



Minutes

NAACCR Board of Director's Meeting

Wednesday, November 15, 2017

2:00 PM – 4:00 PM Eastern

Roll Call

Nan

Board Members Present: Nan Stroup, Deirdre Rogers, Frank Boscoe, Randi Rycroft, Chris Johnson, Heather Stuart-Panko, Chuck Wiggins, Isaac Hands, Maria Schymura, Lori Swain

Board Members Absent:

Ex Officio: Betsy A. Kohler

Staff Member: Charlie Blackburn

Consent Agenda

All

1. Minutes
2. Finances
3. Executive Director's Report
4. Correspondence

THE MOTION TO APPROVE THE CONSENT AGENDA FOR THE NOVEMBER 15, 2017, BOARD MEETING WAS PASSED.

Governance

5. Call for New Items to Agenda

Nan

- a. Chris added discussion of document reviews for 2017-2018

6. Program Updates

- a. **Canada**

Heather

Dr. Craig Earl is the new President of CPAC. He is medical oncologist and started in October. Registries are very busy with the call for data submission. Canadian Council approved the list of Data elements. In November, Vancouver hosted the 4th Annual Canadian Cancer Research Conference. One presentation from this conference was multi-centered and aimed at estimating the current and future avoidable burden of cancer in Canada, due to all known behavioral, environmental and infectious agents up to 2042. The Public Health Agency of Canada is establishing a Canadian Chronic Disease Surveillance System and want to include cancer information. The Canadian Council of Cancer Registries is therefore trying to work with them to incorporate data from the Canadian Cancer Registry rather than them duplicating efforts and capturing the same data which may not be consistent.

b. NPCR

Chris

There was an NPCR Town Hall meeting held on November 1st. They reviewed the Core requirements for NPCR based on Program Standards, the continued emphasis on meaningful use, and talked about a new NPCR data field for 2018 cases that flags a case as having at least one abstract that is an analytic case from a CoC facility. This will be used to know which records to apply which staging requirements to. Data files due at end of November.

c. SEER

Chuck / Nan

Marla Jacobsen from the NCI SEER contracts office is leaving at the end of the month. She has been the contracting officer supervisor. There is no timeline for a replacement at this time. There is still no word on contract negotiations for the SEER proposals. There has been absolutely zero communication at this stage.

7. Debrief on CDC / NAACCR Meeting

Betsy / Nan

Nan and Betsy attended a meeting at CDC in Atlanta. There were several CDC representatives. Some were familiar with NAACCR and others were not. Prior to the meeting, Betsy met with the Strategic Alliances Committee to gain input. Betsy provided the specific details of their presentation and how NAACCR work specifically relates to NPCR registries and staff. Lori asked if there was any clarity they could provide on the upcoming application for the next co-op. CDC said that they were not able to provide specific information. Overall, it was a very productive meeting. CDC was open to having Betsy attend program manager meetings and their Town Hall Meetings in the future. There will be monthly phone calls and Betsy will attempt to uncover as much as she can about the future of the funding.

8. Membership Applications

a. Southern Plains Tribal – Update

Chuck

Chuck has a call for tomorrow. Their epidemiology center (there are 12 of them) is in charge of improving the infrastructure of their territories. This particular health board is responsible for the southwest region. They are securing the set-up of the cancer registry under their purview. They will pull together data from many sources to have their own registry. They are submitting a grant which may benefit them from having a NAACCR membership. However, it needs to be determined if this is the best course or not. Chuck heard from someone that this may not necessarily be a good idea because current registries already do this work and it may be duplicative. Maria noted that they are not yet a full cancer registry and it may be putting the cart before the horse. Nan recommended they could consider being a Sustaining Member Organization. The Oklahoma Registry is an example of this potential overlap. Chuck will update the Board at the next meeting or prior via electronic means.

b. IntegraConnect – Update

Nan

Nan attempted to have a phone conference with their representative this afternoon. They are an EMR vendor. They came across our crosswalk on the web site. Their company is a very young EMR vendor. They have been open less than a year. Specifically their regularity and compliance unit is interested in NAACCR. Nan endorses them as a member.

THE MOTION TO APPROVE INTEGRACONNECT AS A SUSTIANING MEMBER WAS APPROVED

Kristen Beyer – New Application for November

All

Nan and Chuck both know Ms. Beyer and are familiar with her work and past. Mary Foote endorsed her membership. The Board discussed her membership in detail and are in favor of approving the application.

THE MOTION TO APPROVE KRISTEN BEYER AS AN INDIVIDUAL MEMBER WAS APPROVED

c. Need for Reviewer

Betsy

In past years there was a membership committee. However, during the evaluation of committees to improve efficiencies with the committee overhaul several years it was removed. Recently, we have had a change in the types of organizations that are applying for membership. Betsy would like to have a volunteer of the Board that can review the applications and bring information to the Board. Nan asked for a volunteer. Maria Schymura will act as the membership reviewer for future memberships.

WOW Initiatives

9. Virtual Pooled Registry

Betsy

a. Camp Lejeune RFP

Betsy was recently contacted by Battelle to subcontract NAACCR for an incidence study of Camp Lejeune. Betsy and staff have had much conversation with Battelle about this partnership to possibly use the VPR concepts and methodologies. The proposal is due this Friday. Betsy is very encouraged by this partnership. The Board discussed nuances of the proposal and how NAACCR / Battelle would work the partnership. The Board provided some direction on how we should proceed with this proposal.

10. International Cancer Registries

Betsy

No new updates.

11. Registry of the Future

Nan

a. Comments on Report

No new updates other than the continued meetings with the steering committees which discuss the SMP and registry of the future

12. Disposition of other priorities from March

Nan

- a. Volunteerism
- b. Advocacy Strategy – RDU to come up with fact sheet template
- c. Repackage of Data-to RDU
- d. Other Business Options
- e. New Markets
- f. Add Robustness to Any Assessment of Research-to RDU
- g. New Services
- h. Free Thinking

Strategic Alliances

13. Steering Committee Update

Betsy / Chuck

Updates about the Camp Lejeune and CDC meeting were provided prior.

14. NLCTR Membership Request

Betsy

NAACCR was approached by the National Lung Cancer RoundTable to participate in this event. In addition, they have asked about membership to their organization. The Board discussed the benefits to joining this organization and how potential partnerships could come out of a relationship with this organization. NAACCR is not necessarily in a position to join each and every organization that requests us to join but this is worth consideration. Betsy suggested that she attend the meeting in D.C. since it is very close. At that meeting she will evaluate common interests and mission to determine if the Board should consider joining their organization.

15. Status of Membership Dues

Charlie

- a. SMO Dues
- b. All Other Dues

Charlie provided the report detailing membership dues status. In particular, the Board has been monitoring the SMO membership dues. AJCC and CAP are the only SMO members that have not yet paid. Other categories are on pace with past years and in some cases better. Charlie recommended Board action or communication with AJCC and CAP but the others do not warrant specific communication. Given the meeting timeline, the Board will revisit this topic at the December 2017 Board meeting.

Professional Development

16. Steering Committee Update

Deirdre

The last meeting was October 26, 2017. They are finishing presentations of the survey course. The hackathon planning continues. Lori Swain has been participating on the calls to discuss NCRA recruitment and retention efforts. A survey on recruitment and retention will be sent to the membership.

17. One on One Meeting

Nan / Deirdre

Nan has conducted several one on one meetings with Steering Committees. These updates will follow later in each steering committee update. A call was conducted with Board members, liaisons, and leadership of the committee. Much of the discussion and action items revolved around updating the work plan, current events and activities, and implementation of the registry of the future and strategic management plan. Training was a large piece of those plans. Challenges, opportunities, and topic areas were detailed and will be announced at the March Board meeting.

Research and Data Use

18. Steering Committee Update

Chris / Isaac

Their most recent meeting was cancelled. However, a task force meeting of the group did meet to discuss enhancements to certification. They discussed process measures, data measures, and other items that could

enhance certification. Linkages, enhanced file sets, and QC measures were just some of the ideas on how to enhance certification.

An active consent was included in the call for data for the synthetic dataset. Topic ideas have been solicited for the hackathon which will help with the dataset. The responses were excellent and many suggestions were submitted. Isaac continues to meet with a small group to process the suggestions. They expect several to surface for good ideas for the hackathon.

19. One on one Meeting

Nan / Chris / Isaac

A meeting is still pending which will be held on November 27th.

20. Synthetic Dataset Update

Chris

Update provided above.

Standardization and Registry Development

21. Steering Committee Update

Heather / Randi

The meeting was held on the October 26. A meeting has not been held since then.

22. XML Implementation

Isaac

Mary Jane King submitted a listserv detailing a timeline for the implementation. Lori Havener also has been working on similar communication. Isaac will work on combining these schedules into one. A forum will be spun up for these efforts.

23. Survivorship White Paper

Randi

Randi opened this up for discussion last month. This project was previously supported by CDC. However, it is currently not on their list of priorities and is "orphaned." Randi thinks this can be an additional service to cancer survivors and a positive project for NAACCR. Chris asked if Randi knew how many hospitals that this data. Randi was not aware of the total number at this time. Betsy said that she and CDC discussed this briefly and said that they believe in the project but just don't have the resources at this time. Randi thought that she could perform a demo if needed. Chuck thinks this is a terrific idea and provides a critical connect that has been missing. He also voiced some opinions about the oncology side's argument on the applicability to the patient. Where they can be valuable is with a navigator / explainer. He said this is a good example of the ACoS mandating something that can be challenging to implement and make practical. This could be a \$150,000 a year expense which would need to be vetted before proceeding. Maria asked if IMS should review the document to get their view of this. Randi thinks this would be good to obtain input but also add SEER DMS. IT was mentioned that this could possibly be a new source of revenue so it should be at least investigated. Betsy will look into this with IMS and report back to the Board or Randi.

24. One on One meeting

Nan / Randi

The meeting was held and an update will be made at the March meeting.

Communications

25. Steering Committee Update

Lori / Frank

Robin Malicki (Co-Chair) is moving into a new role outside of cancer.

26. One on One Meeting

Nan / Lori

The meeting was held and an update will be made at the March meeting.

Other

27. Puerto Rico Assistance / Contact with Staff

Nan

Nan has been in contact with the Puerto Rico Cancer Registry. She wanted to follow up with their leadership to inquire if NAACCR can be of any assistance in light of the hurricane devastation from late summer. Their registry is operational but not yet fully functional. An extension has been granted for data submission to assist. Nan and Betsy plan to meet with the PR leadership via a web conference later this week. Nan will update the Board after the call.

28. Document Reviewers for 2017-2018

- a. 2018 Volume II Reviewers: Chris Johnson, Frank Boscoe
- b. Implementation Guide: Randi Rycroft, Heather Bryant
- c. Layout: Isaac Hands, Lori Havener (Staff)

29. Adjournment and Next Meeting

The meeting adjourned at 4:00 PM Eastern. The next teleconference meeting of the Board is December 20, 2017.

December 20, March Meeting Objective-Volunteerism
January 17
February 21
March 21
April 18 (Board/Chair)
May 16