



Minutes

September 28 & 29, 2022

Dartmouth Meeting Room, Ivy Wing

Day 1 September 28, 2022

8:30 AM

Roll Call and Start of Day 1

Winnie

Welcome and Site Administration

Winnie/Charlie

Overview of Days

Winnie

Charlie, Betsy, and Charlie welcomed all in attendance and provided administrative background and other details.

Winnie began the meeting and thanked all for coming to to NJ. She asked all in attendance to provide their name and location. Winnie reminded the Board about the strategic initiatives that were done in March of 2022. She also thanked all in attendance with their work on the matrix.

8:45 AM

Ground rules for Strategic Initiatives

Ann Marie

Ann Marie provided ground rules for the strategic initiatives.

- Be realistic.
- Wear your NAACCR hat.
- Stay on track.
- Provide detailed action items.

9:00

Priority Strategies

Winnie/Betsy/Ann Marie

1. Assessment of Priorities

Betsy

Ann Marie reviewed the matrix activities and priorities. Betsy said that they took all the paperwork submitted and tried to identify key factors and if they were already being addressed and underway. Winnie said that it was helpful for the NAACCR Office Team to provide their perspective to the spreadsheet. She wanted to point that out as the group works its way through the activities.

Ann Marie noted that all should view "Sheet 2" in the matrix because it has Board comments for strategic initiatives.

Ann Marie and Winnie think these comments are critical to review as the matrix is reviewed.

2. Board Prioritization Poll Results

Ann Marie

1. Certification
2. Minimal Data Set
3. Volunteer Recruitment and Retainment
4. Informatics
5. Tied: Communication, Case Use, Extended Training, Equity

There was consensus that everyone is comfortable with the first four items. She wanted to speak for those that tied. Communications: Kevin and Monique spoke to this as a priority. Lori Swain said that her view of the communications element is rolled into each of the 1-4 items since if effective communications are not performed, the first four activities don't happen. Betsy considers these activities to be action items for the next few years rather than regular activities.

She provided some examples such as workforce skill development activities. Sarah believes that diversity is at the core of everything we do. Membership, Board, volunteers, and many other areas. She wants us to lead the way in this matter. Lihua noted that NAACCR's basic function is to provide data. Minimal dataset does not align with the granularity that will be needed over time. Winny noted that the activities do not need to be all things NAACCR. It can be collaborative activities also. Betsy thought that another way to think about it is to add items monthly to the BOD agenda. They can be on rotation or multiple items.

ACTION: After discussion, the consensus is to engrain these activities into the Board. Some may be position statements, some back be working groups, some may be a deliverable.

A summary of the 5 items.

Projects

1. Certification
2. Minimal Data Set
3. Informatics

Association of Related Activities

1. Volunteer Recruitment and Retainment
2. Advocacy
3. Succession Planning for Registries
4. Communications

The Board unanimously agreed on the approach above.

Realistic expectations for success

Ann Marie

What does success look like?

1. Implementation plan for each approved strategic initiative is drafted
2. KPI for NAACCR are identified
3. NAACCR's current committee structure is assessed - tomorrow
4. Succession planning is reviewed - tomorrow
5. Thoughtful discussion of Board's Involvement in Resource Development & Relationship Building is undertaken

10:30 AM

Break

10:45 AM

Recommendations for Board Priority Initiatives

Winny

Ann Marie said that the next steps are to

11:15 AM

SPA Roles and Responsibilities

Randi

Randi spoke to the role of the SPA and activities. The group met just prior to the Board meeting to review proposed strategies that NAACCR could consider. They wanted to look at what SPA "really looks like". They thought through what SPA would look like moving forward. Is it an advisory group, steering committee, etc. Their resting place is that SPA should continue as a steering committee. Because strategic alliances is still a priority that it should continue as a SC.

They then talked about what their role will be and how it should be structured. Ultimately, this would need to be formalized by the Board. See Day 1 Supplement notes attached beginning on page 12.

Purpose: SPA's purpose is to support to the Board in their strategic priorities.

Goals: Under the direction of the Board:

1. Investigate strategic opportunities on behalf of NAACCR's BOD and recommend appropriate actions.
2. Foster relationships with key stakeholders and represent NAACCR's interests to achieve strategic priorities.
3. Identify and assess new strategic opportunities and threats and report to the Board.

Responsibilities to the Board:

- Research & evaluate requests from the Board related to strategic priorities. Provide regular updates to the Board.
- Bring new opportunities and threats to the attention of the Board.
- Identify and inform the Board of potential relationships with key organizations

Responsibilities to SCs, SMP WG, etc., connector to groups

- No role with SCs, WGs, etc. within NAACCR, only to the Board.
- SPA is not responsible for managing or monitoring the SMP.

Responsibilities to external groups

HLSG activities need investigation on impact to NAACCR and is assigned to SPA.

- SPA should have representation on HLSG.
- SPA representative is to report HLSG updates to SPA and to the Board.

Membership

- Liaisons to organizations to keep the group informed, identify opportunities and threats.
- President
- President-Elect/Past-President
- ED (rep from HLSG)
- Canadian representation
- Other members are appointed by the Chair/President from member registries
- Chair appointed by the President
- Chair may invite ad hoc advisors based on skill, expertise and need

All members should have demonstrated experience with NAACCR.

Term: The chair and its members serve two-year terms with the same cycle as the President. The chair and members can be re-appointed.

Skills to consider when appointing members (not in charter):

- Mix of knowledge of operations and/or data use
- Assertive/relationship builders
- Has established network and connections
- Communicate value, active listening, visionary

- Influencers
- Member emeritus
- Development/resource promotion background
- Advocacy expertise
- Retired members (or exit interviews) – part of assessment

Where does SPA fit into the structure? Steering Committee

Purpose: To support the Board in their strategic priorities.

Goals: Under the direction of the Board.

Investigate strategic opportunities and recommend

Foster...

Identify...

Research and evaluate

Bring new opportunities / threats

Identify and inform Board of key relationships....

Responsibilities to steering committees were not necessarily required but all steering committees need to work together. However, not formal connection to the SC but yes to the Board. SPA will not be responsible for monitoring the SMP but the work of the SPA will inform and work with the Board. THE HLSG may have a stronger connection to the SPA and they should have representation on the HLSG from SPA. As an example, there are currently connection points . The liaison soul report activities.

Membership: Liaisons to organizations to keep the group informed to maintain connections. President, President-Election . Past-President, ED, Canadian, other members will be appointed by Chair form members registries, Chair is appointed by President. Ad-hoc advisors can be added as needed but for short-term seat. All need to have experience with NAACCR previously.

Skills: Mix of knowledge of operations and data use. Assertive and relationship builders. Established networks and relationships. Visionary skills. They should be influencers. Member emeritus status (base President etc.) is an example. Background in resource allocation. Advocacy expertise. Possibly do exit interview of former members and in particular, past members of the Board.

The committee would be more reactive in strategy rather than generative, while preserving the duty and responsibility of items that should be brought to the Board.

Board input: Sarah voiced her support of this direction and noted that the Board needs to be more generative in monthly meetings as well as in-person meetings. Lori asked if the group asked how the strategic plan will be monitored. It was noted that the SP Monitoring Work Group will continue to monitor the plan. Monique asked if any specific skill set or individual was identified to add to the group now. Randi said not at this time.

ACTION: The next steps will be for Karen and Randi to develop a charter.

12:00 PM **Lunch**

1:00 PM **Implementation of Priority Strategic Initiatives Planning**

1. Planning Next Steps Ann Marie
2. Breakout Sessions
 - a. Year 1 and 2 action plan by priority initiative
 - b. Anticipated long term outcomes
 - c. Funding/Resource strategies

Ann Marie instructed members to break up into their pre-coordinated groups. Activities include the review of the SMP activities, add scope of work, refine major goals, develop a resource plan, develop an implementation timeline, establish milestones, plan for monitoring and evaluation.

2:30 PM **Break**

2:45 PM **Priority Strategic Initiatives for Implementation**

1. Breakout reports

Each breakout group reviewed the major elements of their session. Items such as work plan, goals, action plans, timeline, and other critical areas were shared.

ACTION: A summary of these items will be updated in each group's initiatives section that was originally submitted to Ann Marie Hill.

2. Board Approval of Final Strategic Initiatives Winny

3:45 PM **Key Performance Indicators for NAACCR** **Ann Marie/Sarah Nash**

- Key Performance Indicators PowerPoint

Metrics continues to be a key element of the SMP. Sarah Nash and Angela Meisner are co-chairs of the SMP Monitoring Work Group. Their group does not necessarily do the work but monitor it. Metrics are now being integrated into each Steering Committee. The SC is responsible for measuring SMART Goals and report them back.

Betsy wants to see how we can get some of these training elements done for Chairs on a training module. Possible trainings around strategic planning, metrics, and other elements such as advocacy etc. **ACTION: Betsy would like us to look into that for a training in the summer of 2023.**

Ann Marie went back to the overall purpose and implementation of key performance indicators. Metrics will have the most impact in moving NAACCR forward. They measure on what an organization needs to achieve its mission / goals as a compass of our progress. Can we measure our progress in achieving our mission and major goals? It is critical to show progress to members, Board, and stakeholders.

Suggested Areas of Key Performance Indicators and Measurement

- Improved data quality
- Number of states with gold certification
- Standardization of all NA collecting data the same way

- Standard setters meet timelines
- Look at state cancer controls to see if they include our data, offer best practices (NAACCR to step up to CDC to integrate)
- Listing projects as a benchmark (Firefighters Reg., VPR, NCCR, etc.)
- Training and numbers
- Listing activities such as OVAC type of initiatives

A portion of the way through the certification discussion, Kevin noted that he thought we were going in circles.

4:30 PM **Recap of Day 1, Overview of Day 2, Dinner Plans** **Winny/Betsy**

5:00 PM **Conclusion of Day 1**

Day one concluded at 5PM Eastern.

See Day 1 Supplement notes attached beginning on page 12.

Day 2 September 29, 2022

8:30 AM **Roll Call, Start of Day 2, Overview of Day 2** **Winny**

8:45 AM **Administration Updates (Ann Conf, MFA etc., Fees Update)** **Charlie**

9:30 AM **Audit Presentation by Sikich LLP** **Lauren Groff, CPA, Sikich LLP**

10:15 AM – 10:25 AM **Break**

10:30 AM **Update on NAACCR Investments** **Damon Hofstrand, ML**

11:30 AM **Succession Planning** **Betsy**

Betsy said that she and staff are working on staff succession and planning on a variety of fronts. All options are on the table such as unplanned staff time off, and planned time off. Lorraine and others asked if we have looked at a LOA turning into a retirement. Members thought that there is a way to get around that. Betsy plans on working through the policy and procedure with staff and then will provide draft documents to the Board in November or December 2022. The Board asked clarifying questions regarding NAACCR's FMLA actions (NAACCR is not subject to this requirement). Options or points of clarification were suggested such as donations of time off, legal obligations, and clear documentation for each situation (needed by employee), extra responsibilities for current staff (should existing staff receive extra pay), and other administrative items. Betsy thanked the Board for their input and will get back with them on the next steps. **ACTION: Betsy will refine the succession planning documents and forward to the Board later in the calendar year.**

12:00 PM – 1:00 PM **Lunch**

1:00 PM – 2:00 PM**Review of NAACCR Committee Structure****Ann Marie/Betsy/Stephanie**

1. Steering Committees
2. CIAG & Informatics
3. Board Committees
4. Other Changes (if any)

Ann Marie reviewed the NAACCR committee structure and how major initiatives outlined will fit into each group. The group discussed additional projects that will be assigned as initiatives.

PROJECTS

1. Certification
2. Minimal Dataset
3. Informatics

MEMBER ASSOCIATION MANAGEMENT

1. Communication
2. Recruitment and Retention
3. Extended Training
4. Advocacy and Policy
5. Equity, Diversification, and Inclusion

Ann Marie asked the Board for the OK to proceed with the revised initiatives documents and tweak as necessary to pull together in a coherent way. The Board agreed. **ACTION:** Ann Marie will receive the revised initiatives documents and consolidate as needed to synthesize the work as described in the meeting.

The group reviewed the NAACCR Committee Organization Chart to ensure the activities align properly with the initiatives. It was noted that the SPA needs to be updated in the Organizational Chart. Additionally, the group questions what criteria makes for a steering committee, work group, and other subgroups. The Board discussed the current justification for steering committees. Various opinions were voiced as to the rationale, scope, and role each steering committee will play. The Board brainstormed whether there were new areas. 1. Informatics was the single item that surfaced at this time. This will be discussed later in the process. Any new areas would be considered for the new SMP coming up and not this current SMP.

2:00 PM**Governance**

1. Volume V Update

Winnie/Betsy/Kevin

Kevin volunteered to check with CDC and NCI on the impact of NAACCR and responsibility of all stakeholders. Both NCI and CDC looked into possible professionals who have expertise in this area. They were open to the consideration of pooling together to hire someone. At a minimum Kevin is hopeful NAACCR may not have to fund this activity on own. Betsy said that CDC may be open to adding the activity into the Co Op but no commitment of additional funding was mentioned. The Board wants to ensure the inquiry and subsequent action on work if forefront in their mind so tasks in the Volume are not waiting. Kevin will relay that we are seeking some sort of decision within a few weeks. If there are no solutions provided by CDC or NCI then it is possible NAACCR may need to help bridge the gap.

ACTION: Kevin will circle back with NCI and CDC on the matter to see if any progress has been made on their end.

2. Communications Consultant Hire

Charlie/Betsy

Betsy and Charlie updated the Board on the communications consultant activities over the last month. They are still in the discovery phase and are gathering information for analysis. They kickoff meeting has occurred and meetings with staff, the Communications Steering Committee, and other stakeholders will be completed in coming weeks.

3. Volume II Data Dictionary Rebuild Discovery Phase Update Stephanie

Stephanie reminded the Board as to the volume and breadth of work required for this initiative. She is working with IMS and Monica on finalizing the work plan and details. As it stands now, requests for the DD go through the MLTG via emails and other hap-hazard methods. IMS will be working on building that request pipeline go through a single system. This is a critical part of the system and is needed moving forward. Additional details will be made available as the project moves along. Randi asked if there would be an element built into the system for public comment. Stephanie said that this is a point of consideration that has been discussed but not ultimately decided.

4. Annual Conference Updates (2023 and 2024)

Charlie/Betsy

Charlie said that the planning for the 2023 conference is underway. Operational pieces are on schedule. The program element is also being planned. There is a core planning group that is handling the various schedule changes or adjustments as well as initial concepts of content. Betsy asked any BOD member who wants to help with the program element to please contact her. They will work within the 3 day pattern but make the content more interactive and less didactic. Ideas for workshops, plenaries, and interactivity / panels etc. are desired. Sarah asked if there will be an online version. Betsy said that initial talks are planning a possible mid-year FORUM layout after the conference. Stephanie mentioned that there could be a recorded component, maybe a QR code to view a presentation online on phone. The Board is very interested in the FORUM. Lori Koch said that the feedback from her staff who went to the FORUM was overwhelmingly positive. Charlie also reminded the Board that NAACCR will purposely take a slower approach to booking 2025 until we know how the conference is attended in 2023 and the reception of online offerings. He also reminded the Board about NCRA's offer for co-location in 2025. The Board is interested in exploring that further in the year.

5. Membership Application

Kevin

The membership application of Lynn Giljahn was discussed. Kevin reviewed the application and endorsed the approval. **THE MOTION TO APPROVE THE MEMBERSHIP APPLICATION OF LYNN GILJAHN WAS PASSED.**

2:30 PM

Steering Committee Reports

1. Communications

Lori S./Lihua

The committee has not met for the last four meetings but will meet on Monday. The GLC consultant continues to do work and more updates will be available in September.

2. Professional Development

Kevin/Monique

The group has been focusing on the workplan updates. In some instances making changes to the timeline and even revising the components to ensure cross cutting activities are covered. Also, a new task force, Upkeep TF, will update documents on the web site. They are also focusing on delegating tasks such as the mentor program, application, and how it may work like the MAP program. Lastly, the group is working on presentations like coffee talks. Stephanie discussed how these concepts could be relayed to the office and ensure that they are marketed properly.

3. Research and Data Use

Lorraine/Sarah

Two major elements came out of their last meeting. Data and confidentiality work documents which include a data encryption and multi-factor authentication and best practices for responding to an individual. The AIAN Task Force is being developed to address the measurement issues under equity.

4. Standardization and Registry Development

Wendy/Lori K.

➤ CIAG Fast Data Response

Lori said there no major elements to report from the last meeting. The Minimal Dataset Task Force work was finalized. April Austin will be the Chair. Regarding the CIAG work, Lori felt that any effort will take a considerable amount of time. However, it is important to present what could be done with the right resources.

5. Strategic Planning and Alliances

Randi

The report was provided earlier in the meeting. Randi clarified the membership. She said there are appointed liaisons and have those official liaisons be official members of SPA. This is not necessarily the case. What is needed is mostly a strong connection to what is learned in their meetings so SPA can address them. However, after discussion, it was determined that liaisons would indeed be a member of SPA.

THE MOTION TO APPROVE THE CHARTER OF THE SPA COMMITTEE AS PRESENTED WAS PASSED.

3:00 PM

Break

3:15 PM

Reports

1. Canada

Lorraine

They are in the process of doing a COVID-19 trends report as a briefing note or paper. There is work on the Data Quality and DUPC to develop measurement criteria on measure data by Province. They are also working on wider data strategy NGO Advocacy Group to focus on early data (not final) on COVID indigenous health and trends. These efforts will probably not be with all Provinces but as many that can participate. The Board asked several questions on how they do disparities, specific data collection processes, and other elements.

2. NCRA

Lori S.

NCRA finished their conference in good shape in 2022. Their 2023 meeting will be in May 7-10, 2023 in San Diego. They are currently detailing how they will apply a hybrid model nailed down after 2023. They received 80 abstracts and are currently being graded. She said that the VA initiative continues and provided background on who is helping and what major players are involved with the work. Some of those were involved with the Walk on the Hill participants. Meetings with Senator's offices continue. Once it gets introduced then NCRA will engage us on strategy and what our role will be in the matter. An update on the credential name change is also underway but no further details. The new name should be released between May and July 2023.

3. NPCR

Monique/Wendy

The file report for the previous 5 yrs. cycle was due today. Success stories are due at the end of October. Town Halls are centering around CDC over the last 30 years. No other updates.

4. SEER

Kevin/Lihua

The completeness estimates from NCI are underway to estimate the COVID effects on cancer incidence. They used a variety of data sources to work on this. They are seeing a 6-10% impact on completeness.

4:15 PM

Recap of Day 2, Next Steps, Dinner Plans

Winnie

The next steps and actions were reviewed during the meeting.

Consent Agenda-Board Vote

1. Minutes
 - August 17, 2022, Draft Minutes
2. Correspondence
 - Mid Level Group Notes
 - High Level Group Notes
3. Geocoder Monthly Report
 - Geocoder Report
4. Executive Director’s Report
 - ED Report
5. Membership Applications
 - Lynn Giljahn, Individual Member Application
6. Financial
 - Current Financials

(Cont.)

The membership application was removed from the agenda and discussed separately.

THE MOTION TO APPROVED THE CONSENT AGENDA (MEMBERSHIP REMOVED) WAS PASSED

5:00 PM

Conclusion of Day 2

The meeting concluded at 4:30 PM Eastern. Winnie thanked all in attendance. The work plan and next steps have already been outlined. The next meeting will take place as scheduled on October 19, 2022 via ZOOM.

See Day 2 Supplement notes attached beginning on page 19.

Board Standing Reminders and Information

NAACCR Board Action Items		
Item	Responsible BOD Member / Person	Status
Action items listed in minutes above.		

Schedule of Board Meetings July 2022 – June 2023

3rd Wednesday of each month.

October 19th
 November 16th
 December 21st (Board / Chair Meeting ZOOM)
 January 18th
 February 15th
 March 15th (Board / Chair In-Person TBD)
 April 19th
 May 17th
 June 18th (Board / Chair Meeting In-Person New Orleans)

2022 – 2023 Liaisons

Committee/Priority Area	Liaison(s)
Standardization & Registry Development	Wendy Aldinger and Lori Koch
Communications	Lori Swain and Lihua Liu
Research & Data Use	Sarah Nash and Lorraine Shack
Professional Development	Kevin Ward and Monique Hernandez
Strategic Planning and Alliances	Winnie Roshala, Wendy Aldinger and Randi Rycroft
Mid-Level Tactical Group	Kevin Ward and Colleen Sherman
High Level Strategic Group	Wendy Aldinger and Winnie Roshala

2022 – 2023 Steering Committee Chairs

Committee	Chair(s)
Standardization and Registry Development	Colleen Sherman
Communications	Nan Stroup
Research and Data Use	Jeff Dowden and Heather Zimmerman
Professional Development	Andrea Sipin and Carrie Bateman
Strategic Planning and Alliances	Randi Rycroft

Day 1 Supplement Notes**September 28, 2022****Board Meeting Minutes Supplement**

Board prioritization poll results

1. Certification
2. Minimal Data Set
3. Volunteer Recruitment/Retention
4. Informatics
5. Tied:
 - a. Communication – already made a commitment to it; required in order to be successful on any initiative (business responsibility). Gap – people don't understand where data come from.
 - b. Extended Training – need different training topics
 - c. Case Use – critical juncture, but very complex; what can we change?
 - d. Equity – is this being done by other entities; clarified Diversity, equity and inclusion (population that we reflect and include) and undergirds other initiatives

Lori K:

- Only way to do these initiatives is to have resources, so advocacy is necessary. NAACCR can advocate when registries cannot
- Extended training: Concerned about succession planning

Lihua

- Minimal dataset conflicts with DEI; what's the point. Lihua said with abilities now, is this a moot point?

Cross-cutting/overarching – DEI (underpins everything – lead); communication (necessary); training.

DEI – staffing and data point

Minimal Dataset TF: what is necessary to calculate incidence, and then decide best sources

HLSG, led by NAACCR, partners. Identifying their strategic priorities . Clinical/surveillance use case & minimal dataset. If dependent on involvement standard setters, NAACCR reps can strongly recommend those.

Are there standing Board agenda items for regular discussion? Other projects can be delegated to a group. Some could be a position statement; thought leadership.

Charters – include action steps to support DEI.

Not a priority but will need to work on it: coordinated CFD (HLSG?)

Where we landed

- Set up priority projects for SCs and WGs: certification, Minimal dataset, informatics,

- Three cross-cutting areas to make progress – Board ensuring these priorities go across the organization: R&R, DEI, communication, advocacy, extended training

SPA update – Randi (Suggest referencing separate notes)

Background: for years, NAACCR had strategic alliances SC. A couple of years ago, given the climate, needed more planning focus. Then SPA was created to be more of a “think tank” for strategies NAACCR could consider. Because both the Board/HLSG being more strategic, what does SPA need to do?

Met yesterday to discuss SPA’s focus. See separate notes (Randi read these).

Biggest change is that SPA would take direction from the Board.

Feedback from Board:

- Will only work if the Board will need time for generative discussion for this to work. Will need to set time for these discussions.
- How will the SMP be monitored & evaluated? SMG WG? Will need to discuss as the Board.
 - SMP WG is under the Board
- Will need to recruit new members; don’t want too many. Board input?
- What role will SPA playing in cross-cutting vs. projects?
- Will there be task forces? Likely.

Next steps:

- Randi/Karen will revise the Charter
- Cancel the October SPA meeting; will let the current members know the Board’s decision at their October meeting.

SMP WG:

- Initially helping SC develop the SC
- Oversee the work the SCs are doing. Reviewed work plans
- Feedback to SCs on Goals/objectives
- Reviewed SC metrics (2-3) to share with the membership on progress

Betsy suggested creating a training module on strategic thinking, writing work plans, metrics, evaluation.

Need for the Board & Chairs

Workshop for annual meeting?

Key Performance Indicators or Benchmarks of Success

- Purpose: Communicate success to members and broader community, including partners
- Reviewed NAACCR pillars

- SC metrics are different than NAACCR metrics. Need to be able to showcase success. But many of the SC metrics also reflect NAACCR's status.
- Reviewed pillars:
 - Equip CCRs –
 - **Certification** measures timeliness, accuracy and completeness; how will improvement be measured?
 - Gap – increasing knowledge and engagement in **health informatics** (communication/training link) – new priority area to discuss further
 - Expanding Data Use Outcomes –
 - **Research/publications** - RDU has started this.
 - State **cancer plans** use the data for planning, monitoring and evaluation – perhaps we can influence this through communication/advocacy. Could monitor/review state cancer plans?
 - Promote Policy and Collaborations
 - Partners coming to NAACCR for projects using NAACCR data (VPR has nice measures)
 - Work with OVAC (One Voice Against Cancer); taking to legislature
 - CCNP – rural cancer control – NAACCR could ensure data are sufficient quality to address... capturing pertinent elements
 - Adding gender identity
 - Other groups use our data that are working on policy/burden reduction, etc.
 - Work with liaisons; how to show our value - SPA
 - Add training, not easily captured by one group.

What does success look like?

6. Implementation plan for each approved strategic initiative is drafted
7. KPI for NAACCR are identified
8. NAACCR's current committee structure is assessed - tomorrow
9. Succession planning is reviewed - tomorrow
10. Thoughtful discussion of Board's Involvement in Resource Development & Relationship Building is undertaken

Implementation Plan Break-out discussions – groups to provide:

- Review the current strategic initiative proposal
- Add SOW based on purpose provided – 2 sentences
- *Refine* major goals and objectives (action steps with assigned responsibilities)
- Develop resource plan (staff, materials, equipment, etc.) Discuss sources of funding
- Implementation Timeline (1 year AND 3-5 years)
- Milestones (what does success look like; list your benchmarks)
- Monitoring & evaluation

Informatics Report Out

Overall

- We expanded goals to the communication to the registries and the implications to them.
- We are not addressing current informatics needs, with the highest priority being path reporting in a consistent way. This should be addressed now.

Goals: *[Identify 2-3 major goals that need to be accomplished for success]*

- 1) Strengthen NAACCR's capacity in the informatics arena both today and for the future.
- 2) Provide support/guidance/tools to help NAACCR member registries take advantage of informatics solutions to data collection (current/future)
- 3) Ensure NAACCR is at the table to incorporate new standards as they become available (e.g. how NAACCR engaged in e-path standards).
- 4) Inform registries about efforts that are happening and the implications to them.
- 5) Ensure data paths to registries are equitable (e.g., receiving real-time path reports)

Implementation

- Communicate with registries regarding the language and initiatives that may impact them / why it's important. MedMorph highest priority
- Ask CIAG about timelines for relevance.

Who/resources:

- Underutilizing CIAG – need to task them with monitoring and reporting on initiatives and implications to registries, with recommendations.
- TFs could be created for pieces of this.
- Ideally, we hire a person to coordinate and do the heavy lifting.
- Business case to standard setters is that NAACCR is unique position to help implementation in the larger registry community.

Milestone: central registries are receiving all the reportable pathology in their state.

Milestone: CCR software can efficiently process and consolidate path records automatically

Certification Report Out (Stephanie has it written out)

- Action Plan –
 - Joint task force – RDU & S&RD as co-chairs – CCRs and NAACCR staff
 - Timeline – Start in January 2023
 - Coffee Break – Feb 2023 to get input
 - Review recent years results (RDU)
 - Draft new certification criteria
 - Draft/proposed criteria available (June 2023) – Roundtable for initial reactions
 - Public comment period (discussion forums)
 - October 2023 - published
 - December 2023 – assessment/monitoring criteria; included in the report they get

- December 2024 – benchmarks for certification
- Resources – volunteers, staff, IMS
- Communications – emphasis on achieving the next level of data quality. Include history of past process.
- Could be additional ones.

NPCR has adopted NAACCR's standards – implications? Or getting standard setters involved in the conversation. Should be involved. Membership of the task force.

Minimum Dataset (Stephanie has it written out)

- Define data items for an incident case of cancer
- Edits metafile for minimum dataset (another
- Sept 2022 – chairs were identified and charter completed
- Begin Jan 2022, after CFD
- Jan – Jun – summer – NAACCR coffee break to generate discussion;
- Finalize by January 2024 – gives time to implement
- Members – CDC, NCI, NAACCR, CCRs
- Resources – volunteer and NAACCR staff time

How is this different from CDC's asking for. **Need to resolve with NPCR and COC** (early case capture)

Informatics

Reviewed document already created:

- We expanded goals to the communication to the registries and the implications to them.
- We are not addressing current informatics needs, with the highest priority being path reporting, processing, etc. in a consistent way. This should be addressed now.

Implementation

- Communicate with registries regarding the language/definitions and initiatives that may impact them / why it's important. MedMorph highest priority

Who/resources:

- Underutilizing CIAG – task them with monitoring and reporting on initiatives and implications to registries, with recommendations. Ask them to develop timelines for relevance (from the paper they developed)
- TFs could be created for pieces of this.
- Ideally, NAACCR hires a person to coordinate and do the heavy lifting.
 - Business case to standard setters is that NAACCR is unique position to help implementation in the larger registry community.

Milestone: central registries are receiving all the reportable pathology in their state.

Milestone: CCR software can efficiently process and consolidate path records automatically (could be expanded to other reporting sources).

Biggest challenge is the uncertainty of the tasks and timing.

Is it NAACCR's role to speak on behalf of the registries? Yes, but sometimes they are driven by funding. I.e. \$ invested in mcode – under the purview of that funder; may not have a voice at the table.

Can CIAG let us know where we need to be at the table?

CIAG more proactive

Members are not NAACCR members (Lori K.)

Group needs another NAACCR member but has time and can synthesize the info.

Communication and Marketing

- Need consultant's information
- Add to their SOW, implement the approved recommendations from the communications consulting group (GLC).
- Resource – interest in having staffing/consulting, will wait for consultant
- Milestones – no revision needed
- Timelines – work with GLC; ;year 2+ implementation
- Monitoring and evaluation: review GLC report and develop evaluation for each recommendation the Board adopts. Was the work GLC completed results in improved communications outcomes?

Policy & Advocacy

- Needs a process piece developed
- SOW – SPA identifies issues, tools to assess regulatory and policy opportunities; coalition building and training. Focus on registry leadership advocate for sustained success.
- Additional resources? No Staff and volunteer, 4-6 hours/month
- Milestones: improved regulatory and policy landscape to remove barriers.
- Timelines – 3 years
- Monitoring and evaluation – understanding advocacy priorities of the member organizations done through a survey. Develop the training and deliver to member registries; are we getting the outcomes they wanted?

Equity – research supporting health equity

- Identify what we measure, what we measure well/not well
- Identify what we don't measure but need to
- Partner organizations that collect these data or use the data (health equity researchers)
- WG/TF under RDU – starting an API workforce now (Sarah)
 - 1 year - Infographics/advocacy/annual meeting
 - 2 years - Review variables and baseline assessment
 - 3+ years – what do we not collect

Gender identity – new data item – needs testing. Univ of IA – paper. It's not in the face sheet. Already a standard for use in health care.

NCI supplement – just funded – adding at the clinic helpful.

DEI – workforce

- Punt to SPA – for 5-15 years
- Find other organizations that are working on this
- Now
 - Work with those that are recruiting volunteers
 - Early investigator program to sit in on committee/Board meetings
 - Environmental scan of NAACCR members
 - Mentorship – like people together (people of color)
 - Review of internal policies/procedures of committees, etc. and PD best practices to make sure hiring/electing.
 - Investigate partnership with equity group (Lori S/Betsy)
- What does success look like?
 - What are current practices as benchmark
 - Board, staff, etc. represent North America

Extended training/education

- CTR training is established
- Expand training audience – leadership institute (develop coursework/content); include DEI
 - Year 1 – developing; marketing
 - Year 2 – virtual synchronously – hold training
- Add to mentorship program; targeted opportunities to connect; website; add recognition to mentors
- Day in the life of a researcher – younger researchers – college/PH (RDU) – package a story to targets community colleges, rural colleges, colleges (TF to develop a story and pilot it at one college with focus groups for feedback). Using Linked In mentorship
- Resources – PT staff member

Recruitment & Retention

- Campaign at the org level (pre-MAP); grassroots approach. NAACCR committee members bringing colleagues to sit in on the next call.
- Benchmarks – track demo of our membership. Would need to communicate need for info in DEI initiatives.
- Consider expanding membership

Does NAACCR have a role in developing a skillset. Yes training is needed.

Groups will send to Ann Marie in 2 weeks.

Day 2 Supplement Notes

September 29, 2022

Board Meeting Minutes Supplement

Board Strategies, continued

Decision/next step:

- **Teams** will flesh out proposals/plans within 2 weeks; send to Ann Marie.
- Will **make decisions** at next Board meeting

Projects (flesh out more in 2 weeks; send to Ann Marie)

1. Certification - approved to move forward
2. (needs more discussion - pending) Minimal Data Set
 1. Task Force identifying fields necessary for an incident record, then later an edit set (sending to Edits WG)
 2. Path/physician reports - do we need a record layout for that
 3. CDC focused on early case capture - same as an incident record
 4. NCI wants by February the prior year data - path - partially modeled data. Wants all of the pieces to come in.
 1. How to combine them. Huge need for it.
3. Informatics - approved to move forward

Member Association Management (**Ann Marie** will reframe the following, based on what she receives)

1. Communication
2. Recruitment/Retention
3. Extended Training
4. Advocacy/Policy
5. DEI

Reviewed NAACCR Committee Org Chart (will align with next SMP)

1. SPA - strengthening relationships; help the Board strategize
2. Communications - organization's business to the membership (newsletter - staff did it) - Communications SC said it was insufficient, social media. Communications between SC has gotten more complex.
 1. Communications told RDU to do it.
 2. Permeates the undergirding the organization - not a SC, because overarching.
3. Informatics - now a SC? Do we have staff to help? Could start now.
 1. Informatics institutes now to grow the workforce
 2. Need to define what to focus on it.

Main Board Agenda

1. Kevin contacted CDC/NCI about HL7/FHIR expert to work on Vol. 5. Both said no SME. NCI said maybe she could hire someone. Vicki too. And Vicki talked to Betsy - likely next CoOp cycle and not necessarily funds. Timeline for Vol. 5 revisions. How long is Vol. 5 - there are things that don't work in the current manual. **Kevin** will f/u with them both and that we need to decide in the next 2 weeks.
2. Communications Consultant - initial report - interviewing staff, committee and others. There will be a report before the next Board meeting.
3. Individual member application - Lynn Giljahn. Approved
4. Volume 2 rebuild update - huge investment. In discovery - data dictionary (have started it). Current process is Word docs through MLTG. IMS will be building the pipeline so that requests through a single system - through MLTG, UDS, HLSG, feed into the end. Crafting the workflows are complex (not linear and not well defined) **Lori, Monica, Stephanie working on it**. Huge benefit to partners (\$3000). Will want vendor comments
 1. Can see where data items/requests are in the pipeline. 18-month process.

2023 annual conference - in person

1. VW working with the hotel - everything set operationally. Contract signed pre-pandemic. Sunday (Board), T-Th meeting. Going down in December to review.
2. Program - starting to plan the program; welcome input from the Board. Looking at new formats to capitalize on in person - more interactive. Traditional T, Th. Wednesday would be workshops (included in registration) - leadership institute, epi/stat - need ideas. Panel discussions. Working with a small group.
 1. Sarah - AI/AN and broader issues.
 2. Some sessions online? Hybrid tends not to be successful - sets up for people not coming.
 3. Have a separate Forum - concurrent sessions
 4. But to funded to go, would need to present to go (posters, workshops?) - have a specific poster session time. QR on each poster to get the recording.
 5. Virtual version is critical to meet more people - here's how your work matters.

2024 annual conference - in person, Boise, ID

- Signed a contract with Boise - 3rd week of June
- Hotel selection next week

Post 2024 Meetings

- After 2023, could get a short list of locations, but at a slower pace. Let's see how 2023 goes.
- Co-hosting with NCRA (same location) - NCRA hasn't booked for 2025 yet. Co-location - kickoff plenary and meal functions or common exhibit halls.

Steering Committee Reports

- Communications - nothing to report - will be meeting Monday.
- Professional Development - revisiting/updating work plan; changes/revising timelines. New Upkeep TF to update material. 3 TFs on what to put into mentor/mentee application; website/technical pieces with Angela and Tyler (submission process; similar to MAP); cross-promote with MAP. Open office hours - on a topic and get feedback on what members want. Developing a timeline. No info members until next year, at annual meeting kickoff...

networking. Consider member rewards for mentors. Coordinate with workshops... (interactive); NAACCR talks - push out (Recinda).

- Needs more coordination.
- Betsy - education summit
- A lot of new staff
- RDU - latest meeting, up for vote: 1) Data Confidentiality Documents, 2) MFA primer, 3) Hashing primer, 4) Best practices for responding to data requests from individuals; Also AI/AN TF - Sarah/Recinda discussing. Will talk to Jeff, Heather, Recinda, RDU about possibly broadening the scope. Ann Marie warned about broadening scope. **Let Recinda know this will be coming.**
- S&RD - 2 TF/WGs reported. Minimal Data Set - April Austin chairing. CIAG update - refined position paper on why fast data, fyi. Lori thinks that the content was driven by those who want more than we can provide without significant investment.
- SPA - Randi corrected that the proposed membership; Board liaisons will NOT be members of SPA. Just need to hear what they're learning. Need dedicated time on the agenda for reports. Betsy, Stephanie, Colleen Sherman, Mignon, Randi. Invite Colleen & Mignon to SPA. For appointing new liaisons, will be a standing responsibility.
 - New charge approved.

Liaisons

- Loraine (Canadian) - COVID-19 trends report, wider data strategy with an advocacy group - focusing on timeliness (preliminary data), treatment data, indigenous populations
- Lori (NCRA) - hybrid meeting - San Diego - May 7-10. Received 85 abstracts. VA reporting - Senator Kelly's office. Changing CTR credential name, by May/June
- Wendy (NPCR) - success stories next week. Town halls have about 30 year anniversary. FFR/Reports due today.
- Kevin (SEER) - completeness estimates from NCI. Used SEER path data, NPCR survey data, modeled median effect was 6.7% reduction. Top of the CI is the adjustment factor for their completeness - around 9-10% adjustment. Applied to all registries, even though differential effects. Updated estimates are now in DMS.
 - NPCR/SEER/NAACCR coordinating completeness adjustments
- Betsy (UICC) - going to the meeting in October, presenting on the NCCR. Won't be available for the 10/19 Board meeting.