NAACCR Town Meeting NAACCR Committee Activities – Information & Technology and Uniform Data Standards January 30, 2007

2:00 pm Eastern; 1:00 pm Central; 12:00 pm Mountain; 11:00 am Pacific

Present – Representatives from the following registries and organizations:

1 Canada: Manitoba Cancer Registry

18 U.S.: American College of Surgeons, Arizona Cancer Registry, Centers for Disease Control and Prevention, Florida Cancer Data System, State Health Registry of Iowa, Louisiana Tumor Registry, Massachusetts Cancer Registry, Maryland Cancer Registry, National Cancer Registrar's Association, New Jersey State Cancer Registry, New York State Cancer Registry, North Carolina Central Cancer Registry, Oregon State Cancer Registry, Puerto Rico Central Cancer Registry, Registry Widgets, Utah Cancer Registry, Virginia Cancer Registry, Wisconsin Cancer Reporting System

2 Speakers: Mr. Ken Gerlach – Chair of Information and Technology Committee and Mr. Andrew Stewart - Chair of Uniform Data Standards Committee

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

1. Introduction and Background

Holly Howe

During the Town Meetings, we are taking an opportunity to describe to the membership the activities of the NAACCR Standing Committees and their sub-groups. The Town Meetings provide more detail than the Annual Business Meeting. One purpose is for the membership to become more familiar with NAACCR, a committee-based organization. The other purpose is to let members line up their talents and interests with the various committees.

Holly gave an update from the Leadership Retreat, which was attended by the NAACCR Board Members, Sponsoring Members Organizations, and Committee Chairs. The biennial Leadership Retreat took place in early January in Charleston, SC. At the retreat, they discussed short term (within two years) overarching priorities of the organization.

The Board realized that there is a lot of standardization going on outside of cancer registration, even on an international level. So that the standardization that NAACCR has been working on does not become replaced or obsolete by other standard setters, they decided to bring in experts in Informatics. They invited a speaker, Dr. Peter Winkelstein from the State University of New York at Buffalo, who will also be speaking at a plenary session at the NAACCR Annual Conference. He spent an afternoon discussing the correct words to describe these things. The focus of this is called "interoperability", which means the information will be electronically exchanged easily through departments to hospitals to cancer registries to NAACCR to external data sources, such as death records, electronic health records, etc. There are two types of interoperability:

Syntactic Interoperability is the messaging between systems. Systems need to be able to send messages to each other, retrieve messages and read messages.

Semantic Interoperability is when the information shared is meaningful. Gender is an example of information that is not fully interoperable semantically. In cancer registration, there are more gender possibilities than just male or female, but other standards only have two options: male or female.

The NAACCR Board is focusing on being in sync with electronic health recording and the transfer of electronic information. There will be new committees formed to focus on the electronic environment. Lori Havener will be the point person at the NAACCR office working on these changes.

2. Information and Technology (IT) Committee

Ken Gerlach

The IT Committee is responsible for developing the standard format for data exchange among members and for developing standards to ensure the security and accuracy of transmitted data. There are seven broad areas that the IT Committee is involved with, six of them being covered by work groups.

The **Volume I Subcommittee** addresses data exchange standards and record exchange descriptions. It is trying to facilitate the electronic transmission of cancer registry data among cancer registries. Volume I is the bare bones of how a message should be constructed and is connected to Volume II. Typically, Volume II is developed and completed, then the IT Committee will meet and wrap up Volume I.

The **Pathology Laboratory Subcommittee** is engaged in a number of tasks revolving around electronic pathology reporting. This group maintains the NAACCR Search Term List. The subcommittee distributed the Operations and Guidance for Electronic Pathology Reporting through the NAACCR List Serv in January 2007.

The **Epath Transmission Work Group** looks at the data exchange standards for the anatomical pathology report, so that we can have one HL7 national standard. They have developed Volume V, which addresses Anatomical Pathology Reports. Volume V will be updated periodically. They will be looking at synoptic reporting and conversion from HL7 2.3.1 standard to HL7 2.5 standard. They are monitoring the activities of HL7 Anatomical Pathology Special Interest Group. The Work Group is looking at HL7 conformance testing software, which can ensure that the message or structure is correct.

The **Interoperability Work Group** is a combined effort by IT and UDS. Andrew will discuss this work group during the UDS presentation.

The **Cancer Abstract Transmission Work Group** explores alternate mechanisms or messages to transmit the cancer abstract. This is associated with Volume II. They have reviewed a variety of formats to decide which would be most appropriate. They decided on HL7 Chronicle Document Architecture (CDA) Format. It allows more text information. There is an ongoing pilot study where they are transmitting cancer abstracts in CDA format from a hospital registry to central registry.

The **Security Work Group** is a joint effort between IT and Registry Operations Committees. They will explore information and technology security needs for cancer

registration, bring the information together, and develop guidance where they need to. They plan to look at hardware, software, firewalls, internet transmission of data, webbased applications, data encryption, security policy, and disaster recovery. This group will meet for the first time in February 2007. Ken welcomed anyone with interest to join the group.

3. Uniform Data Standards (UDS) Committee

Andrew Stewart

The UDS Committee will be looking for a new chair because Andrew will be stepping down at the June 2007 Annual Conference.

UDS provides a formal mechanism to review and recommend proposed changes in data codes and/or the addition of new items submitted by NAACCR members to ensure that data remain comparable among central registries and other standard setters. Further, the committee provides a formal mechanism for reviewing and recommending edits of NAACCR-approved data items.

The members of UDS are primarily made up of three different groups:

- The standard setters, such as SEER, NPCR, ACoS, AJCC, NCRA, Canadian Registries.
- A large mix from the state's central registries.
- Commercial software vendors decisions made by UDS have a direct consequence on their products.

There are two work groups:

The **Volume II Work Group** completes the Volume II publication, which serves as a data dictionary for standard setters, vendors, central registries, and hospital registries.

The **Edits Subcommittee** provides a form for standard setters and others to review and monitor the logical content and structure of the EDITS that are used throughout the US in transmitted case records.

There are two ad hoc groups:

The **Implementations Guidelines Work Group** meet when Volume II goes through changes. The Work Group provides a form and mechanism to ensure that changes are adopted in a universal and consistent manner. They most recently completed work in the fall of 2006 on the Implementations Guidelines for 2007.

The **Interoperability Work Group** was formed with one short term and one longer term goal.

The short term charge for the work group is to asses and comment on the feasibility and implementation of the National Provider Identification (NPI) numbers that are distributed by Medicare and Medicaid centers. The NPI is a nationally standardized numeration system to identify providers of healthcare. The Interoperability Work Group defined the NPI, identified to whom NPI numbers were being distributed by the Federal Government, who would be reporting these numbers, and what the numbers would represent. Work was completed and findings were incorporated into the 2007 Implementation Guidelines.

• The longer term charge is to consider NAACCR data items with respect to their continuity with other nationally recognized data standards. This could be a request to look at the syntactic and semantic interoperability that Holly defined earlier. The work group has begun to look at how NAACCR works with dates. We need to have common meaning and common interpretations outside of the registry world.

4. Questions and Comments for IT and UDS

How are committee meetings structured?

Ken Gerlach answered that Vol. I Subcommittee meets as needed. The other subcommittees and work groups meet once a month, as does the IT Committee. During the IT Committee meeting, the subcommittee/ work group chairs give updates. The IT committee oversees the activities of the subcommittees and work groups. Andrew Stewart explained that UDS and its subcommittees and work groups meet once a month, with the exception of Volume II and Implementation Guidelines work groups, which meet as the work demands. Both UDS and IT have scheduled deadlines with the NAACCR Board to complete publications, which may require more work to be completed before the deadline.

Do the committees have websites?

Holly answered that the Committee meeting minutes are posted on the NAACCR website once they are approved by the committees. They usually run one to two months behind the meetings. Check on the NAACCR Website under "About NAACCR" for committee information. More specific questions can be answered by any committee or board members.

What is NAACCR doing to ensure that the national people developing the Electronic Health Record know that NAACCR would like to be involved for cancer registration? Holly replied that there is no assurance, but NAACCR is doing several things. A large portion of time at the Leadership Retreat was dedicated to this. An action plan is coming out of the Leadership Retreat and has been defined as the number one priority for the organization. Lori Havener has been named as the point person for NAACCR. She will make sure that we are interacting with all the people that we need to interact with. Each work group is addressing data items to make sure that data items are fitting into the big picture. NAACCR has chosen the HL7 and HL7-CDA route as a crosswalk to the standard setters. Pilot testing and review of all data elements is being completed. By 2010, we have a goal to put out version 12 of the NAACCR Standards including a new method of transmission, HL7. Lori is attending Health Information Technology Standards Panel (HITSP) and HL7 meetings. Ken and Lori make sure that each meeting is attended by someone from NAACCR so that cancer registration is covered. NAACCR is working with NCI on CABig and making sure that NAACCR Standards are compatible with the vocabularies that are developed. We are keeping memberships and relationships with the groups that we feel we need to meet with about cancer registration.

Is there a committee forming this plan?

Part of the action plan from the Leadership Retreat is to review the interoperability activities of all the subcommittees and work groups. The interoperability activities need to report directly to the NAACCR Board. They may keep their own identity, but there will be an overarching committee to oversee the interoperability activities. More information will be coming out in the next six months.

5. Closing Remarks

Holly Howe

Holly thanked everyone for joining the call. The next Town Meeting in the committee series will be with the Program and GIS Committees and will be held in mid-February. When details are finalized, they will be sent via the NAACCR ListServ.