**November 29, 2023**
**2:00 PM – 4:00 PM Eastern**
**Board Meeting**
**Minutes**

## Roll Call

**Roll and Welcome**                                                                                                        **Wendy**

Wendy welcomed everyone to the meeting and called the roll.

Present: Wendy Aldinger, Winny Roshala, Lori Koch, Lori Swain, Sarah Nash, Monique Hernandez, Bozena Morawski, Kevin Ward, Lihua Liu, Joshua Mazuryk (1 hr.)

Ex-Officio Member: Betsy Kohler (Excused)

Staff: Karen Knight, Stephanie Hill, Charlie Blackburn

## Governance

1.  **Minimum Dataset TF Report / Report of Inter-state Case Ownership            Lori / Joshua**
    ➢   Minimum Dataset Task Force Report
    ➢   ISCO TF Recommendations Report
    ➢   Next Steps

This topic is a continuation of a discussion in October.  The Board decided to assign reviewers for the document. Board members were encouraged to review the documents but not required. A summary was the requested task at hand. The reviewers were:

Joshua, Monique            Interstate Data Exchange
Bozena, Kevin            Minimum Dataset

**Interstate Case Ownership**

Joshua said that there were some issues that need to be looked into further such as lack of software and privacy items (dependencies).  However, this document was well done, and he believes is ready to be released pending the dependencies he mentioned.  He felt as though the Task Force would probably need to be briefly convened again to finalize the items he mentioned. Monique added that confidentiality and privacy also needed attention. There will be a lot of work on how the prioritization and process be impacted. She added that there will need to be some communications between states to work out. Lori Koch added that there will need to be some consideration regarding budget and the interaction between automation and those things that can't be automated.  She does not think this is ready for production but testing and workflow is a good next step. To do that we will need to find an honest broker. Stephanie said that there is a lot to unpack with this type of initiative.  There are several phases which are required to be considered.  We can, however, take small bites such as the owner of confirmed duplicate cases, then we can take a step forward. IMS can help plan and test rules also. Lori said since Illinois is a part of the NCCR, they would be willing to be a test state. Joshua said that all of the discussions were great, but the two items (dependencies) listed above are still required for next steps. Wendy complimented the group on their hard work, and she wants to make sure this moves along. Monique also thanked the group for their hard work. After discussion, it was determined that the next steps are:

1. Obtain a cost estimate.
2. Take this to the HLSC review for input.
3. Connect with NCI and CDC on adoption of this as a proof of concept and see if we can get traction as a test.
4. Consider working with the NCCR registries as a test step. (NCCR funding is not available.)

Post discussion, Bozena asked about PATH discussions and considerations.  Lori Koch said that it was mainly a result of registries who participate and not really intended to specifically omit the consideration of PATH.

**Minimum Dataset**
Bozena and Kevin reviewed the document. Kevin started by complimenting the group on a well-done document. He first highlighted the text where the group outlines the charge.
"The S&RD SC identified the need to first define the minimum data required to inform cancer incidence and larger timeliness initiatives and a task force charter and workplan were written. The S&RD SC established the Minimum Data Set Task Force (TF) and assigned the TF with the objective of developing a minimum data set to inform cancer incidence and determining whether every data item within the minimum data set must have a known value."
He also outlined the specific table of Minimum Dataset ".

Next steps are to sign off on agreed upon minimum dataset using this document as a base.  Then set another task force to try to capture these data in a timely fashion. Kevin asked why laterality wasn't included since it is important for multiple primary determination.  Bozena agreed with Kevin but also mentioned that the group did not sufficiently distinguish between unknown versus missing and asked the Board for input on this.  Kevin agreed and also felt that it is worth trying to 1. Capture them (laterality and/or unknown missing items). 2. Decide if we continue to capture them in the future.

Stehanie and others felt that it would be important to revisit why they were first conceived and the various reasons for the use of this concept of collection. Kevin thought the reason for doing this was early reporting in a timely fashion. After approval, the next steps are:

1. Sign off on a minimum data set.
2. Develop a Task Force that includes funders and how it will be implemented.
3. Go back to group to address laterality and unknown vs. missing.
4. Evaluate cost considerations.
5. Contact NCI and CDC on buy ins and next steps.

Wendy will go back to the committee to summarize the discussions and inquire about the laterality and multiple primaries before Board approval. Bozena asked for refinement of missing versus unknown.

**2. GLC Communications Memo – ACTION**                           **Charlie / Tyler (if needed)**
   ➢ Communications Memo
Charlie forwarded a memo from GLC Communications and Tyler Scott outlining the need for the Board to decide on the status of the Communications Steering Committee.  Earlier in 2023, the Board put the Steering Committee on temporary pause while we worked with GLC on various initiatives.  Over the last 6 months or so, a recommended NAACCR Office - centric model was proposed and developed. Overall structure laid out.  The NARRATIVE 2.0 was

developed and released, and various procedures have been completed. The next step is for the Communications Task Force to be started and a decision on the Steering Committee is required first.

The Board discussed various options, the memo, and short-term / long-term goals of our communications.  Charlie answered questions.  After detailed discussion, the Board will sunset the Communications Steering Committee.

Lori Swain felt that the lengthy and multi-year communications work has pros and cons. The benefits are that there has been a lot of thought to the matter / structure and now action is starting. The work that was done siloed the committee from the process and it was not NAACCR's best look. The movement away from the SC was something we should consider in the future.  If this comes up again with any Steering Committee, she recommends that NAACCR has a different level of engagement with the committee and volunteers. Especially since there were a lot of devoted members and volunteers who put a lot of work into improving NAACCR's communications process and work. Bozena and Sarah asked to change the title of it to a Communications Work Group rather than Task Force. It better represents long term work the group will do.  Lihua and the Board asked the office to look at Standing Rules to identify the best name for the Task Force.  She also asked NAACCR to work more closely with a SC and consultants in the future.  She agreed with Lori Swain about NAACCR needing to improve the relationship and coordinate the committee, consultants, and office on items such as these.  Wendy took a moment to review how we arrived at this point.  The Steering Committee was instrumental in starting the process for NAACCR to evaluate the entire process.  It ended up being a lengthy, multi-pronged approach.  She thought there could have been a better-defined role for the committee as we went through the process. It was a unique situation, but the Steering Committee was the initiator of the process and work and certainly lessons were learned during the period.  Wendy asked for further discussion and no additional comments were voiced. She said we will pass the decision to the committee.  Additionally, a decision will be made on the name of the task force as well as revisions to the organizational documents.

**The motion to sunset the Communications Steering Committee was passed.**

**3.  SMP Work Group Feedback**                                        **Winny / Lori / Karen**
Lori asked the Board for final feedback from the SMP work group steering committee.  No additional input was given, and Winny thanked the Board for all of their past direction and input.

**4.  Program Committee Recommendation on Recordings**                **Charlie**
Charlie reported that the Program Committee investigated various types of recording options for the 2024 conference.  Some were inclusive of all sessions such as plenary and concurrent sessions. Others were a mix.  At this stage, recording all sessions is cost prohibitive given the conference is unable to support a loss in this effort.  However, they discovered that recording just the plenary sessions with the slides being primary and speaker inlay would have almost no impact on overall cost.  He recommended that NAACCR continue to look into this annually in case options change.

**Steering Committee Reports**

**Standardization and Registry Development**

**5.  Steering Committee Update**                                        **Lori / Joshua**

They continue to work on their work plan and goals.  They have not met since last Board meeting.

**Professional Development**

**6.  Steering Committee Update**                                        **Lihua / Monique**

Monique said they are refining their goals and objectives and working on the work plan. Specifically on recruitment and retention of CTR and non-CTR professionals.   They want to develop a roadmap on recruitment and the development of careers in our field including ideas of exposure and targeting.  A major initiative includes defining the current needs, vacancies, and skill sets required in real time.  They set up listening sessions from mentor and mentees so they can obtain information on an ongoing basis.  Monique said the feedback has been very valuable.

**Strategic Planning and Alliances**

**7.  Steering Committee Update**                                        **Wendy / Winny**

   a.   Membership benefits initiative. Word Cloud Visual
   b.   Word Cloud Background

At the last SPA meeting, the group discussed how SPA can implement overarching initiatives.  SPA is trying to figure out what role they plan in each factor.  They also did a project where a survey was sent to the Board and steering committees rating the top benefits of 20 elements complied.  Wendy thanked Monique for her work on the background information.  The information was put into a word cloud as a visual for a use case for communications for multiple settings on why someone should volunteer for NAACCR.  Monique provided some background on the process and rationale which was sent prior to the meeting.

**Research and Data Use**

**8.  Steering Committee Update**                                        **Sarah / Bozena**

Sara said that the committee is looking at strategic initiatives and goals.  They were able to ensure RDU goals and objectives are consistent with the actions of the committee. The Sr. Research Network was reshaped also.

**Program Updates**

**9.**  Program Updates

   •   Canada                                                            Joshua

   Joshua said there had been no meetings since the last Board Meeting.  The CCCR is in their data submission process.  There are a lot of data posts happening at the moment. Lacy David mentioned at the last NAACCR webinar, that they received much of the information form Canadian registries.  They have moved to Cancer PATH Chart, and everyone approved of the topography, morphology combinations. There will be further work on problematic items within the list.  There was a discussion from their DQMC on and that the CCCR tumor size rules stay intact.

   •   NCRA                                                             Lori S.

   They are getting ready to launch their annual conference registration. They go live on December 11th. Exhibit sales are ongoing.  ODS is in effect January 1.  A toolkit was released for members on use and timing of the change. The Counting Veterans Cancer act passed the Senate. It is part of an omnibus bill. If the house

agrees then it will move forward to a committee to assess the original bill but with fewer amendments. Then the bill will become law.  If it dies in the House, then they have options for future sponsorship.  ACS CAN decided they were not going to support the act.  Ahmedin Jemal from ACS helped the group improve their knowledge of registry data and led to an eventual letter to the Veteran's Affairs Committee to support the bill.  She offered NAACCR and NCRA to meet with representatives at ACS CAN for some education on our work. Lori will reach out early in 2024 on this topic.

- NPCR                                                                                    Monique / Wendy

NPCR files are due on Thursday. A Town Hall is scheduled for the 8th.  A performance measure meeting refresh is also scheduled in the future.

- SEER                                                                                    Kevin / Lihua

SEER submissions were due November 1st.  Annual reports are due in February. The report is more manual and run primarily out of SEER DMS.  The NCCR registries participated in a children's oncology group linkage. The SEER program tries to push two linkages. 1. United Healthcare (bilateral data exchange) and 2. VHA linkage to connect with the national dataset.  There were some concerns with meeting the reporting requirements and registry providing information back to patients.

Monque had a question on the VA linkage and said FL is pursuing the same kind of bilateral reporting with some of the NPCR States.  This is currently one of the areas that's a sticking point for them, because to provide information back to them, they are under the idea that this is would be like a data linkage request and would have to go through the same procedures that an outside organization would receive those data back. She asked how SEER is handling that in terms of, accounting for the data request process, the linkage request process for more of a bilateral relationship and how it is that being handled.

Kevin said he was not able to speak exactly as to how it would be resolved because he was just not involved at that level.  Specific issues have not been addressed yet, but contact has been made with the VA on this type of situation and if they have legal authority. He will be happy to share it as information becomes available.  Lihua also voiced some concerns from CA but in the interest of time, it was decided to discuss this a little later offline.

**Other**

**10. Quick Reminders**                                                                  **Charlie**
   a. Board Survey
   b. December Board / Chair Meeting
   c. March Meeting

The Board self-assessment survey will be sent before the end of the week. It will be due by December 22, 2023. The March meeting is finalized the week of March 11, 2024.  Charlie will send information next week to all attendees.  The December 20th meeting is a Board / Chair meeting. This is funded by NAACCR.

**ITEM #14** Boone application was brought up for discussion. Kevin did not know much about this individual, but Lori Swain and Stephanie Hill were aware of her and said she previously worked for a registry. The Board approved and passed the membership.

**The motion to approve the Constance Boone Individual Membership application was passed.**

### Consent Agenda

11. Minutes
    a. October 18, 2023 Draft Minutes
12. Correspondence and Updates
    ➤ None
13. Membership Application
    ➤ Boone Membership
14. Board Timeline
    ➤ Board Timeline
15. Geocoder Monthly Report
    ➤ Geocoder Report
16. Executive Director's Report
    ➤ Report will be given in December.
17. Financial
    ➤ Current Financials

The Item #14 Boone membership application was removed for discussion.

**The motion to approve the consent agenda for November 29, 2023 was passed.**

### Adjournment and Closed Session

18. **Adjournment and Next Meeting**                      **All**
19. ED Transition Group Update – Closed Session Standing Item        Wendy / Sarah

    NAACCR staff excused themselves and the closed session was held. The ED Transition Group Update will remain as a standing item for the foreseeable future.

| NAACCR Board Action Items | | |
|---|---|---|
| Board Standing Reminders and Information | | |
| **Item** | **Responsible BOD Member / Person** | **Status** |
| | | |
| Form a new task force to implement the minimum data set in a timely manner. | Steering Committee | In progress. |
| Reach out to the task force to ask about laterality and refinement of missing versus unknown in their description and table. | Wendy | In progress. |
| Review and recommend new title for "Communications Task Force" to WG or other. | NAACCR Office | Completed |
| Review and promote credentials in MyNAACCR for member completion. | Charlie | In progress. |

| Convene a group to detail the value of NAACCR membership benefits. | Board | Completed |
|---|---|---|
| Data Dictionary Funding: Randi said that she would like to investigate ideas to recoup costs through charges in some way in the future. Possible subscription or ask of sponsors for funding of this activity.  Kevin seconded the concept of identifying users of the system for support. This topic will be added to the action list of the Board. | F&P Subcommittee | In progress. |

**Schedule of Board Meetings July 2023 – June 2024**

**3rd Wednesday of each month. 2:00 PM – 4:00 PM Eastern**

- December 20  Board / Chair Meeting 2:00 PM – 3:00 PM; Board Only 3:00 PM – 4:00 PM
- January 17
- January 31 4:00 PM – 5:00 PM Mid-Year Financials Presentation by Charlie to Finance and Personnel Subcommittee
  *Presentation will be made to F&P Subcommittee but all Board members are invited as optional attendees. Written report and presentation slides will be sent to Board for review and questions.*
- February 21
- March 20 – Possible In-Person TBD - Board / Chair Meeting 2:00 PM – 3:00 PM; Board Only 3:00 PM – 4:00 PM
- April 17
- May 15
- June Boise, ID TBD Board / Chair Meeting and Board Only

**2023 – 2024 Liaisons**

| **Committee/Priority Area** | **Liaison(s)** |
|---|---|
| Standardization & Registry Development | Lori Koch and Joshua Mazuryk |
| Research & Data Use | Sarah Nash and Bozena Morawski |
| Professional Development | Lihua Liu and Monique Hernandez |
| Strategic Planning and Alliances | Wendy Aldinger and Winny Roshala |
| Mid-Level Tactical Group | Kevin Ward, Jenna Deniaud and Heather Stabinsky |
| High Level Strategic Group | Wendy Aldinger and Winny Roshala |

**2023 – 2024 Steering Committee Chairs**

| **Committee** | **Chair(s)** |
|---|---|
| Standardization and Registry Development | Heather Stabinsky and Jenna Deniaud |
| Research and Data Use | Jeff Dowden and Angela Meisner |
| Professional Development | Andrea Sipin-Baliwas and Carrie Bateman |
| Strategic Planning and Alliances | Randi Rycroft |