



Minutes

NAACCR Board of Director's Meeting

Wednesday, September 18, 2019

2:00 PM – 4:00 PM Eastern

Roll Call

Randi

NAACCR Board Present: Randi Rycroft, Antoinette Stroup, Maria Schymura (slightly early departure), Isaac Hands, Kevin Ward, Lorraine Shack, Angela Meisner, Wendy Aldinger

Board Member Excused: Lori Swain

Ex-Officio Member: Betsy Kohler

Staff: Charlie Blackburn, Lori Havener

Consent Agenda

All

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

Maria

Removed from consent agenda for discussion.

5. Correspondence
 - Geocoder Report
 - Mid-Level and High-Level Strategic Group Notes

Membership application of METAvivor was removed from the consent agenda for discussion. See item #3 below.

The motion to approve the consent agenda for September 18, 2019, was passed.

4. Membership - METAvivor

Maria noted that they appear to be an advocacy group focused on metastatic breast cancer. Based on what they stated in their membership application, Maria's concern is that they do not understand cancer registry data. They seem to be under the impression that NAACCR has better data on stage than SEER does. Betsy said that they have not contacted Recinda on this yet. After discussion it was determined that Maria will contact them to inquire more about their interest and report back to the Board. **Board Action:** Maria will connect with METAvivor to seek further information and report back to the Board.

Governance

6. Call for New Items to Agenda

Randi

- **Komen Grant Opportunity**

Betsy mentioned that NAACCR was approached by Komen for the Cure to distribute information for a funding opportunity to create breast cancer community profiles. After researching this opportunity, it appears well suited for NAACCR to apply for funding. Liz Ward, Recinda, and Frank Boscoe are the team leading the application process. The application is due on September 25, 2019. Betsy will keep the Board updated on the progress.

7. Susan Bolick Retirement

Betsy / Randi

The NAACCR office was informed the Susan Bolick is retiring soon from the South Carolina Cancer Registry. Susan is a past Board member and has been very active with NAACCR for many years. The Board discussed ways to recognize Susan for her contributions to NAACCR and the cancer surveillance community. **Board Action:** The NAACCR Office will start the process of completing a Board resolution for Susan Bolick's retirement.

8. 2020 Election Suggestions / Nominating Committee Update

Kyle / Maria

Maria provided a report on where the Nominating Committee is with the election process. For 2020, the positions that are open are President – Elect, SMO Representative, and three Member-At-Large positions. Several names were presented as potential candidates when the group last met. They are very interested in approaching current Board members that qualify for positions. They have already made contact with Lori Swain as a potential SMO representative. Lori is interested in running for election again but has asked the committee to inquire with other SMO organizations that are eligible to sponsor a SMO representative. Charlie added that the committee is seeking ideas of potential nominees across all positions.

The previous Nominating Committee members began work on developing standard operating procedures; this year's Committee is on track to complete this task.

On a separate note, Maria said that if Kyle is going to remain on the calls then she will step off the calls as a Liaison. When he gets back to work, Randi will check with Kyle on his interest to stay on the committee. After discussion regarding Kyle being on the committee and running for the board, the Board does not think there is a conflict with Kyle being the liaison and running for office also.

Betsy reminded the Board that our Parliamentarian has advised the Bylaws Committee to be careful of how much direction the Board has in the election process. Suggestions are encouraged and as NAACCR members they all have the right to give input and make nominations. However, she said there should not be too much direction from the Board. It must remain a member driven activity. It is noted that this has never been an issue in the past, it was just noted as a simple reminder that the Board be cautious of over involvement and influence in the process. **Board Action:** Randi will connect with Kyle to see if he wants to remain on the committee as a member and Board liaison.

9. Program Updates

a. NPCR

Wendy / Nan

Success stories are due in a few weeks. Town Hall Meeting will be on December 3. NAACCR submitted the NACDD report on September 6, 2019. We are waiting on work of the review. Staff will be in Atlanta in early October. Work will continue through 2020 at this time.

b. SEER

Kevin / Angela / Kyle

Kevin said that last week NCI held their latest hackathon with the Department of Energy (project that involves auto-coding of pathology using machine learning and NLP). The new RFP was issued for the SEER expansion. A conference call regarding the RFP will be held on October 30. Questions are due NCI on September 30. NIH's HINTS survey is going to do a cancer survivorship survey with eligible patients being identified through SEER registries.

c. Canada

Lorraine/Randi/Betsy

Submission of TNM is not required from Stats Canada. Some registries are having trouble and they decided to remove the requirement. There is still work on staging and coding for pediatrics. Finalized information will be available in coming months.

Standardization and Registry Development

10. Steering Committee Update

Isaac / Kevin

August 22 was the last meeting. Important areas of topic were Interstate Data Exchange guidelines. The new guidelines include new columns to Vol II which indicate minimum data elements and minimum edits for cases exchanged with other states. SC reviewed 2018 readiness survey results and will present to the HLSG. SC discussed the Vol V revision work and difficulties surrounding that. Recommendation is to move everything to XML for Vol V standards. There has been discussion on how the data dictionary can be enhanced to better meet researchers needs. Eric Durbin spoke on the informatics group and its formation.

11. Interstate Data Exchange Guidelines

Lori H.

The Interstate Data Exchange Document was sent to the Board for review in the weeks prior to this meeting. Kyle, Angela, and Lori Swain were the reviewers. Each provided their document reviews in advance of the meeting for the Board to digest the changes. The Board discussed the updates and changes in detail. Lori Havener went over each reviewer's comments and addressed their observations. The Board discussed the major changes and which ones need to be updated or discarded for various reasons. In particular, there was discussion on section 1 of Lori Swain's comments. After discussion, it was determined that the changes proposed will work just fine. References to emails will be removed for protection of those involved.

THE MOTION TO APPROVE THE INTERSTATE DATA EXCHANGE DOCUMENT PENDING SUGGESTED CHANGES WAS PASSED.

Communications

12. Steering Committee Update

Kyle / Angela

The update will be provided in October. There was no September meeting.

Strategic Alliances

13. Steering Committee Update

Nan / Lori S.

Nan said that the team charter will be sent to Lori Havener today.

- **Ci4CC Update**
NAACCR had a call with Ci4CC representative to discuss how our two organizations could collaborate. Two potential projects emerged from that discussion: 1) help with revamping Vol II to make it more user-friendly for the research community; 2) a project related to 'real-time' reporting. At their in-person meeting, Ci4CC members will be asked if there's interest in either of the projects. No other updates at this time.
- **OVAC update**
There was a meeting last week but no budget has been approved. There is no knowledge if the suggestions to increase CDC and NCI budgets will be pushed though or not. There is a Hill briefing scheduled for Oct 22nd, at which Vicki Benard from NPCR will be part of a panel and her role will be to discuss cancer registries. Their annual meeting is tentatively set for December but no firm date has been set yet.

Research and Data Use

14. Steering Committee Update

Maria / Lorraine

The last RDU meeting the primary item was to review the work plan. Comments were received and will be implemented. She noted healthy discussion on cancer facts sheets and cancer clusters. Hannah is working on

this initiative of the fact sheet and will continue to be involved in that process. The next meeting will take place during the last week of September.

15. Data Confidentiality and Security Survey

Angela

Angela showed the survey to the Board. This has long been in development with the committee. Nan and Randi commented that there were some typos and possible confusion on the transition between topics. Nan also asked why there were signatures for Nan, Betsy, and Randi – perhaps the letter should be signed by Recinda and Liz. Those that provided comments felt as though the survey was fairly long. The Board discussed nuances of the theme of questions and practicality of sections. Most feel as though there needs to be some further dialogue before it is sent. They want to break it up into pieces where a single person can answer in each discipline. They want definitions added with clarification of what they mean. They thought that some questions could have more than one answer. Check for clarity of questions, conditional logic flow, and spelling. **Board Action:** Angela will get back with Recinda to give input. The Board will send feedback to Angela for specific changes by September 27, 2019.

Professional Development

16. Steering Committee Update

Wendy / Lori S.

The last call was August 22. The LMS Survey Course continues to be updated. The telecommuting document is almost complete. NAACCR is still seeking input on the ETC trainings (CDC cooperative agreement work). Jim Hofferkamp is receiving input on that project from registries.

Angela is working on new member initiatives. She is considering a meet and greet at the NAACCR conference. This may include NAACCR members, Chairs, and Board Members. Betsy said that this could be referred to the Program Committee. Nan will bring this to the planning committee group.

17. 2020 Conference Update

Nan

A meeting was held this week. They changed the theme to “Cancer Surveillance... Keystone to Progress.” Several speakers are already confirmed. The logo should be completed by the end of the month. The first hackathon planning meeting will be held next week.

Other

18. Board Self-Assessment Update

Lori S. / Kyle

This update will be provided next month.

19. Board Policy Initial Review

Lori S.

- Note: Update set for October.

This will be brought up as a specific update by Lori Swain at the October meeting.

20. Adjournment and Next Meeting

All

- October Meeting 1 hour. Audit presentation scheduled.

Nan reminded the Board that Chair and Committee updates will be needed for the October Board / Chair meeting. This will be discussed at the next meeting of Nan, Betsy, Randi, and Lori.

Scheduled Board Meetings 2019 – 2020

Board/Chair: 2:00-3:00 PM Eastern; **New Date: October 9**

Board Only: 2:00-4:00 PM Eastern:

November 20

December 18

January 15, 2020
 February 4-5
 March 18
 April 15 (Board/Chair)

May 20
 June 21
 In-person; 2020 Annual Conference, June 21-26

NAACCR Board Action Items		
Item	Responsible BOD Member / Person	Status
September 2019 Action Items		
Maria will connect with METAvivor to seek further information and report back to the Board.	Maria	
The NAACCR Office will start the process of completing a Board resolution for Susan Bolick's retirement.	Charlie	Completed
Randi will connect with Kyle to see if he wants to remain on the committee as a member and Board liaison.	Randi	
Angela will get back with Recinda to give input. The Board will send feedback to Angela for specific changes by September 27, 2019.	Angela/Board members	
August 2019 Action Items		
None		
June 2019 Action Items		
Angela Meisner is interested in possibly attending the OVAC meeting that NCRA will participate in (Hill Event).	Angela	
May 2019 Action Items		
Betsy will ask Liz Ward to draft a summary response for the Board to look at regarding specialty registries.	Betsy Kohler	
Kyle will work with the NAACCR office will develop a guided tour recording for new Board members.	Kyle Zeigler	

2019 – 2020 Liaisons

Priority Area	FY19 Liaisons	FY20 Proposed
Standardization & Registry Development	Isaac Hands Wendy Aldinger	Isaac Hands Kevin Ward (Junior)
Communications	Lori Swain Kyle Ziegler	Kyle Ziegler Angela Meisner
Research & Data Use	Maria Schymura Angela Meisner	Maria Schymura Lorraine Shack (Junior)
Professional Development	Deirdre Rogers Randi Rycroft	Wendy Aldinger Lori Swain

2019 - 2020 Document Reviewers

Document Review	Primary Reviewer	Secondary Reviewer
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Standards Volume V	Angela Meisner	Maria Schymura
Standards Volume I (June 2020)	Nan Stroup	Lorraine Shack
Standards Volume II (June 2020)	Isaac Hands	Kevin Ward
Implementation Guidelines (FY2021)	Wendy Aldinger / TBD	Kyle Ziegler / TBD
Interstate Data Exchange	Kyle Ziegler	Lori Swain / Angela Meisner

Board Priorities for 2019

1. Building Relations with CI4CC, OVAC, CCCNP
2. SMP Renewal and Progress Dashboard
3. Succession Planning and New Hires
4. Bylaws
5. Membership Categories
6. SMO Representative
7. Steering Committee Quorum Necessary?