

Strategic Planning and Alliances Steering Committee
January 7, 2025
Notes

Attendance			
Members Present: Randi Rycroft (co-chair) Monique Hernandez (co-chair) Karen Knight		Eric Durbin Mary Jane King Iris Zachary	NAACCR Staff Present: Stephanie Hill Lori Havener Ann Marie Hill Visitors:
AGENDA ITEM	DISCUSSION		ACTION/FOLLOW-UP
1. Roll			
2. Review notes – Randi			Approved
3. Updates from the Board – Wendy Karen reported the Board is preparing for the Board/Chair in-person meeting in March and plans to discuss the High-Quality Registries document at the new Board meeting. Randi reported that she presented two documents at the December Board/Chair meeting, the High-Quality Registries document and the current version of the patient advocacy portfolio. The Board and SC Chairs will review the High-Quality Registries document and provide feedback.			<ul style="list-style-type: none"> Lori will post the High-Quality Registries document to the Board/Chair Share site and remind SC Chairs and the Board to review and provide feedback.
4. Portfolio for Patient Advocacy – Randi/Monique Randi and Monique reviewed version 3 of the draft document created for patient advocacy groups. During the Board presentation of the portfolio Lori Swain suggested putting the “ask” up front or at the top. Another comment from Lori S. was that with today’s political climate it seems that the world is motivated through fear. Is this something the SC should consider with the portfolio?	<ul style="list-style-type: none"> The SC agree to moving the “ask” to the top of the document. There is some hesitation with using fear to motivate people. Ann Marie suggested asking, “what would the world look like with no cancer registries?” Is there a way to balance this concept? Monique suggested expanding the idea so people have a better understanding e.g., the use of data to make decisions about appropriate treatment; without central registry data mammography age would not have dropped to 40; data helps make decisions about screening guidelines and resources, etc. Iris inquired whether the Dwindling Resources section should be retained. 		<ul style="list-style-type: none"> Randi and Monique will update the draft document based on the Board and SC feedback.

	<ul style="list-style-type: none"> • Monique mentioned that without central registry data the patient advocacy groups would not have the information to support their activities i.e., advocate for their group. • The SC agreed with the concept of adding information about what would it be like with no central registry data. • It was suggested to incorporate the funding piece in with the educating legislator's section. • Randi reported that the Board suggested creating a separate infographic for the resources part and the who we are section. The SC agreed with the Board suggestion. • Ann Marie mentioned the SC should consider capturing some of the suggestions into a list of talking points. 	
<p>5. Central Cancer Registries an Essential Overview (Central Registry 101) session at NAACCR Annual Conference – Randi</p> <p>Randi presented an outline for her section for the Central Registry 101 session. The outline includes sections on the value of central registries, typical roles, major players in cancer surveillance and the resources for central cancer registries.</p>	<ul style="list-style-type: none"> • Value of Central Registries: it was suggested to add research • Typical Functional Roles: it was suggested to add Education/Training, Matching for Clinical Trials, Automated Data Capture, Data Manipulation, AI, and Machine Learning. • Major Players in Cancer Surveillance: there was discussion about what is meant by “major players”. It was suggested to add Canadian Council of Cancer Registries, Stats Can, Canadian Partnership Against Cancer, Public Health Agency of Canada (responsible for pediatric registry), Hospitals/Health Care Providers, American College of Radiologists, CYP-C (Canadian childhood and young adult group), NCRA, Other (CBTRUS, LLS, etc.) • Resources for Central Registries: add Standards, CiNA data, Education and Training Work Group (Canadian education group) 	<ul style="list-style-type: none"> • Randi will update the outline and post it to Share for the SC to review/comment.

	<ul style="list-style-type: none"> Consider reorganizing the outline. For example, Education would be a category with the resources listed underneath. 	
<p>6. Narrative or Social Media topics – Wendy</p> <p>Randi mentioned that pending Board decision, there may be a NAACCR Narrative article on the high-quality registries document. Eric mentioned the recent news associating alcohol with cancer. Unfortunately, it is not likely that registries have any good data about this so this will be difficult to address.</p>		
<p>7. Potential SPA member – Randi/Monique</p> <p>Randi shared that there was a recommendation for a potential SPA SC member to help with advocacy outreach or ideas around that topic. Laura LeBlanc is head of the media relations for Keck School of Medicine at USC. Her job is to promote research and activities of the school; however, she was impacted at a young age by deaths in her family due to cancer and then she was diagnosed with cancer 3 times.</p>	<ul style="list-style-type: none"> Ann Marie suggested it would be good to have a patient’s voice at the table for NAACCR, a unique perspective that NAACCR could benefit from. Randi inquired whether a patient advocate would be a constituency that the Board could consider. It is important to define her role, or any patient advocate, on the committee. 	<ul style="list-style-type: none"> Monique will reach out to Laura to have an initial conversation to tell her about NAACCR and see if she has any interest. Monique will report back to the SC at which time there will be further discussion to form a suggestion to the Board.
<p>8. Liaison Reports – Randi/Monique</p> <ul style="list-style-type: none"> ACoS: Randi reported there is nothing to report from the American College of Surgeons as they are between meetings. HLSG: Karen reported the HLSG is working on a slide deck for the value of population-based cancer surveillance. MLTG: Mary Jane reported that the MLTG is preparing for v26 and will be reviewing field test results. OVAC: Randi reported the focus is on the continuing resolution and the new administration, and maintaining the ask to increase funds for NCI, NIH, and CDC. Comprehensive Cancer Control National Partnership: Randi reported they are wanting to put on an educational series related to rural health. The target audience is the cancer coalitions across the country. They are putting together a panel of experts in various aspects of rural health. Randi is 		

discussing this with Karen to identify a NAACCR representative.		
9. Summarize meeting for reporting to the Board – Randi/All <ul style="list-style-type: none"> • The March 2025 in-person Board/Chair meeting in Savannah. The primary focus for the meeting is around advocacy. • The continued work on the document for patient advocacy groups. 		
Next Meeting:	February 4, 2025 @ 11:30-1:00 ET	