NAACCR 2007 Call for Data Help Line
September 29, 2006
3:00-5:00 PM Eastern Time

Present Representatives from the following registries and organizations:

3 Canada: Alberta Cancer Registry, Manitoba Cancer Registry, New Brunswick Provincial Cancer Registry

31 U.S.: Arizona Cancer Registry, Los Angeles Cancer Surveillance Program, Northern California Cancer Center, Centers for Disease Control & Prevention, Colorado Central Cancer Registry, District of Columbia Cancer Registry, Metropolitan Atlanta & Rural Georgia SEER Registry, Illinois State Cancer Registry, Indiana State Cancer Registry, Information Management Services, Inc., IMPAC Medical Systems, Inc., Louisiana Tumor Registry, Maine Cancer Registry, Massachusetts Cancer Registry, Mississippi Cancer Registry, Missouri Cancer Registry, Nevada Statewide Cancer Registry, New York State Cancer Registry, North Carolina Central Cancer Registry, North Dakota Cancer Registry, Oregon State Cancer Registry, Pennsylvania Cancer Registry, Puerto Rico Central Cancer Registry, Rhode Island Cancer Registry, Rocky Mountain Cancer Data System, South Dakota Cancer Registry, Tennessee Cancer Registry, Texas Cancer Registry, Vermont Cancer Registry, Virginia Cancer Registry, Washington State Cancer Registry

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

This is an opportunity to go through Call for Data 2007 materials in the order they are on the website. These minutes are just a highlight of the detailed documents.

NAACCR developed a password protected system in 2006 in order to streamline the Call for Data process. NAACCR Main Contacts were sent a password in early August. Send Joellyn an email if you have any problems with passwords.

Materials are located at www.naaccr.org under Quick Links on the homepage. The 'Information for Vendors Involved in the NAACCR 2007 Call for Data' link contains the materials outside of the password protected system.

SUBMISSION INFORMATION, DEFINITIONS, & DOCUMENTATION

Data Quality Criteria and Standards

The criteria are the same as last year, except:

- Data years have changed to 2000-2004 for NAACCR Combined Rates, 1995-2004 for CINA Deluxe File and 2004 for Registry Certification.
- Timeliness deadline date is December 1, 2006.

General Instructions for NAACCR Data File Submission

The general instructions include:

- Contact information for Joellyn Ellison and Andy Lake at IMS.

- Step 1 is to submit data for 1995-2004 by December 1, 2006.

- Step 2 is clarification to submit 1995-2004 data in ICD-0-3. NAACCR would like Myelodysplastic Disease, Benign Brain Tumor, and Borderline Ovarian Tumors cases that were reportable in ICD-0-2 to be included in the file. The tumor cases will not be used to calculate rates for CINA. The purpose of collecting those cases is for the CINA Deluxe Analytic Research File.

  - For the research file, NAACCR wants all cases that are reportable by NAACCR standard in 2000, even if it is not reportable in the 1995-2004 period. If you have an ICD-0-2 code, then you should report it in ICD-0-2. If you have an ICD-0-3 code, then you should report it in ICD-0-3. If you don't convert ICD-0-2 to ICD-0-3, NAACCR will convert them before using them. ICD-0-2 codes are for the time period when registries were using ICD-0-2 codes.

- Step 3 requests that records be sent using NAACCR record layout version 11.

- Step 4 requests that registries perform the duplicate assessment protocol. This is required for registries that want to be evaluated for certification or included in combined rates. When you have accessed the forms, the sample size for your registry is listed under the link 'Get Your Sample Size'.

- Step 5 is for US registries. It requests that results of any and all linkages that have been performed with the Indian Health Service, data element 192 be included. The Summary of the Data Submission and Process Verification Form will ask which years you have linked your data to the Indian Health Service.

- Step 6 requests that US registries run the Great Circle Distance Calculator Program and insert the results on the file submission. The SAS program is run on the registry's file and creates a temporary dataset. The output should be placed in columns 1399-1428. The information is mileage information for up to five facilities.

- Step 7 requests that registries run the Rural Urban Beale Code Program. This is not required if you are submitting county codes.

- Step 8 requests that US registries run the NHIA v.2 on all cases from 1995-2004. This information is used for Hispanic research.

- Step 9 requires that registries run the NAACCR Call for Data 2007 EDITS metafile on their file submission to be considered for certification or inclusion in combined rates or on the research file, CINA Deluxe. NAACCR requests that you resolve all errors, report the number of errors on the edit form, and fax the summary EDITS report to NAACCR. You may receive errors that are for your information only. Joellyn will send a list of the EDITS that will not be considered for Registry Certification at your request.

- Step 10 requires registries to run the Inter-record EDITS Utility. There is a link to the NPCR website where the utility is housed. The summary form will need to be faxed to NAACCR.

- Steps 11-13 describe creating your data file. Options to send data file to IMS have not changed.

- Step 14 requests that you complete the forms on the NAACCR website for your registry's data submission by December 1, 2006.

- Step 15 asks registries to review, sign, and fax the National Program Registry Certification Release Form.

- Step 16 asks registries to review, sign, and fax the Call for Data Assurances Agreement.

- Step 17 asks registries to review and update the Members Data Access Protocol. This is information on your registry's IRB and how to access data. We are developing a webpage that will be available in early November to access and change your information. This will give researchers an overview of what IRB requirements are needed by each state's IRB.

Copy of NAACCR 2007 Call for Data Letter

This letter was sent in early August to invite registries to submit their data and highlighting what was new on this year's Call for Data.

Definition of Requested Incidence Data for CINA and CINA Deluxe

This form defines the cancer sites that NAACCR is requesting for CINA and CINA Deluxe. The table includes the data items request for CINA. The new items are the Collaborative Stage items, IHS Link, and the Great Circle Distance Calculation.

Definition of 2004 Incidence Data for Registry Certification

This form defines the cancer sites that NAACCR is requesting for Certification. The table includes the data items request for Certification. The new items are the Collaborative Stage items and the IHS Link. Benign Brain Tumors are reportable for 2004.

DATA TOOLS FOR 2007 CALL FOR DATA

NAACCR Method to Estimate Completeness

The worksheet for 1995-2003 data is posted on the website. We will calculate the completeness in January using the updated rate ratio from the SEER registries which would include the 2004 data. The SEER data is embargoed until the spring, so the information may be different when calculated with the most up-to-date information. The DECC has voted to exclude Breast Cancer from the model for one year because they feel it will make the method more accurate.

Great Circle Distance SAS Program

The Great Circle Distance SAS Program and Instructions are linked side by side on the webpage. Let Joellyn know if you have any questions concerning the Great Circle Distance SAS Program.

Rural Urban Beale Code Program

There are no changes on the Rural Urban Beale Code Program from last year. The information about the Beale Codes and what they mean is listed under the 'Information' link.

NHIA SAS Program

This is a link to another portion of the NAACCR website where the data tools are contained. It is recommended to read the NAACCR Guidelines to learn the procedures, codes, and the definitions. The NHIA v. 2 process map is available. You will need to have the 1990 Hispanic surname list when running the program. The splong.dat file and the state-county file for 2000, located on the NAACCR website, are needed to run NHIA v.2.

NAACCR 2007 EDITS Metafile

NAACCR 2007 EDITS Metafile contains a link to the CDC website if you need to download the EDITS or Gen EDITS Lite software.

Interrecord EDITS

The Interrecord EDITS is linked to the NPCR website. The software system is listed at the bottom of the page under Interrecord EDITS stand-alone program 2007 v. 4.0.9. This is updated for version 11 and works with ICD-0-2 and ICD-0-3 coded data.

FORMS

After submitting a form, you can choose the Principal View and print the information that you have submitted to NAACCR for your records. All fields on the forms with an asterisk (*) are required fields. Forms can not be saved to finish at a later time. You could fill in the form and cut and paste to Word to save the information, but information would have to be re-entered. There is a 20 minute inactivity cutoff. The main contact of each registry will receive an email confirmation when the forms have been submitted.

Registry Certification Evaluation Form

If we have any questions about your file this form provides the contact information for the following:

- Person Designated to Receive the Confidential Report
- Person Designated to Provide Technical Information

National Program Registry Certification Release Form

Canadian registries will be asked for permission to send certification information to Statistics Canada. US registries can fill in the information for NPCR or SEER to receive the certification information. This form will need to be signed and faxed to the NAACCR office at 217-698-0188.

Identification of Duplicate Records Form

There is an instructions link and sample size link, which is used to run the duplicate protocol.

Summary of Data Submission and Process Verification Form

This form consolidates two forms that were used last year. Instruction and definitions have a link to assist with death clearance information. There is also a link to the Great Circle Distance SAS Program in case you came to this form before completing the Great Circle Distance Calculation. Enter data year submitted and the base year for conducting death clearance (the year that the registry began the death clearance process). In the Death Clearance Conducted column, choose yes or no according to whether or not death clearance was conducted for that data year. Include the number of DCO records, in situ bladder, and in situ breast cases in the third column. US registries will need to know if the IHS link was conducted and the Great Circle Distance Program was run on the file submission. The grand total will include the number of DCOs on all the cases. At the bottom, a definition is given of the death clearance process.

NHIA v.2 Verification Form

Canadian registries will not see this form. NAACCR wants to know whether the SAS Algorithm provided by NAACCR was used or if you used another algorithm written by your registry. Also, include whether the steps were followed manually. Joellyn will add a fourth option "Ran algorithm written by software vendor".

EDITS Summary Form

The EDITS Summary Form asks for the number of records processed, number of errors, number of warnings, and your name. Fax final summary to the NAACCR office at 217-698-0188.

Interrecord EDITS Summary Form

The Interrecord EDITS Summary Form asks for the number of records processed, number of errors, and your name. Fax final summary to the NAACCR office at 217-698-0188.

NAACCR 2007 Data Assurances Agreement

The NAACCR 2007 Data Assurances Agreement does not have changes from last year, except the dates.

Attachment A – Primary data uses

A. Evaluate data items and their data quality. Development of the research file. Annual summary of quality assessments for the CINA Deluxe file for 1995-2004 data.

B. Produce standard aggregate cancer incidence rates. Produce Cancer in North America 2000-2004. Produce cancer surveillance information. Fill data requests using the NAACCR data analytic file. Aggregate data. Provincial cancer data. Cancer site specific data. In January 2006 at a Town meeting the registries said they are comfortable with these specified uses of their data.

   - The Annual Report to the Nation on the status of cancer plans to include the results of the Indian Health Service link, for the publication of statistics for American Indians/Alaskan Natives populations.

C. Produced aggregate cancer statistics for CINA Plus on-line.

D. Evaluate 2004 data for registry certification.

E. NAACCR would like to use the data with the county variable for American Cancer Society's Cancer Facts & Figures. NAACCR would provide the researchers at NCI with the data for a modeling project. ACS will conduct an analysis to enhance the incidence projections.

Secondary Uses of Data

- Researchers request use of the CINA Deluxe file by submitting a proposal to Holly Howe, Chair of the Research Proposal Review Subcommittee.
- After subcommittee review and approval, the proposal is sent to the NAACCR IRB for approval.
- Specific registry consent by project is obtained from the registries for research to begin.
- NCI Cancer Profiles is planning to expand and include Canadian registries this year. NAACCR would like Canadian registries to consent to have their data used in the secondary uses.

We have a revised informed consent process for CINA on the research page, which gives more detail on when a registry can resend their permission for data. Contact Joellyn with any questions.

Attachment B – Data Confidentiality Agreement for Researchers

No changes from last year.

Attachment C

Outline of the NAACCR Scientific Editorial Board's policies and procedures.