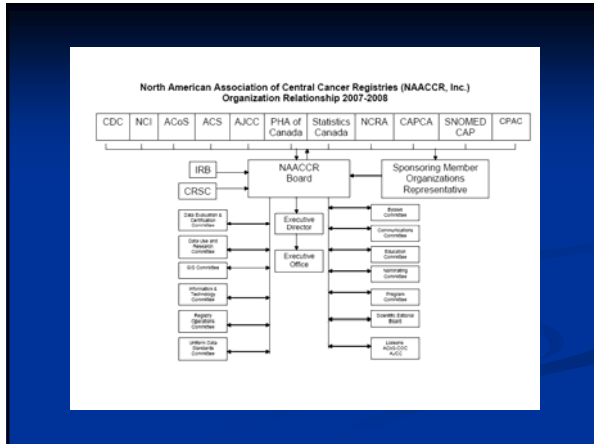
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## II. Data Standards

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- ### Data Standards
- Volume I: Data Exchange Standards and Record Description
  - Volume II: Data Standards and Data Dictionary
  - Volume III: Standards for Completeness, Quality, Analysis, and Management of Data
  - Volume IV: Pathology Laboratory Electronic Reporting

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# III. Education and Training

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## Education and Training

- Webinars (2008-2009)
  - Series subscription of 6, 9, or 12 webinars
  - Purchased by central registries, hospitals, etc.
  - Topic Areas
    - 6 site-specific
    - 3 coding and staging
    - 3 data use




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## New Webinar Series

- 10/2/2008 Collecting Cancer Data: Bladder
- 11/6/2008 Coding Pitfalls
- 12/4/2008 Collecting Cancer Data: Leukemia, Lymphoma, and Other Hematopoietic Malignancies
- 1/8/2009 Measuring and Minimizing the Disclosure Risk of a Cancer Data Public Use File
- 2/5/2009 Collecting Cancer Data: Pharynx
- 3/5/2009 Cancer Staging In-depth
- 4/2/2009 Collecting Cancer Data: Central Nervous System
- 5/7/2009 Using the National Death Index in Registry Mortality Ascertainment Activities
- 6/4/2009 Collecting Cancer Data: Prostate
- 7/9/2009 Advanced Coding & Abstracting
- 8/6/2009 Collecting Cancer Data: Breast
- 9/3/2009 Assessing and Using Cancer Data

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## Education and Training (cont.)

- CTR Exam Readiness Webinars (starts September 2008)
- Workshops at Annual Conference
  - Central Registries: Design, Management, and Use
  - SEER\*Stat and SEER\*Prep
  - Advanced Topics – Survival Analysis for Cancer Registry Personnel
  - Other special topics (Specialized Training for Trainers)
- Regional Workshops
- Targeted Institutes

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## Online Training Modules

- CDC-NPCR Fundamentals of Registry Operations CDs



- CDC-NPCR How to Collect High Quality Data Cancer Surveillance Webinars

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## Other Training

- **Mentor Fellowship Program** – provides an opportunity for one-on-one training with a mentor in a specific central cancer registry operation.
- **Process Improvement Program** – provides state and local tumor registrar associations, as well as other groups of cancer registry professionals, with the resources to include a process improvement workshop as part of their annual meeting. The workshops are designed to be a 1/2-day meeting to enhance data quality through improved collaboration and communication between central registries and local cancer registrars/reporters.

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## IV. Certification

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### NAACCR Certification

- Completeness of reporting
- Completeness of information recorded
- Percent death certificate only
- Percent duplicate cases
- Passing abbreviated version of the NAACCR edits
- Timeliness of reporting



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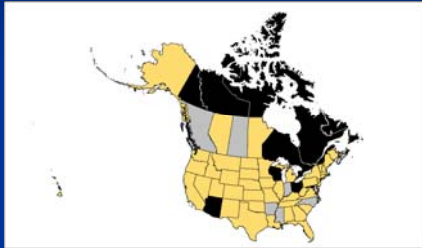
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### 2005 Certification



Gold Certification Silver Certification Not Certified

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### V. Data Use

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### Call for Data Uses

- *Cancer Incidence in North American (CINA)* Monograph (Volumes I and II)
- *CINA* in SAS (can be downloaded from NAACCR website)
- *CINA+* Online – interactive public query system
- *CINA* Plus in SEER\*Stat – more flexible queries; statistical testing; application required
- *CINA* Deluxe

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## Call for Data Uses (cont.)

- *CINA* Deluxe
  - Multi-registry aggregated database (includes only registries that meet inclusion criteria for data quality);
  - Designed for cancer surveillance research;
  - Proposal required;
  - Must have approval from the Research Proposal Review Subcommittee and the NAACCR IRB; and
  - Must sign confidentiality agreements.

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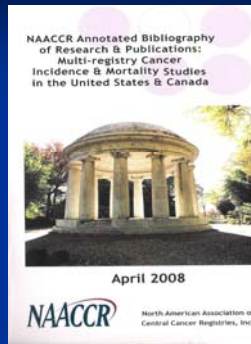
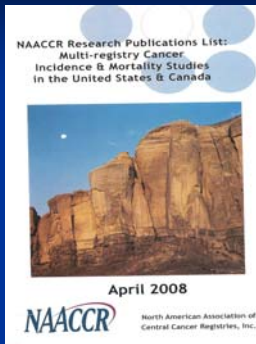
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## Data Use




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### Cancer Incidence Statistics

Cancer reporting is mandated through state or provincial laws. NAACCR registries from each state or province voluntarily submit their non-identified data annually for evaluation and publication to NAACCR. After NAACCR receives the data, members of the **Data Use and Research Committee (DURC)** compile the data for publication in *Cancer in North America (CINA)*. An online interactive query system called **CINA+ Online** is available, and statistics and descriptive reports can be generated from the data.

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**NAACCR The NAACCR Narrative**  
Spring 2008 Edition [www.naacr.org](http://www.naacr.org)

**L. M. R. Queen, Robert J. Smith, Andrew P. Ross, Richard Edwards, Andy Fisher, Lisa O'Connor, Dan Shaker, Steve Blaine**  
Health equity performance

**David Dunlop gets his wings with help from Anthony Rossini and Lisa Seltzer**

**Mark Rice, D. M. R. Mark Thompson, Lee Hershner, Tim Corbin, Andrew Stewart, Leah Johnson**  
Fund from Laura Chapman

The NAACCR 2008 Board/Chair/SMO Meeting was held in San Antonio, TX on March 27-28, 2008. See story on Page 4.

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[www.naacr.org](http://www.naacr.org)

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