## Strategic Planning and Alliances Steering Committee September 25, 2023 Meeting Notes

Attendance				
Members Present:	Monique Hernandez	NAACCR Staff Present:		
Randi Rycroft (chair)	Iris Zachary	Karen Knight		
Winny Roshala	Mignon Dryden	Ann Marie Hill		
Mary Jane King				

AGENDA ITEM	DISCUSSION	ACTION/FOLLOW-UP
1. Roll – Karen	<ul> <li>Randi reported Dennis stepped down from the committee.</li> <li>Members were encouraged to recommend additional members,</li> <li>perhaps someone with informatics background.</li> </ul>	Randi will reach out to potential members.
2. Review September 5 <sup>th</sup> notes – Randi	<ul> <li>Discussed action items from last time. Winny said the Steering Committee's goals and objectives are priority over asking the Board how they will make requests of SPA SC.</li> <li>Monique/Wendy will be discussing DEI resources in a future Board meeting. Monique is reaching out to other Board members to discuss.</li> <li>Minutes were approved.</li> </ul>	
3. Updates from the Board – Winny/Wendy  Winny said the Board meeting was held last week; at the Board/Chair meeting there was discussion about the next Strategic Plan and timeline for goals due by the Steering Committees. This week's Coffee Break will present the plan for manager/director feedback. To wrap up the current plan, Steering Committees will provide their usual updates.  Wendy said the Board identified Board members for the Certification Task Force. Mary Jane said she was interested in serving on the Task Force.	<ul> <li>Randi suggested it may be good to include on the Certification Task Force representatives from registries that struggle with certification.</li> <li>From the Chairs only meeting last week, the other Steering Committees are keenly interested in communicating/collaborating with other Steering Committees. This will be necessary for some of the new initiatives.</li> </ul>	
4. NAACCR membership benefits – Randi  Karen showed the draft Word cloud to the group. She eliminated those with minimal responses.	<ul> <li>Based on current data, the group agreed with the size of the words.         The more concrete benefits turned out larger.     </li> <li>Discussed the challenge of ranking these, i.e., whether to prioritize based on members only vs. the entire surveillance community.</li> </ul>	Ann Marie will     investigate the use     of a proprietary     word cloud tool.

Five people completed these and need more from the members.	<ul> <li>Randi said VPR was not large, despite it being unique in the US. Ann Marie said respondent perspectives drive the responses; if there had been more people responding with an analytical perspective, the results may have been different.</li> <li>Mary Jane suggested sharing this with the Board and other Steering Committees to rank them. We would have to reduce the number of options and would need to determine if this is member or community focused. Ann Marie may be able to get access to proprietary software to help with this. Monique suggested using Google Forms if we share with others.</li> <li>Decision: share with Board and other Steering Committee members.</li> <li>In order to do this, we will need to reduce the list significantly and choose whether it will be focused on members or the surveillance community.</li> <li>Mignon asked about the purpose of the exercise. Randi said originally, NAACCR thought it would be important to understand and communicate the benefits of NAACCR. It could impact alliances and funding opportunities. It also came up when the Board was discussing costs/fees, so it would be helpful to have the benefits of membership.</li> <li>Mignon added that she agrees with focusing on registry member benefits and showcasing benefits to individual members especially since they are the ones who engage in the different committees and work groups and serve on the board and we want to attract additional individuals to join in the cause.</li> <li>Monique said the word cloud could be useful across different platforms with new employees, partners, advocacy work, etc. to promote NAACCR</li> <li>Decision: will focus on member benefits; understanding a member is a registry with individuals in it.</li> </ul>	Randi/Karen will discuss offline and will send to the group a proposal for how to share the list, and a reduced list (<=20).
<ul> <li>5. Draft workplan goals to align with strategic priorities – Randi</li> <li>Karen reviewed the edits made to the work plan so far and the group reviewed the remaining strategic initiatives: <ol> <li>Expanded training – SPA's role to identify specialty topics beyond CTR-training.</li> <li>Advocacy – SPA will need to lead this effort.</li> </ol> </li> </ul>	<ul> <li>2024-2027: Goals and objectives are required for the first deliverable, not any more granular than that (initially).</li> <li>The group reviewed the two goals and agreed the ones already in the work plan are appropriate.</li> <li>The group reviewed the objectives as well. For Goal 2, objectives 1 and 3 are similar. These objectives were revised.</li> <li>Decision: the goals and objectives are final. Tasks may change after feedback.</li> </ul>	Randi will submit the goals and objectives to the SMP WG.

3. Diversity, Equity, Inclusion and Respect – SPA SC has already done a lot of work on this. Monique said that the consultant suggested NAACCR needs to identify a process for addressing this; and the process may be just as important as a finished product. She suggested we need more education about DEI from an expert. Mignon said it may be good to provide a webinar to the members. Randi noted this would be directed from the Board.	
See https://www.hcinnovationgroup.com/interoperability-hie/article/53063442/health-data-utility-from-vision-to-reality-in-many-states and Benefits for State Governments and Pubic Health - ONC TEFCA RCE (sequoiaproject.org); Trusted Exchange Framework and Common Agreement (TEFCA)   HealthIT.gov  Randi said in some states, there is movement in creating health data utilities. Based on her reading, they are the next generation that HIEs started, but goes beyond the ability to exchange clinical data, but is intended to bring in additional data sources (like public health data) to create an actionable data warehouse. One of the use cases: child in an ER with asthma, would allow the family to link to resources to help in reducing the attacks (i.e., filters, pest control, etc.).	<ul> <li>Iris said she was approached and told that all the cancer registry data would be pulled into the health data utility. Missouri is one of four states that have these agreements. She was alarmed and there was a lot of misunderstanding among this group about cancer registry data. She spoke to their Department of Health, and there is a task force to get social data. At this point, these are only concepts, but it is something that may be applicable to all cancer registries. She said these come after interoperability as they include data sharing.</li> <li>Randi mentioned the TEFCA link.</li> <li>Randi asked: If health data utilities get implemented in other states, what do we think of this. Would it be useful to have the cancer registry in these? And what would the use case be? Randi does not immediately see a use case for cancer just yet.</li> <li>Mary Jane reported that in Alberta, Epic is required. Canadian Partnership Against Cancer are also working on something similar in sharing data. Ontario is creating a data lake for research.</li> <li>Iris shared another link: <a href="https://www.civitasforhealth.org/wp-content/uploads/2023/03/Civitas-HDU-Framework-Final-2023-03-26.pdf">https://www.civitasforhealth.org/wp-content/uploads/2023/03/Civitas-HDU-Framework-Final-2023-03-26.pdf</a></li> <li>Ann Marie said the health data utility may only be useful for treatment or clinical trials, but less so for prevention, since registry data is post-diagnosis. Mary Jane said yes, but we go to great lengths to make sure it is accurate; it could be useful to obtain/share stage data.</li> </ul>
7. Liaison updates, if available – Randi/All	
Randi is now the official liaison to the American College of Surgeons.	

There were no other liaison reports, due to lack of time.	
8. Summarize meeting for reporting to the Board – Randi/All	
We will submit the 2024-2027 goals and objectives.	
Next Meeting is scheduled for November 7 <sup>th</sup> , 11:30 – 1:00 ET	