

**NAACCR Town Meeting
NAACCR Research Program Update
May 30, 2007**

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

Present – Representatives from the following registries and organizations:

2 Canada: Alberta Cancer Registry, Manitoba Cancer Registry

36 U.S.: Alaska Cancer Registry, Arizona Cancer Registry, Arkansas Central Cancer Registry, Centers for Disease Control and Prevention, California Cancer Registry, Cancer Registry of Central California, Los Angeles Cancer Surveillance Program, Cancer Registry of Northern California, Colorado Central Cancer Registry, Georgia Comprehensive Cancer Registry, Cancer Data Registry of Idaho, Illinois State Cancer Registry, University of Illinois-Chicago, Indiana State Cancer Registry, Information Management Services, Inc., State Health Registry of Iowa, Louisiana Tumor Registry, Maine Cancer Registry, Maryland Cancer Registry, Massachusetts Cancer Registry, Michigan Cancer Surveillance Program, Missouri Cancer Registry, National Cancer Institute, National Cancer Registrar's Association, Nebraska Cancer Registry, Nevada Statewide Cancer Registry, New Jersey State Cancer Registry, New York State Cancer Registry, North Carolina Central Cancer Registry, North Dakota Cancer Registry, Ohio Cancer Incidence Surveillance System, Oregon State Cancer Registry, Puerto Rico Central Cancer Registry, Texas Cancer Registry, Utah Cancer Registry, Virginia Cancer Registry

4 NAACCR Staff: Dr. Holly L. Howe, Moderator – Executive Director, Royale Anne Hinds – Assistant to the Executive Director, Lori Havener - Program Manager of Standards, Shannon Vann – Program Manager of Education & Training

Introduction

Holly Howe

This town meeting is an opportunity to give brief updates on the research program. Holly would like feedback from members on the processes that are going on and feedback on two research projects that were started approximately a year ago. Holly also has feedback from the researchers to share with the registries.

1. Active Consenting by Registries

A. When submitting data during the NAACCR Call for Data, registries consent to have their data used for primary uses. The primary uses include having data published in the CINA monograph; using high quality data for the Annual Report to the Nation, CINA Plus Online, and CINA Deluxe; and having data included in projections for American Cancer Society's Facts and Figures.

B. Other research tools have been developed this year at members' requests – CINA in SAS and CINA Plus in SEER*Stat. CINA Plus in SEER*Stat is not publicly available. It is only available to NAACCR members. The members must fill out a form requesting access to the data and give a brief description of how they will use the data. They must also sign an assurance agreement that states they will not use the dataset to identify

individuals or anything else that would be considered inappropriate. Last year, one of the committees decided there was a slight risk of identifying individuals, so NAACCR has been using the active consent process. This means if the registry director does not get back to Holly, their data are not included. No registries have said “no” their data could not be used. How do the registries feel about including these data as a primary usage? Or do the registries still want it considered a secondary use with a separate consent process?

- Illinois, Alaska, Iowa, Idaho, Manitoba, and Louisiana are okay with using passive consent.
- Nebraska, Arkansas, Maryland, and North Carolina would like it to be active consent because their state sees this as re-released data. Holly pointed out that states can still choose not to have their data included by using passive consent. NC said they would be able to use passive consent with the option to choose.
- Colorado will check into what is acceptable for their state to use and get back with Holly.

Decision: The data will be considered a secondary use in Call for Data materials, but the passive consent process will be used.

C. Who is authorized to consent release of data from the registries? NAACCR keeps three lists: the main contact, registry directors, and voting delegate. Holly has been sending the consents to the registry directors only. Should we create a new list that would give other individuals consenting authority?

Virginia, Nebraska, California, Maine and Manitoba would like the director and an alternate person named.

Decision: Holly will send a request to the directors after the annual meeting for two persons at each registry who can have consenting authority. Directors must be the one to name the person(s) with consenting authority. Holly will create an Outlook distribution list from the names sent to her and consents will be sent to all people on the list.

2. Grant from Susan G Komen Foundation

A. NAACCR has received its first large grant from a non-profit foundation. NAACCR developed a project through the GIS Committee. The project looks at the distance between a patient’s resident address and the health care facility address where the patient gets breast cancer diagnosis and treatment. The abstract, goals, and objectives for the project are attached to the agenda. NAACCR is teaming up with the GIS Lab at University of Southern California to develop a tool to do the computations in batch mode. The tool would also be available to researchers to identify transportation barriers and routing issues on a myriad of projects where distance is a factor. This is a three year grant with the following timeline: year one, develop the tool; year two, pilot test in several cancer registries; year three, available to the public to download for a fee.

B. Only five states completed the Great Circle Distance calculations last year during the Call for Data. NAACCR needs it to be tested in all US states. Information is needed on validity of the meaning of “facility” in relation to help potentially refine standards for these variables. Please submit it this year as the information will be useful for the Komen project too.

3. Editorial Board for CINA

An invitation was sent to the membership to join the Editorial Board for CINA. There was a large number of volunteers. The volunteers chosen will oversee the process of Call for Data submission, with an expansion of responsibility to cover all CINA data uses. The Call for Data will come out in early August, again as an electronic submission process.

4. Preparation of Highlights for CINA 2000-2004

This summer, two internships are being offered for data research and analysis. One internship is being funded by C-Change and will be completed in California under Tina Clarke Dur at the Greater Bay Cancer Registry. The intern will be completing a data analysis project using the CINA Deluxe dataset. The second intern is working at the Massachusetts Cancer Registry and will be doing an analysis of the CINA data submission, resulting in a 5-10 page summary of Highlights from the CINA monograph 2000-2004.

5. Update on Sister Study & Osteosarcoma Study

It takes six months to a year for registries to go through local hurdles to have data available for a research protocol. With the Osteosarcoma Study it seems to take three to five years for the cancer centers to prepare for the study. NAACCR needs to let researchers know it is not a quick process.

The Sister Study received negative responses from registries that originally said they were interested in participating. The registry-specific research matrix data on access protocols for researchers on the NAACCR website does not seem accurate because the Sister Study has received some responses that registries cannot contact patients when the matrix states they are involved in patient-contact research. Holly also noticed that updates sent by registries involve a change in many to require active consent of physicians before a patient name can be released, rather than a passive consent. Comments from the discussion are:

- Ohio would like to be involved in Sister Study, but the size of the study has prevented them from doing it, so far. Because their state has a law that prevents the registry from contacting patients without physician consent, the Ohio registry would have to contact physicians, 24,000 patients, and get IRB approval. They are still trying to participate in the study with help from the American Cancer Society.
- New Jersey was exempt from IRB approval. In their state, it was considered recruiting, not being involved in research. The registry sent out approximately 11,000 letters and recruited almost 300 sisters to enter the study in New Jersey.
- Nebraska Cancer Registry did not have to get IRB approval, but did not have the manpower to do all the work. So the Study is doing almost all the work (preparing 4,000 letters) and the Nebraska Registry just needs to address the envelopes.
- Iowa said their cost was too high for the Sister Study. It would be easier if the researcher had already told them their financial limits before they worked on the budget.

- Ohio feels that the registry's limited resources are the biggest holdup. Other researchers take on more responsibility by going to the IRB and completing the mailing.
- Arizona could not participate because they need the researcher to go to the IRB, not the registry.
- Illinois said their cost was too high for the Sister Study.
- Michigan can't let the researchers do the mailing; they have to be done by the registry. The follow-up protocol to non-responders can be time consuming and that raises the cost.
- In Los Angeles, the studies are inexpensive because the researchers have been able to get IRB approval and send the letters themselves. But because there are so many breast cancer projects going on in the area, they were not able to participate in the Sister Study per a California law.
- Brenda suggested that cost can be determined by characterizing registry responsibilities and determining target number of responses.
- Holly would like to be more knowledgeable for future researcher requests. It seems there needs to be a greater understanding of cost and resources available to each registry and who will be responsible for taking the study to the IRB. Considering the different state scenarios, NAACCR could better determine definition of responsibilities and cost of the study to create a budget.
- Ohio did not have any problems during the Osteosarcoma Study. The researchers put in their application for the IRB and got approved.
- In Maryland, the Attorney General is currently reviewing the definitions and policies. Diane suggested a column on the Excel spreadsheet that defines how patients can be contacted.
- Manitoba replied in writing after the Town Meeting. Their response was, "We do facilitate contact with patients (for research). Researchers would still have to go through our local Ethics Board and CancerCare Manitoba's Research Impact Committee - the latter ensures that we don't overstudy a patient group (eg., breast cancer). We can help the researchers in our local processes but there are the usual forms to complete. We also have standard wording that we like to have explaining how the patient was identified and who they can contact if they have questions about the study or have "bad memories" resurrected (our psychologists make themselves available but we need to involve them). We have a process whereby the registry mails out the package outlining the study and the consent form - the consents/replies can be sent back to the researchers directly. We would definitely incur some costs in manpower - and a recent experience has shown that identifying patients and getting packages organized, and facilitating approvals, can be quite labor intensive. (Our recent partnership with the National Cancer Institute of Canada on a survivorship study has been illuminating - we're tracking how much it will cost, but they've offered us up to \$30k for 1,600 patients with one follow up contact. We'll know soon if the real cost is \$10k or \$30k or something in between. All contact with patients - before they consented - was through the registry. Note that if the researchers change their questionnaires/consent forms it is chaotic with the IRB!) I'd be happy to join Vivien's committee (or at least, on an ad hoc basis) to describe our experience."

Holly described a new research subcommittee of the Data Use and Research Committee that Vivien Chen is chairing. The group wants to expand the spreadsheet which currently contains the initial information only. For researchers to do the work more effectively, they will need more information and registries need to provide more

information. This tool can be greatly expanded and next year it may be an Access query. Vivien suggested grouping the registries into different types of research, such as registries that can do linkage. Holly suggested having a Town Meeting in the next year to discuss how to improve the information and what details to include.

6. Updates on Researcher Access Database

During next year's annual Call for Data, there will be a form that will automatically update the data immediately. Vivien's group will expand it to make it more useful, but this may not be available until the following year.

7. Closing Comments

Holly thanked everyone for joining the call and their comments on the Town Meeting. She hopes to see everyone at the Annual Conference in Detroit.