

Minutes
NAACCR Board of Directors Meeting
Wednesday, September 20, 2017
2:00 pm – 4:00 pm Eastern

Roll Call

Nan

Deirdre Rogers, Frank Boscoe, Lori Swain, Randi Rycroft, Maria Schymura, Nan Stroup, Chris Johnson, Heather Stuart-Panko

Board Members absent: Chuck Wiggins, Isaac Hands

Ex Officio: Betsy A. Kohler

Staff Member: Charlie Blackburn

Consent Agenda

1. Minutes
2. Finances
3. Membership
4. Executive Director's Report
5. Correspondence
 - a. IMS Proposal

Nan proposed moving ITEM #5 to be discussed with ITEM #25 and #26 below.

THE MOTION TO APPROVE THE REMAINING CONSENT AGENDA FOR THE September 20, 2017, BOARD MEETING WAS PASSED.

Special Item

See Item #26 Below "XML Implementation SRD Steering Committee"

Governance

6. Call for New Items to Agenda

Nan

Nan asked for new agenda items. She suggested discussing the AJCC report from Frances Ross if there is time. If not then this will be discussed in October.

7. Recommendations to Nominating Committee

Betsy

- a. Board composition

The Nominating Committee submitted a timeline for the upcoming election. Betsy reviewed the proposed timeline and activities. The Nominating Committee is asking for nominations currently. Please forward any suggestions to Betsy or Nan. Open seats include President-Elect, Sponsoring Member Organization Representative, and Three Member At-Large positions. It was determined that Lori Swain would run again for the SMO position. We will send a letter to eligible SMOs inviting them to name a candidate and notify the Nominating Committee of this action.

b. Self-Assessment

Betsy also asked the Board to consider any weaknesses or expertise gaps on the Board in relation to the SMP and Board activities for candidates. Nan asked Board members to consider the gap that will be left when Chris and Frank both vacate their positions in June.

Nan will contact Kyle regarding another recruiting video for the election.

**8. Decision Regarding Continuation of Lori as SMO
Representative Role on Board**

Nan

See above.

9. Program Updates

i. Canada

Heather

CPAC is planning Train the Trainer webinars to be broadcast in the coming weeks. Duplicates between the Provinces are being addressed. They are also preparing for the NAACCR Call for Data submission. CPAC has just released a publication on End of Life Care. This came out of Canadian recommendations on how providers should move forward. Heather anticipated that this will impact registries at some point.

ii. NPCR

Chris

Funding announcements have been sent out and many NPCR registries have experienced significant cuts in funding. Call for Data is being prepared by registries. The new contract for cooperative agreements allow for support of funding for Registry Plus. CDC is planning to make this cloud-based system. He also mentioned there would be other reporting requirements from the cooperative agreements and leadership committees with comp cancer groups.

iii. SEER

Chuck/Nan

Nan believes that there has been some movement with the RFP review. Some registries have been notified that the application was disallowed and others that their application is in review. She mentioned there are plans to institute a new SEER completeness estimate. Betsy asked to see if it could be shared with NAACCR to see if we want to adjust our methods.

10. CDC Future Funding Strategy for Cooperative Agreement Betsy / Nan

NAACCR tried to continue discussion on the future of the CDC Cooperative Agreement funding restructure which would include NAACCR bundled with other entities. NAACCR asked for further information on this concept but was told that CDC could not discuss this. However, a call with, Mary Lewis and Vickie Bernard is scheduled for October 2

11. March Board/Chair Meeting Nan/Betsy

Charlie said that he will need some direction as to when and where the March Board/ Chair meeting will take place. The Board would like to look into Princeton, NJ during the first two weeks of March. Charlie will get pricing options.

12. Bylaws and Standing Rules Lori

Lori proposed reviewing the Standing Rules and Bylaws of the Association. She also recommended a parliamentary review of these guidance documents. Maria and Lori will work together to review these documents. Lori will connect with Maureen MacIntyre to see if she is interested in assisting. Lori anticipated feedback and suggestions by the March Board meeting.

13. Public Comment on Cervical Cancer Nan

Nan received information on Cervical Cancer public comment solicitation part of the Healthy People 2030 initiative. She sent an email to the Research and Data Use chairs on this idea to see if they were interested in bringing this up at a steering committee meeting. Chris said that there is an initiative to have the survival methodology as a part of the HP 2030 initiative.

WOW Initiatives

a. Virtual Pooled Registry Betsy

A proposal was submitted and accepted for the VPR work for four more years through 2021 as option years. Betsy and Charlie were successful in negotiations to keep this budget level despite NCI efforts to reduce staff time and to reduce consultants in the subsequent years.

b. International Cancer Registries Betsy

A proposal was submitted and accepted for the Global CR-CS work for four more years through 2021 as option years. There were some budget reductions incurred.

c. Registry of the Future Nan

i. Comments on Report

A final report was developed for the Registry of the Future. The report was submitted to the Board. Nan and Betsy would like to receive comments from the Board on next steps and way to proceed with the findings. Special attention should be paid to the recommendations section, which needs development. Nan wants this on the October agenda for discussion. Nan and Betsy complimented the editor, Mike Bykowski, for his excellent work.

ii. Short-Term Strategy /Next steps

The Board also needs to focus on the next steps regarding the Registry of the Future. The Board needs to decide which, if any of these initiatives can be pursued in the next six months to a year.

iii. NCI ROF Proposal (see attachment)

The Board also needs to provide guidance to the NCI who wishes to move forward with the new data sources initiative.

d. Disposition of other priorities from March

- i. Volunteerism
- ii. Advocacy Strategy –RDU to come up with data models
- iii. Repackage of Data-to RDU
- iv. Other Business Options
- v. New Markets
- vi. Add Robustness to Any Assessment of Research-to RDU
- vii. New Services
- viii. Free Thinking

Nan asked for quick updates on Committee Reports in the interest of time.

Strategic Alliances

14. Steering Committee Update

Betsy/Chuck

Presented in report.

15. CDC Visit September / October

Betsy/Nan

Discussed earlier in meeting.

16. Status of SMO Dues

Charlie

Presented in report.

17. NPCR Grantee Ancillary Meeting Follow-Up

Nan

Tabled until October.

Professional Development

18. Steering Committee Update

Deirdre

Tabled until October.

19. Hackathon Update

Frank/Isaac

Frank said that the University of Pittsburgh was interested in partnering with NAACCR on the Hackathon event. A preliminary budget was forwarded to the Board for discussion. Frank said that if approved, the Hackathon would be implemented into the NAACCR Annual Conference during the weekend preceding the meeting. Frank thinks that most participants would be local. The NAACCR Synthetic dataset would be an excellent tool or element for this event. He said that this would need Board OK to move forward on this. He does not think that there is a need to an official vote but more of a verbal approval. He

estimates that up to 50 participants could attend. This is planned to be a one-time event and not something that would recur. After discussion, the Board endorses the progress of planning this event. The next step would be to finalize the plan and budget. Frank will take this back to the group and present finalized plans at the next Board meeting.

20. NAACCR 2020 Philadelphia, PA

Betsy/Charlie

Charlie and Betsy have been working with Venue West to secure a property for 2020 in Philadelphia, PA. Several other cities were considered for this year which include Charleston, Indianapolis, Memphis, Hartford and others. This is a Loews property. Betsy and Nan have visited the hotel and found that it sits in an excellent location and is a wonderful property. All aspects of the property and contract are good except the food and beverage. Charlie presented a report that outlines the estimated costs for food and beverage. It is estimated that it will cost approximately \$20,000 more in F&B than a typical conference. There are ways to explore some reductions or savings in other areas to account for this estimated overrun but he wanted to make sure the Board understood this problem. After detailed discussion, it was decided that the Board wanted Betsy and Charlie to proceed with final negotiations with the hotel but to try to resolve the issue with F and B one more time. Charlie will continue to work with the hotel and Venue West to minimize this cost without compromising too much on quality or quantity. Charlie and Betsy thanked the Board for their input and direction.

21. Volunteer Time Impact

Nan

There have been several pieces of communication circulating among various committees on the strain of changes for 2018 and volunteer time. The Board is very concerned about volunteer time and volunteering can have on members with the various data changes and stress at their registries. Members discussed how concerned they are individually as registry employees as well as Board members about the work strain on the registry community. They collectively want to keep making efforts to minimize stress at work as a result of NAACCR activities. However, most NAACCR activities are closely tied with the 2018 changes. Nan thinks that she can craft a message of encouragement and thanks to all volunteers.

Research and Data Use

22. Steering Committee Update

Chris/Isaac

Presented in report.

23. Synthetic Dataset

Chris

Chris said that he will work with David Stinchcomb on finalizing the dataset in coming months.

Standardization & Registry Development

24. Steering Committee Update

Heather/Randi

Presented in report.

25. XML Proposal-IMS Work

Isaac

The Board previously approved the Call for Data IMS work via electronic vote. This will move forward and benefits will be realized for this Call for Data year.

26. XML Implementation SRD Steering Committee

This item was discussed at the top of the Agenda. Fabian Depry was the guest in attendance assisting with the discussion. Fabian presented the Board with an implementation timeline to transition to an XML format record file. He believes that this timeline may be a bit aggressive and wanted some input on this recommendation from the Board. The Call for Data in 2018 would require XML. Accomplishment of this is closely tied to NAACCRPrep tool. The timeline allows for a 9 month transition period for all others to transition toward a XML transmission format. The Task Force also recommended a peer assistant program for anyone needing assistance with the transition. Fabian also itemized certain nuances to full transition to XML. He said that it will be important to remove the flat file option since users will naturally be interested in avoiding the new standard.

Nan asked how much of a burden this would be to vendors and if conversations took place with NCI and Joe Rogers from CDC to see the impact of Registry Plus. Fabian said that there had been discussions with CDC but they would be best to determine the exact impact. Fabian also mentioned that there are discussions to transition NCI products to XML format. SEER*Stat is probably the largest product that will be impacted. He does not know the exact timeline but would follow NAACCR closely on our actions.

Nan asked Randi and Heather if the S&RD SC had any important points to bring up. They said that besides the timeline; there were no other significant items to note. Randi did mention the itemized numbering in the proposal and how they wanted to keep the points 0 and 1 in that order.

Chris asked if there are "enticements" that could be offered to submit XML instead of the flat file but none were identified at this time. Nan thinks that if CDC and NCI also follow this timeline then it will help in the process of adoption. Nan asked if there were any Board members that have issues with the proposal. Maria thinks that receiving XML reports from reporting facilities is a large benefit. Maria wants to be careful that hospital registry software companies are in a position to make this change.

Nan asked the group for a motion on the recommendation.

THE MOTION TO ACCEPT THE RECOMMENDATION AS PRESENTED WAS PASSED. MARIA SCHYMURA ABSTAINED.

Communications

27. Steering Committee Update

Lori /Frank

Presented in report.

Other

28. April Fritz-Mention On Web Site-Other Recognition

All

Tabled until October.

29. Adjournment and Next Meeting

The meeting adjourned at 4:35 PM Eastern. The next teleconference of the Board will be October 11, 2017. One week early.

Time: 2:00 PM – 4:00 PM Eastern

Dates:

October 26, March Meeting Objective-Advocacy

November 15, March Meeting Objective-Finances

December 20, March Meeting Objective-Volunteerism

January 17

February 21

March 21

April 18 (Board/Chair)

May 16