## **NAACCR Town Meeting**

# NAACCR Committee Activities – Institutional Review Board, Scientific Editorial Board, and Cancer Registration Steering Committee March 22, 2007

1:00 pm Eastern; 12:00 pm Central; 11:00 am Mountain; 10:00 am Pacific

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

**2 Canada:** Manitoba Cancer Registry, Cancer Care Ontario

**12 U.S.:** American Cancer Society, Centers for Disease Control and Prevention, University of Southern California – Keck School of Medicine, Massachusetts Cancer Registry, Michigan Cancer Surveillance Program, National Cancer Institute, National Cancer Registrar's Association, Nebraska Cancer Registry, New Hampshire State Cancer Registry, New York State Cancer Registry, North Dakota Cancer Registry, Virginia Cancer Registry

**3 Speakers:** Dr. Holly L. Howe – Chair of Institutional Review Board, Dr. Myles Cockburn - Chair Scientific Editorial Board, Dr. Elizabeth Ward – Cancer Registration Steering Committee

**3 NAACCR Staff:** Dr. Holly L. Howe, Moderator – Executive Director, Royale Anne Hinds – Assistant to the Executive Director, Lori Havener - Program Manager of Standards

1. Introduction Holly Howe

This is the last of the series in Town Meetings on NAACCR committee activities. The NAACCR Board's goal was for each Committee Chair to have the opportunity to describe their committee activities to the membership. NAACCR is an organization that is run by committees and their activities are led by volunteers with NAACCR staff support. The Town Meetings provide more detail than the Annual Business Meeting.

### 2. Institutional Review Board (IRB)

**Holly Howe** 

The IRB is charged by the Board to review all projects that are NAACCR sponsored or that use NAACCR data files prepared from the aggregation of registries' data through the annual call for data or through special studies using criteria to protect human subjects. The IRB operates under federal guidelines. All IRB materials (forms and guidelines) are posted on the NAACCR website under "About NAACCR".

**Members** - Holly Howe serves as the chair and John Fulton serves as the vice-chair. The Administrative Coordinator of the IRB, Royale Anne Hinds, keeps the IRB in compliance with federal guidelines, monitors ongoing projects, and prepares materials for review. The Board consists of six voting members and six alternate members, all of whom attend all meetings. Alternate members only vote when the voting member with whom they are matched is absent. Diversity is important, such as varying expertise, degrees, interest areas, race, and gender. There must be a non-NAACCR affiliated member on the IRB. In the past, the IRB has had trouble locating people to serve in this capacity.

The members can serve up to two three-year terms. The IRB uses a rolling term so that each year four go off and four go on. There is online training on the Office for Human Research Protections (OHRP) website that must be completed by each member. A certificate of completion is kept on file for each member at the NAACCR office.

**Meetings -** The IRB meets twice per year for approximately 30 minutes to review the work that has been completed over the previous six months. Reviews are conducted throughout the year, so the bi-annual meetings use a summary of projects that have been terminated, projects under annual review, and new proposals.

**Reviews -** Proposals are reviewed by the Research Proposal Review Subcommittee of the DUR Committee before coming to the IRB. Most reviews conducted are exempt reviews. Policies are set up to facilitate the reviews. Any proposal that is only using the standard data variables in the standard defined way in CINA Deluxe can be considered an exempt project. Exempt projects only require one reviewer. If that reviewer feels that it should be an expedited review, a second reviewer is enlisted to complete another review and the more conservative of the two reviews is followed. The IRB has not had any projects that require a full board review. Once the reviews are conducted, they are mailed to the entire board, so they may comment or ask questions on the results within two weeks of completion.

### **Questions and Comments for the IRB**

- Marsha Reichman asked if the IRB has ever had a request to get a specimen from a registry in addition to the data. Holly responded that the IRB has not had that type of request.
- Marsha asked if a non-cancer person at NCI would be eligible to serve on the IRB.
   Holly replied that they would be eligible as long as there is no affiliation with NAACCR. Marsha may have an interested person.
- Brenda Edwards said they have a list of advocates that may be interested in serving on the IRB.
- Myles Cockburn suggested local IRBs may also have people interested in serving on the NAACCR IRB.
- Brenda asked if the membership and minutes are posted on the website for the IRB meetings. Holly responded that the members are listed within the IRB Guidelines on the NAACCR website. The minutes of the meetings and the summaries that are used to track the work of the IRB are not posted on the website. Holly said the ongoing projects can be found in the annual NAACCR Annotated Bibliography of Research & Publications in the "Research in Progress" section. Even though a new initiative, the research done from CINA Plus in SEER\*Stat cannot be tracked and these will not be included in NAACCR's Annotated Bibliography.
- Hannah Weir requested clarification on the CINA Plus in SEER\*Stat use being tracked. Holly has a list of who has access to the data, but does not know what projects they are working on and what publications may come out of their work. The access to the data file is restricted to NAACCR members only.
- Kurt Weiss asked if there is a time limit to CINA Plus in SEER\*Stat access. Holly said access is for one year or until the next data set is released. At that time they need to reapply and sign a new Data Confidentiality Agreement. This type of access does not require IRB review.
- Myles Cockburn asked if the information on the website indicates they should run publications through the SEB. No, the website does not indicate they should have

reviews completed by the SEB. Holly will check the researcher agreement to see if it indicates that publications should go through the SEB.

## 3. Scientific Editorial Board (SEB)

Myles Cockburn

The SEB is charged by the Board to organize and implement a peer-review process for scientific work by NAACCR Committee(s) or NAACCR researchers that results in manuscripts for public dissemination. The work is based on data that are not in the public domain. Scientific documents for public dissemination prepared by or for NAACCR must be reviewed by the SEB. The SEB is responsible for scientific review prior to release or publication.

The reviews of the SEB include the NAACCR website and the Annual Report to the Nation (ARN). Recently, they have been trying to clarify exactly what should and should not be reviewed by the SEB. All research comes through Holly, who decides if it needs to go through the SEB process. As the Chair of the SEB, Myles is responsible to make sure the manuscript receives appropriate review in a timely manner. There is a liaison between the SEB and the Board of Directors. Currently, there is a Chair, plus two other members. They will be recruiting for a third member in the future. The SEB members have two important tasks:

- 1. They keep the Chair informed of possible reviewers.
- 2. They meet 2-3 times per year to review activities and discuss updates of the SEB.

The members tend to be the default reviewers if there is a short deadline. For example, the Annual Report to the Nation must be turned around in two days. There are 15-20 manuscripts to review each year. The turn around time is 2-8 weeks, but it can take longer in some situations. There is a database of reviewers with their expertise, so that a reviewer can be easily located. The review is similar to the same review that you would receive when submitting to a journal. The intent is to have high quality material coming from NAACCR. Manuscripts are reviewed by two to three experts. Myles summarizes the reviews and provides an acceptable as is, acceptable with changes, acceptable with changes requiring resubmission or unacceptable rating. It doesn't seem to be a duplication of effort, because they are the same changes a reviewer from a journal would make them change. If the authors do not agree with the reviewer's comments, the SEB would like to know the author took the comments seriously. NAACCR doesn't have the recourse of a journal by not being able to publish the manuscript. The SEB reports the number of manuscripts to the Board of Directors and what the results were.

### **Questions and Comments for the SEB**

• Brenda Edwards asked if the SEB tracks the path of the manuscript after it has been reviewed. Myles responded that once the SEB makes their final designation, their responsibility is complete. The author is required to notify the Board of what happened to the final paper. Holly responded that every project that has been approved by the IRB is followed up on through the Annotated Bibliography process. NAACCR asks that any publication be sent back to NAACCR so that we can share it with the membership. Many authors forward the publications, but not all are returned to NAACCR.

Brenda asked if the SEB keeps track of all the papers that come from CINA Deluxe.
 Myles said the SEB does not know that information. Holly said that the Annotated Bibliography usually describes the source of the data.

## 4. Cancer Registration Steering Committee (CRSC)

**Elizabeth Ward** 

The CRSC is charged by the Board to ensure coordination in the development and implementation of major data items, standards, and procedures related to cancer registration, including changes initiated by NAACCR member organizations and those initiated by external organizations.

The CRSC evolved from two different groups, the Implementation Oversight Board and the NAACCR Board/Sponsoring Member Organization meetings. Holly started the Implementation Oversight Board by gathering people on in informal basis to periodically discuss the implementation of benign brain coding and collaborative stage. The NAACCR Board/SMO meetings brought a group together as they discussed changes or new standards being developed by their organizations. Other members would express interest in participating because of the relevance to their work. They realized that there was a need to bring the standard setters together to work on changes. At the NAACCR Leadership Retreat in 2004, it was decided to bring the two groups together and formalize the Implementation Oversight Board into the CRSC. They would meet regularly and have a Chair. Their goal would be to bring ideas of workgroups and changes to the CRSC at the inception phase. The CRSC has representation from each of the Sponsoring Member Organizations, Canadian Registry, and NAACCR, including the Chairs from UDS and ROC Committees. The CRSC has been meeting in the current configuration every two months for a year and a half. Some activities of the CRSC include:

- Providing an opportunity for the various groups to react to changes or activities going on within the UDS and ROC Committees.
- Dealing with issues that come up through the GIS Committee. They had the GIS Chair attend the CRSC meeting to represent the committee's recommendations.
- Reviewing the ROC's project on new death clearance processes.

#### Questions and Comments for the CRSC

 Holly commented that the IOB was not fulfilling the needs of everyone. The CRSC has been successful and fulfills the original needs.

## 5. Closing Remarks

**Holly Howe** 

Holly thanked everyone for joining the call. She hopes that everyone is looking forward to the Annual Meeting in Detroit. The committee meetings, which are open to anyone, are taking place on Monday, June 4<sup>th</sup> from 1-5pm. The schedule is listed in the program or you can contact the Chair for the meeting time. Feel free to attend a meeting. If you are interested in joining a committee, you can contact the chair of the committee directly or Holly can link you to them.