NAACCR 2007 Call for Data Help Line
October 1, 2007
2:00-4:00 PM Eastern Time

Present Representatives from the following registries and organizations:

2 Canada: Alberta Cancer Registry, Manitoba Cancer Registry

42 U.S.: Alaska Cancer Registry, American Cancer Society, Arizona Cancer Registry, Arkansas Central Cancer Registry, California Cancer Registry, Los Angeles Cancer Surveillance Program, Colorado Central Cancer Registry, District of Columbia Cancer Registry, Florida Cancer Data System, Georgia Comprehensive Cancer Registry, Hawaii Tumor Registry, Illinois State Cancer Registry, Indiana State Cancer Registry, Information Management Services, Inc., IMPAC Medical Systems, Inc., Maine Cancer Registry, Maryland Cancer Registry, Massachusetts Cancer Registry, Michigan Cancer Surveillance Program, Mississippi Cancer Registry, Missouri Cancer Registry, Montana Central Tumor Registry, National Cancer Registrars Association, Nebraska Cancer Registry, Nevada Statewide Cancer Registry, North Carolina Central Cancer Registry, North Dakota Cancer Registry, Ohio Cancer Surveillance System, Oklahoma Cancer Registry, Oregon State Cancer Registry, Pennsylvania Cancer Registry, Puerto Rico Central Cancer Registry, Rhode Island Cancer Registry, South Carolina Central Cancer Registry, South Dakota Cancer Registry, Tennessee Cancer Registry, Texas Cancer Registry, Utah Cancer Registry, Vermont Cancer Registry, Virginia Cancer Registry, Washington State Cancer Registry, Wyoming Cancer Surveillance Program

3 NAACCR Staff: Holly Howe – Executive Director, Royale Anne Hinds – Assistant to the Executive Director, Shannon Vann – Program Manager of Education and Training

Introduction

During this Town Meeting, we have an opportunity to go through Call for Data 2008 materials. This year includes a PowerPoint presentation which covers some changes from previous years in the Call for Data process. The slides are on the NAACCR website at http://www.naaccr.org/index.asp?Col_SectionKey=11&Col_ContentID=358.

On the left-hand side of the NAACCR homepage under the Cancer Research section, you can find the Annual Call for Data Materials. The login button is located at the bottom of the Annual Call for Data Materials page. The login passwords for the Call for Data form submission were mailed to the Registry Directors in mid-August.

New Personnel to the Call for Data Process

The following registries have new staff working on the 2008 Call for Data:

- Michigan
- District of Columbia
- South Carolina

- Nevada
- Wyoming
- Maryland

Please call Holly in the next couple of weeks if you need help with the materials. She can walk you through the documents on the website.

General Instructions for NAACCR Data File Submission

The new CINA Editorial Subcommittee of DURC has streamlined the Call for Data documents.

The general instructions include:

- The 2008 Call for Data is due by 5pm Central on December 3, 2007. This includes:
  - A data file being FTPed or sent to IMS.
  - All forms completed and submitted to NAACCR through the electronic process.
  - All consent and signature pages faxed to NAACCR.

- The Call for Data is a voluntary activity and all submissions are requested, not required. There are requirements to qualify for certain uses. All tools developed assume that if you choose to participate, the submission will include all requested items. If you chose not to submit something that is requested, you will have errors in EDITS.

- The Call for Data documents include:
  - The Call for Data Letter – If you don't have the letter with your password, you will need to get it from the Registry Director/Main contact. He or she is the only person to whom NAACCR will give the password.
  - Checklist for Reviewing Consent Requirements for All NAACCR Data Uses - This checklist was developed in the last year to help registries decide if there is a privacy concern for your state. The checklist tells the privacy officer which data elements are included, the level of detail, and which variables are included.
  - Data Selection Criteria Based on Case Reportability – helps programmers decide which codes to choose for each year.
  - Definition of Requested Incidence Data for All CINA Applications – gives a definition of all requested data elements to submit for CINA.
  - Definition of Requested Incidence Data for Registry Certification 2005 – gives a definition of all requested data elements to submit for registry certification.
  - General Instructions for Data File Submissions – helps you prepare the documents in the proper order.
  - Call for Data Assurances Agreement – needs to be signed by the registries.
  - Protocol for Assessing Duplicate Cases for CINA and Registry Certification – same as last year.
  - Summary of Data Quality Criteria and Standards – same as last year.

- Data Tools for the Call for Data are optional submissions and will not affect the registries' ability to be certified or meet the inclusion criteria for CINA Deluxe. The tools are always located on the NAACCR website and include:
  - NAACCR Method to Estimate Completeness – provides an approximation of your completeness before you submit.
  - Great Circle Distance SAS Program Instructions – has been recently updated.

- Rural Urban Beale Code Program Information – NAACCR will run the program using the county identifier if the U.S. registry does not run it.
- NHAPIIA SAS Program – used to enhance Hispanic and enhanced Asian/Pacific Islander identification among cases. The program outputs into the designated columns in the NAACCR transmission layout.
- Guidelines for: NHIA v2 and NAPIIA – information on the NHIA v. 2 and NAPIIA algorithms are always available on the NAACCR website.
- NAACCR 2008 EDITS Metafile – Within the EDITS Metafile, there are two EDITS sets. One if you are submitting for CINA and registry certification purposes and the other if you are **only** submitting for certification.
- Configuration Files for GenEdits Plus Edit Sets and Edits
- Inter-record EDITS – includes a link to the CDC website.

- The registries decide what they want to submit based on how they want their data used. The editors of CINA will decide if a submission meets the criteria for the various uses. For example, if you choose not to submit the Great Circle Distance, then the data will not be available to the NAACCR GIS committee, but it does not affect inclusion in CINA or registry certification. If you choose not to clean up critical Inter-record EDITS errors, the data will be included in the state information, but not in CINA Combined rates or CINA Deluxe.
- Directions have been streamlined to reduce repetition of information and eliminate risk for inconsistent information among NAACCR documents.
- Electronic Forms Submission has three tracks to choose from: CINA Uses Only, Registry Certification Only, or Both CINA and Registry Certification. The appropriate forms will come up depending on what you choose. They will be pre-loaded with relevant information to your registry.
- Once submitted, no changes can be made to the online forms. If changes are needed, you will need to print the form, note the changes manually, and fax the revised form to Holly Howe at 217-698-0188.
- There will be multiple data quality assessments completed including registry certification criteria and incidence statistics.
- There will be one Call for Data Metafile with two EDITS sets to choose from. The new GenEdits Plus includes the July 2007 update for Collaborative Stage Edits and new SEER Edit on Race.
- EDITS for Certification is new and includes only registry certification variables:
  - Age
  - Race
  - Site Variables
  - Sex
  - County
  - Death Certificate Only (DCO)
- To be in CINA Combined or CINA Deluxe, the registry must be 100% error-free in critical variables, such as age, sex, site/type. For non-critical errors, such as Treatment, Great Circle Distance, Collaborative Stage, if errors are found in these fields, the all data for the variable will be purged on CINA Deluxe.
- With CINA EDITS Set, NAACCR assumes all requested variables are submitted. NAACCR runs different edit sets for various uses and NAACCR uses the results.
- Inter-record EDITS requires 100% error-free to be included in CINA Combined Rates and CINA Deluxe. Inter-record EDITS is not required for certification.

- Assessing Duplicates needs to be completed twice. Once for 2005 Registry Certification and again on all years (ex. 1995-2005) submitted. The sample size selection is the same as requested in other years.
- NAACCR Asian Pacific Islander Identification Algorithm (NAPIIA) takes Asian NOS cases in Race1 and tries to assign them to a more specific Asian race code.
- The NAACCR Hispanic and Asian Pacific Islander Identification Algorithm (NHAPIIA) SAS program is a combination of the Hispanic and Asian Pacific Islander Algorithms.
- Other Changes of Note
  - Include all *in situ* tumors for **all** reportable sites. If a state does not consider an in situ tumor of a particular site reportable (e.g., cervix), then still include what you have as reportable.
  - In situ tumors are not considered as invasive malignancies, thus they will not be included in QA assessments for certification or fitness of data use.
- Great Circle Distance – the GIS Committee is currently evaluating the 4 states that submitted last year. It would be beneficial if additional states submit this year to aid in refinement of the directions. It will also be useful to help in the development of Road Network Distance Algorithm, a project that we have received funding from the Susan G Komen for the Cure Foundation.
- Data Assurance Agreement – sign and fax or send electronically with electronic signature to the NAACCR office. Consents that are included are:
  - one active secondary use for U.S. only to approve releasing the data with county identifier to the American Cancer Society for Fact & Figures.
  - one passive secondary consent for Canada only is to create provincial profiles.
  - two other passive secondary uses for U.S. and Canada: delay adjustment project with NCI statisticians and CINA Plus in SEER*Stat.
- Additional File Needs:
  - Puerto Rico – we need population data
  - Canada – we need population and mortality data from Statistics Canada
  - Guam – we need population and mortality data
  - SEER – we need population and mortality data for states and Puerto Rico (new NCHS agreement)
- Registry Certification Results will be released directly to Registry Directors as soon as they are available. Data reports will be embargoed until April 15, 2008.
- Data releases to national programs must be handled directly by the registry.

QUESTIONS

Ques.
Does the Hispanic recode algorithm recode like the Asian Pacific Islander algorithm recodes the Asian NOS cases? Ans.
No, all unknown Hispanic ethnicity is assigned to Hispanic or non-Hispanic categories.

Ques.
Why is it different?
Ans.
Because one is dealing with ethnicity and the other is dealing with race and the sensitivity/specificity of the surnames list is different. Read the documents on these two algorithms that are available on the NAACCR website for more details.

Ques.
What if someone is reported as two minority races for NAPIIA?
Ans.
There is not a standard, but UDS is working on this. Right now we are only dealing with Race1.

Ques.
How will sending all *in situ* cases affect the completeness report?
Ans.
In situ is not an invasive tumor so it is not included in statistics or evaluation of completeness. Will it be excluded from measurement of duplicates? If duplicates are *in situ* field, it should not be included on report of duplicates because it is based on invasive tumors.

Ques.
How will this be affected by the VA directive?
Ans.
A decision was made by the NCCCS that the two U.S. national programs would be responsible for making requirements to their program participants to complete a spreadsheet on impact of reporting. It has gone out to SEER program registries. Holly was unsure whether the request has been sent to NPCR registries. NAACCR Agreed that this task was better left to the programs that could require completion of the worksheets. NCI has developed a way to analyze the data and make projections. At the end of the analysis, everyone will have information of the impact of the lack of cases reported by the VA for 2005.

Ques.
Is NAACCR requiring census tract certainty for completeness?
Ans.
Check in the list of Call for Data items. It is not a variable used for certification or determining fitness for use.

Ques.
Will NHIA switch “Unknown” for Hispanic to the proper code?
Ans.
NHIA recodes all “Hispanic Unknown” to either Hispanic or non-Hispanic. There are no “Unknown” values left on the file after running NHIA.

Ques.
Does the Great Circle Distance Calculator automatically populate the file?
Ans.
Andy Lake responded that he believes it will populate the columns.

Ques.
Should that populated field be plugged into the registry database? Will the registry require it next year?
Ans.
Holly responded that it would be up to each registry if they want to save.

Ques.
Why are duplicates run on all years and not just the last five years as done in previous years?
Ans.
The CINA Deluxe file is data that goes back to 1995. We need to make sure the data are fit for use.

Closing

The Editors for CINA products and the Certification Committee will be in full swing after the first of the year. Feel free to call Holly if you have questions. If you have problems or questions with data transmission or getting files to IMS, call Andy Lake at IMS. Contact information is available in the Call for Data materials.