

**NAACCR**  
**North American Association of Central Cancer Registries**  
**Overarching Goals and Tasks**  
**2005-2006**

- 1. (Highest Priority) The Real Time Reporting Group will:**
  - a. Map current transmission standards to modern methods in full synchronicity with NHII standards, including SNOMED, HL7, XML, LOINC, etc.**
  - b. Focus on informatics**
  - c. Look for ways to connect NAACCR to national efforts to develop the electronic medical (health) record.**

***Primary Issues:***

- Registries use 1980s technology in the 21<sup>st</sup> century regarding data exchange formats
- Need to focus on informatics
- Data transmission issues; e.g., security and real time reporting from E-path, LIS (laboratory information systems), electronic medical records, discharge/disease index
- Registries have more opportunities for data sharing/mining if they were able to exchange data in various formats, such as HL-7, SNOMED, ICD-9, CPT (Current Procedure Terminology), and J-codes (a pharmaceutical billing code, part of the Healthcare Common Procedure Coding System - HCPCS)
- Need to identify and assess existing data standards to maximize potential leverage of data, data elements, processes, and partners
- Need to integrate NAACCR (including Canadian perspective) into overall national efforts through organizations such as NCCCS (National Coordinating Council for Cancer Surveillance), C-Change, and NHID (National Health Informatics Development); NAACCR should be able to speak from a position of highest authority/expertise with a unified voice in regard to cancer surveillance and research efforts in the US and Canada on issues such as making public health policy decisions, electronic medical records, and data transmission standards

***Feasibility Index (good-average-low): GOOD***

***Proposed Solutions:***

- Use organizational, agency, and individual subject matter experts (SMEs)
- Identify outside expertise, build bridges, and get input
- Identify registries on the “bleeding edge” of E-path, data management systems (DMS), LIS, and other state-of-the-art systems and processes

***Tasks:***

- Update and give a status report of past efforts
- Identify a vision for the future that includes XML, HL7, LOINC, SNOMED, LIS, E-path
- Continue to assess and update the NAACCR document, “Implementation Guide for Transmission of Laboratory-Based Reports to Cancer Registries using Version 2.3.1 of the Health Level Seven (HL7) Standard Protocol”
- Expand base of knowledge in NAACCR by bringing in additional SMOs (sponsoring

- member organizations) being brought in for their subject matter expertise
- Expand constituencies and stakeholders to include possibly API (Association for Pathology Informatics), NHII, APHA, (American Public Health Association) and vendors at some point
- Translate existing NAACCR data transmission standards to current NHII standards, including SNOMED, HL7, XML, and LOINC

***Responsible NAACCR Parties:***

- New task force with representation from IT; UDS, Registry Operations, BOD, and Executive Office

***Leadership role:***

- NAACCR, NCI, CDC, ACoS; pathology informatics Subject Matter Experts possibly Michael Beschish (College of American Pathologists), Sharon Winter (University of Pittsburgh Medical School), Joyce Nyland (City of Hope National Medical Center), Brenda Edwards (NCI/SEER), and Phyllis Wingo (CDC/NPCR)

***Time Frame:***

- 1-2 years

**2. (Very High Priority) Establish a mega oversight committee for evaluation of the introduction, acceptance, and implementation of new standards for cancer registries.**

***Primary Issues:***

- Need to validate/introduce/ announce any proposed changes to the field of cancer registration much earlier in the process when they may affect registry operations (possibly as a participant), putting feasibility and pilot studies into the context of developmental activities that relate to registry operations, data collection and benchmarks, and data usage. This addresses registry infrastructure and building capacity for being a research resource.

***Feasibility Index (good-average-low): GOOD***

***Proposed Solutions:***

- Establish a high-level Implementation Oversight and Monitoring Committee (IOMC) or an Integration and Coordination Committee (IACC), the name being important to convey its function.

***Tasks:***

- Identify who should be on the IOMC
- Define the process for bringing new issues/ proposed registry operations or changes to the IOMC
- Define a feedback loop for IOMC and constituencies
- Identify logistical support mechanism to staff and maintain the IOMC

***Responsible NAACCR Parties:***

- NAACCR Executive Office
- NAACCR SMOs
- NAACCR Members
- NCCCS

**Leadership role:**

- The IOMC itself would be chaired by one SMO on a rotating basis (with a term limit of a year or two).

**Time Frame:**

- One year

**3. (Very High Priority) Establish a NAACCR Task Force to address retention and recruitment for all cancer surveillance staffing needs in 2020. This group will:**

- Interface with NCRA to define their scope and progress on their R&R effort**
- Identify gaps**
- Address size and skills of the workforce needed using a “Futuring” perspective.**

**Primary Issues:**

- Registries nationwide report difficulties in identifying qualified staff for all positions within central and hospital registries. We anticipate long-term staffing shortages that will worsen with the aging of the population and the concomitant increase in case reporting.
- Cancer surveillance careers are not well known to potential candidates, and there is a lack of career track formal training in cancer surveillance specialties.
- The changing demands on cancer surveillance systems require changing skill sets for employees, and training does not keep pace with demand for these skills.
- Retention of staff once hired.
- These issues are long-term problems that will require years of attention.

**Feasibility Index (good-average-low): GOOD****Proposed Solutions:**

- Explore and develop ways to effectively recruit new staff to various cancer surveillance professions including epidemiologists, statisticians, certified tumor registrars (CTRs), IT, GIS etc.
- Develop methods to assess staffing needs in the future (to 2020 and develop plans to meet these staffing needs.
- Explore methods to limit attrition in the field and retain qualified employees.
- Work with C-Change on their workforce initiative to assure that cancer surveillance professions are included in their priorities, and on mutually beneficial activities.

**Tasks:**

- Convene a work group within the Education committee that will include members such as: the NCRA Education Chair; NCRA president, other SMO liaisons, work group chair, surveillance epidemiologists, IT staff, statistician, registry representative (Susan Van Loon - NJ). Chair will also invite participation from entire NAACCR membership
- Develop plans and timelines for each topic (1. effective recruitment, 2. future staffing, 3. retention, 4. working with C-Change). Identify areas being addressed by NCRA and or other SMOs so as not to duplicate efforts.
- If feasible, appropriate and if there is sufficient funding, the group will meet with NCRA R&R work group either at the NCRA or NAACCR annual meeting to share progress and

strategies and involve the ACoS to focus on coordination of effort in R and R

- The recruitment group may wish to develop informational packets to be distributed to area high schools, colleges, universities and schools of Public Health to be used in recruitment activities during career days, job fairs, career counseling sessions, etc. These would cover CTRs, epidemiologists, IT, management, research assistants, etc.
- The staffing needs group or the recruitment group may wish to develop generic job descriptions for aforementioned positions and provide these to the central cancer registries for them to distribute to appropriate facilities within the state
- A survey of NAACCR members on R-n-R activities within each registry may be appropriate to define successful approaches.
- Explore the value of holding a “Futuring” workshop to identify knowledge, skills, and size of a cancer surveillance workforce in 2020
- Become active on the C-Change Cancer Workforce Team to increase awareness of cancer surveillance staffing needs and opportunities and leverage support with a larger national effort on the topic.

***Responsible NAACCR Parties:***

- Education Committee

***Leadership role:***

- Mignon Dryden as Education Chair; R-n-R Work Group Chair

***Time Frame:*** By December 2005 assess status and evaluate progress. Update time frame

- 4. (High Priority)** Develop and define standards to ensure validity of data definitions (content) across cancer disciplines [at least clinical, oncology, pathology, surveillance, and registration]

***Primary Issues:***

- Need to ensure that those diagnosing and treating cancer and using cancer data understand the implications of terms/codes/standards, etc. and that they are coordinated in a meaningful and valid way.
- Make sure constituencies are aware of what data definitions are different
- Assess validity of making changes, focusing on the use of the data as well as their collection.

***Feasibility Index (good-average-low):*** GOOD

***Proposed Solutions:***

- Partner with ACoS, CAP, and appropriate Canadian authority
- Take plan approved by the Board and present to the SMOs to invite them to join us.
- Share plan with C-Change; working through NCCCS since they were originally approached to take this lead
- Hold meeting to discuss and present issues; define solutions; and assign responsibility to the various constituencies.

***Tasks:***

- Standardize diagnostic and treatment protocols to develop a standard approach to capturing data.
- Address ambiguous terms, histology characterization, multiple primary rules
- Interface with the IOMC (overarching goal #2 above)
- Tie to real time reporting regarding content validity to ensure that valid content will be

- reliably captured
- Get initiative coordinated with C-Change leadership and NCCCS (who was originally approached by C-Change)

***Responsible NAACCR Parties:***

- Board of Directors, SMOs

***Leadership role:***

- Executive Office [??? Leadership role but not responsible party??] ??with tie to NCCCS perhaps???

***Time Frame:***

- One year to plan meeting; second year to hold meeting and develop plan
- Note: C-change dollars available through December 2005 for a meeting.

**5. (High Priority) Define and assess surveillance needs for various outcomes that will include:**

- CDC core/advanced surveillance concept;
- NCI typology of registries concept;
- NCCCS initiative on “incidence and beyond;
- All NAACCR constituencies (US & Canada)

***Primary Issues:***

- Disconnect between users and collectors of cancer registry data.
- Awareness of the quality, completeness, and availability of data.
- Consideration of the uses of the data balanced with the cost to collect the data.
- Political: use of the data justifies the existence/cost of the cancer registry..

***Feasibility Index (good-average-low): HIGH***

***Proposed Solutions:***

- Conduct a two-phase survey:
  - First, ask central cancer registries and SMOs to identify their stakeholders and to state how they use cancer registry data;
  - Second, contact stakeholders to discover current and potential uses of the data.
- Describe different uses (outcomes) in relation to the data needs

***Tasks:***

- Construct a matrix that includes categories of use/products/data elements required for the use.
- Develop assessment tool to evaluate data for various uses
- Publicize results
- Develop a cancer control document that outlines basic procedures for using cancer incidence and mortality data to enhance and evaluate cancer control efforts.

***Responsible NAACCR Parties:***

- Central registry members, SMOs
- Interface with NCCCS activity
- Assign follow-up and oversight of developmental work to the Data Use and Research Committee (DURC) (perhaps the Research Subcommittee?) or a special ad hoc group

***Leadership role:***

- NAACCR Ad Hoc or DURC

***Time Frame:***

- 12-18 months