

Strategic Planning and Alliances Steering Committee
May 4, 2023
Meeting Notes

Attendance		
Members Present: Randi Rycroft (chair) Betsy Kohler Stephanie Hill	Dennis Deapen Jenna Mazreku Monique Hernandez	Mignon Dryden Iris Zachary Winnie Roshala
Guest: Anjali Goswami		NAACCR Staff Present: Karen Knight Ann Marie Hill
AGENDA ITEM	DISCUSSION	ACTION/FOLLOW-UP
1. Roll – Karen		
2. Review April notes – Randi	<ul style="list-style-type: none"> Notes approved. 	
3. Discuss value of NAACCR – Randi/Anjali Anjali presented to the group her work, including membership benefits, DEI & Policy/Advocacy: <ol style="list-style-type: none"> Identify NAACCR membership benefits with the intent to recruit additional sponsoring members. Interviewed eleven members. The biggest value was the data standards because used most often. Created a value proposition statement. Identify DEI practices to develop or collaborate with others to reduce disparities in cancer burden and improve internal work environment. Did research/assessment of practices from partner agencies. Could use volunteer-led groups, external sources such as TED talks, or invite speakers from different organizations to speak on DEI strategies/importance in the workplace. Noted there may be a collaborative opportunity with Stand Up 2 Cancer to help them develop education materials related to standards for clinical trials or help promote their work. Identify policy/advocacy best practices and opportunities for funding/partnership. Learn from partner agencies. Leverage strengths to provide unique services to strengthen alliances with partner agencies and for successful collaboration. 	<ul style="list-style-type: none"> The group acknowledged the amount of work she provided in a short period of time and thanked her for her efforts. Regarding Stand Up to Cancer, Dennis said he thought they were a fundraising organization. Population based cancer registries have rarely overlapped with clinical trials work, except to show how clinical trial enrollment does not well represent the general population. He wondered if e-path could be used for identifying patients for clinical trials. A bill was introduced in CA and passed but the clinical trial program was not implemented. Ann Marie said they have been successful in fundraising and provide grants. But recently they have been encouraging equity in recruitment for their clinical trials. She wondered if NAACCR could use our data to educate them and potentially become a source of providing data. Ann Marie asked if the value proposition was based on the interviews. Anjali confirmed it. Monique said leveraging external resources for DEI would be the best way forward for that initiative. She asked if there were other partner organizations to consider. Anjali said there were, and she will provide them in her report. Monique said that would be helpful in marketing who we are for future projects. Randi asked if any of the interviewees said anything unique. Anjali said a couple of people said NAACCR is valuable to have a voice to have an impact on standards and processes. 	<ul style="list-style-type: none"> Anjali will share her slides with the group as well as her documents when complete.

<p>She also outlined some potential financial implications of four additional partner organizations. This would open opportunities for visibility, collaboration, funding, advocating for policies, etc.</p>	<ul style="list-style-type: none"> Anjali has a number of documents including example DEI best practices and research of partner organizations. 	
<p>4. Updates from the Board – Randi</p> <p>Randi said the Board is still determining their specific strategic initiatives.</p> <p>One deliverable for the Board is our next committee report, including progress on metrics, due June 1. Randi will draft the report and may send it to the group for feedback.</p>		<ul style="list-style-type: none"> Randi will draft the report and metrics.
<p>5. Discuss what makes a high-quality registry – Randi/All</p> <p>One of the Board’s strategic initiatives is updating certification. They asked that the SPASC describe what would make a high-quality registry.</p>	<p>Ideas discussed by the group:</p> <ol style="list-style-type: none"> Having collaborations with other registries and other external organizations. Examples: cancer advisory boards, NCI cancer centers. (Monique) Discussed whether it could be measured. Randi said may not need to measure at this point. Following more aspirational standards. (Dennis) Data use. (Betsy) Being the voice of cancer data for cancer control in a state; advocating for participation in research, funding, etc. (Dennis) Using linkages to enhance their data (Stephanie) For operational standards, include recommendations in revised NAACCR Standards Vol. III for the qualitative activities that make a successful registry. (Stephanie) Leadership in the cancer surveillance committee – participation, innovating, etc. May not be appropriate for certification, but perhaps for an “exceptional” acknowledgement. (Ann Marie) Stephanie said the College has an “exceptional” by standard. Encourages going above and beyond. (Stephanie) SEER has done this as well. Share data back to reporting facilities (i.e., hospitals), such as a profile on facility assessments. (Winny) Culture within a registry to innovate. (Winny) Deduplicate cases between registries to improve data quality. (Betsy) Improve deduplication within a registry. (Stephanie) 	<ul style="list-style-type: none"> Members to send any additional ideas to Randi. Randi will create a summary for the group working on certification.

	<p>12. Are there additional data quality measures? Have DCO rates by top five cancer sites? This could have registries prioritizing those sites. Or unknown race levels varying by site. The group noted they should be aware there may be unintended consequences. As path-only or claims reports increase, complete race and stage decreases.</p> <p>13. Add % missing/unknown for more fields.</p> <p>14. Coverage of reporting sources, i.e., ensuring physician and independent lab reporting. NPCR’s annual evaluation includes percentage of reporting by source type. Need more than 0% of path, clinical, DCO reporting, for example.</p> <p>15. As we get new data items, how do we provide feedback on data quality on an ongoing basis? (Winny)</p> <p>16. Conduct activities to ensure data is complete and accurate. For example, link path report to Lexus Nexis to determine if a Florida case, link with DMV to enhance/validate race. (Monique)</p> <p>17. Efficient processes, i.e., more automation and few manual processes. (Wendy)</p> <p>18. Ensure staff are fully trained and up to date. (Wendy)</p> <p>19. Have CTRs on staff? NPCR standards include this. (Stephanie)</p>	
<p>20. Assessment of potential/current partners – Randi/All</p>	<p>Tabled until the group can review Anjali’s reports.</p>	
<p>21. In person meeting at NAACCR Conference – Randi</p> <p>SPA SC is scheduled to meet on Wednesday afternoon, June 21, 4-5 p.m. CT.</p> <p>We will have a remote connection option, which will likely be a phone.</p>		<ul style="list-style-type: none"> • Karen will follow-up with Charlie on updating the timing on the Conference page.
<p>22. Liaison updates, if available – Randi/All</p>	<p>Canadian Council of Cancer Registries held their annual meeting this week – Betsy reported they want to coordinate more with NAACCR on educational activities. They are also working on process maps in their registries, which have turned out to be challenging. They also talked about consolidating resources at the federal level to support the provinces and territories. They promoted involvement in NAACCR committees and noted how collaborative our processes are.</p> <p>HLSG is narrowing down their activities/priorities, will be meeting at the conference and will be providing an update at the conference.</p>	

	MLTG asked NAACCR to clarify the roles/processes of UDS versus MLTG. As a result of the Toronto Staging items not being approved, they will be looking at implementation issues earlier in the process. A subgroup is recommending a small advisory group to review any items that may have implementation issues. They would produce a list of questions for MLTG to review.	
23. Summarize meeting for reporting to the Board – Randi/All	Randi will provide the Board with a summary of what entails a high-quality registry and pieces from Anjali’s work, if appropriate.	
Next Meeting is scheduled for June 6 th at 11:30 am ET		