

Strategic Planning and Alliances Steering Committee
August 1, 2023
Meeting Notes

Attendance		
Members Present:	Monique Hernandez Randi Rycroft (chair) Wendy Aldinger	Dennis Deapen Betsy Kohler
	Monique Hernandez Iris Zachary Mignon Dryden	
		NAACCR Staff Present: Karen Knight Ann Marie Hill
AGENDA ITEM	DISCUSSION	ACTION/FOLLOW-UP
1. Roll – Karen		
2. Review June 21st notes – Randi	<ul style="list-style-type: none"> Minutes were approved. Ann Marie suggested prioritizing member benefits via a word cloud. 	<ul style="list-style-type: none"> Karen will investigate using a word cloud tool.
3. Updates from the Board – Randi This topic was skipped due to agenda item 4.		
4. Review of Board Strategic Priorities and initiatives – Wendy / Ann Marie Wendy: Wendy and Ann Marie are speaking to all Steering Committees to review the strategic priorities report. In January 2022, the Board reviewed the strategic planning process; in March 2022, the Board met with Steering Committee chairs to discuss projects and created strategic pillars to guide choices. The group met several times throughout 2022 to finalize strategic priorities. Steering Committees asked their Committee members for feedback. This year, the Steering Committees reviewed how to incorporate changes in their work plan. Now it is time to move forward with acting on the priority initiatives. Ann Marie shared the specific strategic initiatives and the role of the SPA SC. Specific activities that will involve SPA SC include the following: <ol style="list-style-type: none"> 1. Certification criteria (RDU, SPA and S&RD) – SPA’s role will be from a big picture perspective. This group has 	Dennis said he will review the report. He asked if it had been shared with the membership. Ann Marie said the report was just completed in June; there has been a lot of work with the SCs, who have worked with their workgroups and task forces. The next step will be to engage with the membership. Monique said to monitor trends in informatics and interoperability, we will need to identify subject matter experts. Since this is such a broad topic, it will be important to identify how we will monitor. Karen shared her work with CIAG, HLSG’s priorities, and the Cooperative Agreement with CDC. It is difficult to learn and stay abreast of the work happening in standards, policy, AI/NLP, etc. so it may help to narrow down the focus. Ann Marie suggested looking at the implications for central registries if ONC creates fields that healthcare will be using. Randi agreed but it will be difficult without understanding the details. Randi brought up a topic Dennis brought to her related to Health Data Utilities. This will be discussed on the September agenda.	<ul style="list-style-type: none"> Karen will share Ann Marie’s slides with the group.

<p>not been launched yet. (This effort is intended to start soon.)</p> <ol style="list-style-type: none"> 2. Informatics/interoperability – CIAG knows this is coming, as does PD SC. SPA’s role is to monitor emerging trends and advise on NAACCR’s role. (Longer term) 3. Improving race and ethnicity reporting – RDU has started this. SPA’s role is to pay attention to what is happening outside of NAACCR; are we in compliance with standards outside of NAACCR? 4. Expanded training – SPA’s role to identify specialty topics beyond CTR-training. 5. Advocacy – SPA will need to lead this effort. 6. Diversity, Equity, Inclusion and Respect – SPA has already done some work on this, but this is on the back burner for now. Anjali’s work earlier this Spring will be available when it is time to revisit. <p>Ann Marie said the group will need to prioritize. Rutgers did ask if the group needed an intern but may not be a good fit.</p>	<p>Karen reported that she has reached out to CDC to provide the interoperability presentation they provided at the conference to the wider NAACCR audience. Others agreed this material needs to be available to the community.</p> <p>Randi said we will need to decide out of all the activities what we will work on first.</p> <p>Ann Marie said that major goals for the next strategic plan are due October 6.</p>	
<p>5. Finalize NAACCR membership document – Randi</p> <p>At the last meeting, the committee reviewed the list of membership benefits. After the meeting, some were marked as available for members only. Randi also added member benefits listed on the member sign-up page on the NAACCR site.</p>	<p>Randi asked the group to make recommendations for some of the benefits that could be a member-only benefit but are not currently. Some ideas included the following:</p> <ol style="list-style-type: none"> 1. Reduced rates for education 2. Data dictionary 3. Toolkits (at least some of them, i.e., professional development ones) <p>Randi noted that it is possible to have a NAACCR account and not be a member.</p> <p>Ann Marie asked where NAACCR is a voice for its members or the cancer surveillance community? Randi said she thinks NAACCR is a voice for its members and has a voice in the surveillance community. Mignon agreed and said NAACCR is a voice particularly in developing/approving data items.</p> <p>Ann Marie asked Dennis if there are benefits that are specific to researchers. Dennis said the benefits are profound for research, but these benefits have become routine. Before NAACCR, every registry</p>	<ul style="list-style-type: none"> • Karen will send everyone the revised list.

	<p>defined their own fields, definitions, etc. and there were no standards. In addition, the VPR has changed how epidemiology cohorts can be facilitated that were logistically and financially not possible before. Studying rare cancers or small populations requires data from multiple locations; because of NAACCR, there are no limitations to small areas and the data are consistently collected. Dennis said NAACCR's work has had the biggest impact on epidemiology in the last three decades.</p> <p>For next time, we will consider which benefits the Board should consider as member only benefits.</p>	
<p>6. Education of advocacy groups – Randi</p> <p>Randi shared an announcement from Komen in which they are creating a registry for breast cancer patients in order to increase participation in clinical trials. She said we have seen one-off registries being developed in the last few years, but perhaps these efforts could have been handled by other means. Examples include the Firefighters Registry, Ovarian and Familial Cancer Registry, National Childhood Cancer Registry.</p> <p>Komen's registry is interested in capturing patient-reported outcomes. In light of what we want to do regarding partnerships, how would we go about educating them about what NAACCR does and how we could partner.</p> <p>She also noted there have been discussions about collection of patient-reported outcomes in the past.</p> <p>How can we educate advocacy groups about the availability of population-based cancer surveillance data?</p>	<p>Randi asked the group for their thoughts about NAACCR's involvement:</p> <p>Monique said there may be opportunities for the VPR. Without it being population based, how can they provide generalizable results? She said why not reach out and see how we could support or make recommendations.</p> <p>Dennis said he has been supporting starting registries, including the Firefighters Registry, Mesothelioma Registry, NCCR, etc. There is a lot of interest in these registries from Congress. He thinks this is a great question to address. He thinks many of these registries will rely on population registry data to supplement their data. What is different about most of these initiatives is patient engagement. State registries rarely have patient engagement by tradition and design. Should we rethink that model? These registries help fill gaps and offer a lot of potential.</p> <p>Betsy said we worked closely with Komen on projects in the past; they understand who we are and what we do. But perhaps there are new individuals there; how would we educate them.</p> <p>There are opportunities to advocate, education and partner with organizations. Randi said ideally, we do this education without reacting to press releases.</p> <p>Ann Marie said about 10 years ago, Betsy brought up this idea of collecting patient-reported data. She asked if there should be some best practices for specialized registries since they do not understand how to do these. If there are issues, there could be negative consequences for registries.</p>	<ul style="list-style-type: none"> • Randi will reach out to Komen to learn more.

	Monique asked how we learn more about the project. Randi offered to reach out to them but not as a representative of NAACCR.	
<p>7. Continue assessment of potential/current partners activity – Randi</p> <p>This topic was not discussed due to time limitations but will be a high priority item for the September agenda.</p>		
<p>8. Liaison updates, if available – Randi/All</p> <p>Karen reported that at the July HLSG meeting, Dr. Nelson reported the College’s work on collection of progression and recurrence and synoptic reporting methods to support collection of that information.</p> <p>Randi was nominated to be the liaison to the CoC but has not heard back yet.</p>		
<p>9. Summarize meeting for reporting to the Board – Randi/All</p> <p>Randi will let the Board know we are finalizing the membership benefits document and will be reaching out to Komen.</p>		
Next Meeting is scheduled for September 5 th 11:30 – 1:00 ET		