

**NAACCR Town Meeting**  
**NAACCR Committee Activities – DURC & DECC**  
**October 10, 2006**

**3:00 pm Eastern; 2:00 pm Central; 1:00 pm Mountain; 12:00 pm Pacific**

**Present** – Representatives from the following registries and organizations:

**1 Canada:** Manitoba Cancer Registry

**22 U.S.:** American Cancer Society, Arizona Cancer Registry, California Cancer Registry, Los Angeles Cancer Surveillance Program, Centers for Disease Control and Prevention, Terry Dolecek, Illinois State Cancer Registry, IMPAC Medical Systems, Inc., State Health Registry of Iowa, Kentucky Cancer Registry, Louisiana Tumor Registry, Maine Cancer Registry, Mississippi Cancer Registry, Missouri Cancer Registry, National Cancer Registrars Association, New York State Cancer Registry, North Carolina Central Cancer Registry, Ohio Cancer Incidence Surveillance System, Pennsylvania Cancer Registry, Rhode Island Cancer Registry, Texas Cancer Registry, Washington State Cancer Registry

**2 Speakers:** Dr. Maria J. Schymura – Chair of Data Use and Research Committee (DURC), Dr. Thomas C. Tucker – Chair of Data Evaluation and Certification Committee (DECC)

**3 NAACCR Staff:** Dr. Holly Howe, Moderator – Executive Director, Joellyn Ellison – Program Manager of Data Evaluation and Publication, Royale Anne Hinds – Assistant to the Executive Director

**1. Introduction and Background**

**Holly Howe**

The NAACCR Board decided at their June 2006 Annual Meeting they would like the membership to have the opportunity to learn more about the NAACCR committees and their activities, goals, and focus. NAACCR plans to schedule monthly Town Meetings to feature two or three NAACCR Committees. The Board would like NAACCR members to become involved in the committees, if they wish.

**2. Data Use and Research Committee (DURC)**

**Maria Schymura**

The Data Use and Research Committee activities include reviewing the Call for Data materials and the production of the CINA monograph and the CINA Research file. The work of the committee is completed at the work group level and the subcommittee level.

**Latino Research Work Group** has disbanded because they completed the NHIA Algorithm v. 2. The main revision in version 2 allows registries to option whether they want the surname portion of the algorithm to be applied uniformly across their entire registry or to restrict it to counties with a high prevalence of Hispanics.

**Abstract Review Subcommittee** was formed prior to the Boston Annual Meeting in 2005. The Program Committee, which changes each year with venue changes, did the abstract reviews prior to 2005. We needed a uniform process for evaluating the

abstracts submitted for the annual meeting, so the subcommittee was formed to complete reviews.

**Asian/Pacific Islander Identification Panel** (Frank Boscoe, Chair). Frank presented the progress of this group at the Regina Annual Meeting in 2006. They have been working on an algorithm to assign more specific Asian race code to the Asian, NOS category. The algorithm draws on name lists from Diane Lauderdale and a name list produced by participating NAACCR registries. They have finalized the Asian portion and are currently looking at the Pacific Islander, NOS category. The panel has members from registries with a high proportion of Asians and Pacific Islanders. Registries can volunteer to participate in testing of the algorithm by contacting Maria Schymura or Frank Boscoe at the New York Cancer Registry.

**CINA Production Subcommittee** (Joellyn Ellison, Chair) The subcommittee provides cancer registry expertise, evaluates data quality from the file submissions, reviews registry data to determine those with high incidence data quality to be included in the combined rates, and provides editorial support. In 2006 Call for Data, 65 registries responded and 43 US registries met the high quality incidence data criteria for inclusion in the NAACCR Combined Rates.

**Confidentiality Subcommittee** (Colleen McLaughlin, Chair). Goals are to develop a bibliography of reference materials related to confidentiality and data use which will be made available on the NAACCR website, develop model policies and procedures for the release of identifiable and de-identified data and address barriers to participation in CINA Deluxe research projects and to examine suppression and rules to determine whether these present barriers to researchers.

**Rapid Case Ascertainment Work Group** (Carol Lowenstein, Chair). Carol conducted a survey of all registries to determine where they stand in regard to rapid case ascertainment. Forty-nine members responded and 21 have had some form of rapid case ascertainment. Once approved by the NAACCR Board, the survey results will be posted on the NAACCR website. The group will work on administrative and operational issues particularly in areas of electronic pathology and IRB and HIPAA issues related to rapid case ascertainment.

**Research Proposal Review Subcommittee** (Holly L. Howe, Chair). The subcommittee, formerly called CINA Deluxe Advisory Group, reviews all requests for access to the CINA Deluxe file. Formerly, there were two processes where proposals were reviewed, but the review processes have been consolidated to one within this subcommittee. The frequency of reviews has increased from twice a year to quarterly. The subcommittee has developed an operations manual which outlines the review procedures. The manual can be found on the NAACCR website in the NAACCR Research Program section.

**Research Subcommittee** (Vivien W. Chen, Chair). The subcommittee has not formally convened yet. The goal is to enhance the use of registry data for research. Vivien is in the process of refining the short term goals, so that prospective members will know what they are volunteering for.

In the next year, the DURC hopes to form a group to help develop for the Call for Data materials. Since the Call for Data has gotten more complex over the years, they will ensure the Call for Data materials are easy to understand and use.

Joellyn is the liaison for the Data Use and Publication Committee, which is a Canadian committee that advises the Canadian Council of Cancer Registries. The DUPC is similar to the DURC. Joellyn's expertise is lent to this committee and Joellyn regularly reports back to the DURC on the Canadian DUPC's activities.

Maria encourages everyone to contact her with issues that fall under her committee. Volunteer interested in joining DURC or its subcommittees may contact Maria Schymura.

### **3. Data Evaluation and Certification Committee (DECC)**

**Tom Tucker**

The Data Evaluation and Certification Committee was formally established at the Boston Annual Meeting. There are 14 members from North America, who primarily work in epidemiology and biometrics. It merged two ongoing functions that have been kept as two separate activities – certification and high quality data standards.

Certification activities include:

1. Addressing adjustments for Hispanic population in the way we adjust for differences in black and white populations in calculation of completeness estimates. The DECC continues to examine this complex issue to ensure that the numerator and denominator are correct. The Hispanic group is large and includes many subsections, such as Puerto Ricans, Cubans, Mexicans, etc. who appear to experience cancer in different ways.
2. Evaluating breast and prostate cancer incidence to mortality rate ratios and how they affect completeness estimates. There is evidence that changes in screening penetration greatly affect the accuracy of the estimation of completeness. The IMRR is showing changes (lack of stability) in the past few years in the US and a different penetration of screening and thus different IMRR in Canada. So for one year, breast cancer is being removed from the certification estimate because it is not reliable. Prostate cancer has never been included in the model for the same reason, but is being reviewed to see if the ratio is sufficiently stable one time to include.
3. Deciding if modeling techniques can be used as methods for estimating completeness of case ascertainment.
4. The incidence to mortality rate ratio model has a great deal of logic behind it if you can establish that the rate ratios are stable. And if you can establish that the incidence and mortality data is accurate and complete. We are looking for a better way to estimate true differences in case fatality. If this could be done, then the only remaining variable in the model in completeness of case ascertainment.

Evaluating data for research use activities include:

1. Do we need additional edits for CINA Deluxe?
2. Making a matrix of missing data and key variables by major type of cancer available to researchers. Researchers can then decide which anonymized data they would like to include in their research project. This product has been completed and in a conversion process for web accessibility
3. Adjusting mathematically for missing data. We would like to develop this into a SAS program to use with CINA Deluxe dataset. A proposal to develop this tool has been approved by NAACCR and if the project is successful, we will develop the algorithm

into a SAS tool program and make it available to all NAACCR data users through the NAACCR website, Research Program section.

One participant expressed concern about the 2004 breast cancer rates not being included in the certification submission. Tom reassured her that it will not have a negative impact on anyone. The problem is there are differences in screening throughout North America, which impacts the rates. Registries don't have control over the differences in screening. There are indications that breast cancer incidence rates are stabilizing and possibly even a decrease. A decline in incidence does not happen at the same rate throughout North America which makes the relationship of incidence and mortality an unstable indicator. Prostate cancer has not been included for the same reason – unstable indicator. There will be a very careful process before prostate or breast cancer rates are added to the model.

Another participant asked if completeness on the 5-year data for CINA would be completed the same way as certification. Tom responded that yes, the process is the same for both registry certification and CINA.

Another person asked if the decision to exclude breast cancer rates was made even though in situ is already excluded. Tom responded yes, in situ was already excluded.

Maria Schymura asked about the likelihood of putting breast cancer back in to the model next year. Tom responded that they will monitor the rates on a year-to-year basis, looking for good evidence before adding it back in.

A question about the quality of death certificate data was asked since registries must defer to the death certificate. Tom responded there maybe concerns about mortality data, but if processes are followed, registries are generally certified in spite of misclassifications. Cancer is documented as having greater cause of death validity than other diseases and if DCOs are cleared sufficiently, then the resident impact is minimized.

#### **4. Closing Remarks**

**Holly Howe**

Holly expressed appreciation for the NAACCR Chairs and their leadership in the areas where they have experience and passion. Participating on committees can foster leadership among registry staff and increase satisfaction with their jobs. The next Town Meeting will be in November with the Nominating, Communications, and Bylaws committee chairs reporting.