NAACCR Town Meeting
Discussion of Researcher Data Requests to NAACCR
&
NAACCR Research Program Development
January 10, 2005
1:00 PM Central Time, 2:00 PM Eastern Time

Present: Representatives from the following registries and organizations:

Canada: Manitoba Cancer Registry, New Brunswick Provincial Cancer Registry, Yukon Cancer Registry

U.S.: Alabama Statewide Cancer Registry, Alaska Cancer Registry, California-Los Angeles Cancer Surveillance Program, Colorado Central Cancer Registry, Idaho Cancer Data Registry, Illinois State Cancer Registry, Iowa State Health Registry, Maryland Cancer Registry, Louisiana Tumor Registry, Massachusetts Cancer Registry, Metropolitan Atlanta & Rural Georgia SEER Registry, Minnesota Cancer Surveillance Program, Missouri Cancer Registry, National Cancer Institute, New Jersey State Cancer Registry, New York State Cancer Registry, North Carolina Cancer Registry, North Dakota Cancer Registry, Ohio Cancer Incidence Surveillance System, Oklahoma State Department of Health, Pennsylvania Cancer Registry, Rhode Island Cancer Registry, Texas Cancer Registry

NAACCR Staff: Leader - Joellyn Ellison, Program Manager, Data Evaluation and Publication, Holly Howe, Executive Director, Susan Sullivan, Administrative Assistant

Opening Remarks — Holly Howe

Following the previous NAACCR Town Meetings Holly and Joellyn have received positive feedback that cancer registries find the meetings very informative. NAACCR is really gaining some momentum as we learn more from the submissions to NAACCR on the CINA files. We foresee continued growth as we try to develop acceptable procedures for registries.

One of Dennis Deapen's visionary statements for his tenure as President was to facilitate the use, and to grow the use of registry data in research. This meant both at the local level and nationally on how NAACCR might assist registries in that endeavor as well as data that are submitted to NAACCR for more purposes.

With today's meeting we hope to get feedback on some new questions that have come to us. We want to use your comments to help us set up the direction, procedures, and processes related to growing our research program at NAACCR.

1. General Feedback on Call for Data 2005 File Submissions — Joellyn Ellison

We have completed two data quality steps in processing your CINA (Cancer in North America)/ NAACCR submission: we have run a frequency distribution on all submitted variables and we have run the NAACCR Call-for-Data EDITS metafile. Both reports are attached to this email for your information and review.

General Comments on the First Data Quality Indicator Run-NAACCR File Submission

Thank you for your NAACCR file submission. Overall, the files were improved from last year and were evidence of a job well-done by registry staff!

Please check this first data quality run on your NAACCR file submission immediately and let us know if there are any errors. Please be aware of any cases coded as invalid or unknown, according to the NAACCR Standards and Data Dictionary, Volume II, as these cases will be excluded from any evaluations for CINA, Certification and CINA Deluxe.

Several cautionary notes from this year's call for data are listed below:

1) Many registries had instances of cases coded to an invalid county code. Please check before you submit your file to NAACCR, that all your cases are coded to a valid county code, according to the NAACCR Data Standards Dictionary, Volume II.
2) Many registries had instances of malignant cases (on the behavior code) with a sequence number of 60, 61, or 88 (reserved for nonmalignant cases). In addition, some registries had malignant cases coded incorrectly to cancer sequence 21 (invalid code). Be sure to edit these cases on your registry data base. An edit will be added to the Call for Data EDITS metafile before the 2006 file submissions and this edit will generate an error that will need to be resolved to achieve a gold standard on this data quality indicator.
3) Some registries submitted county code and had incorrect Beale code information in the rural/urban fields (positions 227-230). Please check with your software vendor to make sure these fields are cleared in the event that you would need to submit Beale code information.
4) Some registries had an unknown date of birth and date of diagnosis on their file. Registries should review their registry files to ensure that a missing month for date of birth and date of diagnosis is not contributing sizable numbers to this output.
5) Some registries had unknown age at diagnosis on their file. Registries should review their registry files to ensure that unknown age is not contributing sizable numbers to this output as these cases will be excluded from all uses.
6) Non-valid, non-state residents, in situ tumors other than breast and bladder, and cases without an age or gender will be omitted from CINA statistics. This means that the case count you submitted might be different than the counts that are reported in CINA or registry certification. The count of codes is evident for each variable.
7) Many registries had cases coded as Non-US resident, 0, or unknown county. The Non-US resident and '0' cases will be dropped from all analysis and statistics reports, and only the unknown county cases will be held against the <=3% certification standard. Please check your DQI table so you are aware of any cases that will be counted.
8) Some registries had cases coded as cancer sequence unspecified, these cases will be excluded from any multiple primary analysis on the CINA analytic file.

Please let me know if there is any help or assistance I can provide.

A couple of recommendations for additions to the NAACCR Call for Data Edits Metafile were made, Joellyn will explore these requests with Susan Capron.

2. Researcher Data Requests to NAACCR **Holly Howe**

NAACCR has been receiving an increased number of requests from researchers to give information to them to either write proposals or to do some other kind of planning if they already have a funded project to identify a sub-set of registries that they would like to involve in their research.

One example that Holly spoke of that would be applicable to other situations was a study started by the Lilly Company on a drug that they manufacture to prevent osteoporosis progression. When the

drug became approved at the FDA, there was a study that had been recently published showing that there was an increase in osteosarcoma in animals. In approving the drug by the FDA, they required Eli Lilly to conduct surveillance of persons who are starting the drug to see if osteosarcoma developing.

We have been contacted by Lilly and their advisory group to identify states that have the most cases in persons 40 years old and older plus some national statistics. We have the data from the CINA submission. This doesn't fall into the category to be a research proposal. Normally NAACCR has an IRB review to get registries' consent to use their data for this purpose. We really want to be able to feedback information to the researchers more quickly. We want to see how some states feel about this as we are identifying individual states with their actual case count. The Osteoporosis group is waiting for me to respond to them after this call with information on how the states feel about NAACCR releasing this information or if the registries would prefer a proposal with an IRB review. Holly opened the floor for comments on how states feel about us supplying information from previous years' data submissions to researchers.

a) A representative from the Louisiana registry asked for verification that NAACCR would only be supplying the numbers and that we would not be consenting to the researchers do a case control study, or other studies. Holly responded that NAACCR would only be supplying the numbers. A representative from Pennsylvania stated that it would be fine with their registry for NAACCR to supply the numbers to the researcher. The representative from North Carolina felt this would be fine as long as the number was not less than five cases. Holly responded that perhaps NAACCR could make a policy that we would not release data if there were five or fewer cases. Rhode Island agreed it would be acceptable for NAACCR to release their information in this manner. Holly stated that her policy would be to supply the registries with the numbers given to the researchers.

3. NAACCR Research Program Development Holly Howe

NAACCR is receiving requests from researchers wanting to do a multi-registry study such as the Seventh Day Adventist Study. The researchers need to gather information on registry contacts, on access to registry data, to find which states do rapid case ascertainment, follow-up, and etc. Information the registries share with the researcher could eventually be posted on the website so researchers would not have to call the individual registries. The researchers could then concentrate on which states best meet their research protocol. Another example is the Osteosarcoma 40+ Project. Researchers want to set-up interviews with cases of osteosarcoma to identify exposure to this new drug. A third example is a group that does health service research for a drug company. They need information on state specifics, site specifics, and number of cases. If this were a drug that was going to helpful in treatment, we would surely want to assist those who are manufacturing it. Future Town Meetings might be a good approach for researchers to describe their studies and solicit questions from registries.

a) A representative from Missouri is concerned about their specific restrictions on what their registry can provide. Holly responded that NAACCR could be acting as a broker between all the registries and researchers by sharing information. We are helping the registries expand the use of their data, and are helping researchers have easier access to identifying where they need to go get the data. Once that is done, all transactions take place between the researcher and the registry. NAACCR would only facilitate bringing the two parties together.
b) Pennsylvania's representative feels this is a useful tool for researchers. It would also benefit the registries as a directory that would provide information up front to help the researchers pick and choose where to maximize their research. He further stated that he was less excited with the Town Meeting approach for the researchers as the meeting might get bogged down with individualized questions.
c) The Louisiana representative stated that it is important for us to get involved in research projects like these examples. She felt the forum of the Town Meeting would be beneficial to

the registries. The New Jersey representative agreed that we could all learn from questions from the other registries; but stated a moderator would have to keep the call moving, with more detailed question for the researchers being handled off-line.

d) Holly further stated that NAACCR could absorb the workload at this point in time. We would be growing the research program in a methodical way, slowly over time. Holly also noted that research projects are another potential revenue source for registries.

The group agreed that with a strong moderator the Town Meeting approach would be very helpful and NAACCR staff may extend invitations to researchers for this purpose.

4. NAACCR Outcomes Grid **Holly Howe**

The Coordinating Council is interested in defining a set of minimum data elements by their use in cancer research. The Outcomes Grid is a response to that need, and results of interviews conducted of researchers and what data elements are needed for different types of research.

a) The New York representative questioned the Data Quality Assessments. Holly responded that a number of organizations that are all represented on the National Coordinating Council for Cancer Surveillance met last summer and came up with six new initiatives that the Cancer Surveillance Community needed to address. One of them was how to begin assessing what registries need to collect, what new variables we need to add, knowing that every new variable adds cost, diminishes returns and takes away from things that are currently taking place in registries. We want to encourage registries to be more than just a resource for incidence statistics and we want the registries to become better used for a variety of uses. Not only research, but also cancer control applications, prevention, and etc. NAACCR has an interest in developing a helpful research brokerage. Hannah Weir and Holly have started working for the Coordinating Council identifying data usage. Development has begun on a matrix of variables needed for various uses.

4. Closing Remarks **Dennis Deapen**

The direction for NAACCR to help researchers by being a facilitator is a very exciting opportunity for NAACCR and registries. Thank you so much for your interest and input!

Information about future town meetings will be advertised on the NAACCR listserv and posted on the NAACCR website.