

Strategic Planning and Alliances Steering Committee
September 3, 2024
Meeting Notes

Attendance			
Members Present: Randi Rycroft (co-chair) Monique Hernandez (co-chair) Mary Jane King Eric Durbin	Mignon Dryden Wendy Aldinger Jenna Mazreku Iris Zachary	NAACCR Staff Present: Karen Knight Tricia Kulmacz Stephanie Hill Ann Marie Hill	Visitors: Bozena Morawski Joshua Mazuryk
AGENDA ITEM	DISCUSSION	ACTION/FOLLOW-UP	
1. Roll – Tricia			
2. CERT TF update – Bozena Morawski / Joshua Mazuryk Bozena reviewed the draft criteria from the task force that's made up of a diverse set of membership that will be presented to the Board. We got some feedback on when the Board thought it might be best to engage the membership on some of these updates. Their conclusion was to give the Board an opportunity to comment on these proposed criteria, and then anything that moves forward out of that body would be shared with the membership at large and standard setters. For the standard setters it's more of an FYI. We propose maintaining the gold and silver categories and adding a gold plus certification category. The idea behind this is that silver and gold are categories that represent the standard surveillance activities that we should all be doing to have high quality surveillance data. Gold plus is intended to recognize registries that are really involved in promoting data use of their data. What I am presenting today will be just sort of the theoretical framework that we have discussed. The thresholds have not yet been fully flushed out. We recommend that all the certification criteria be applied to the current or most recent year of incidence data. Any criteria designed to evaluate fitness for use for survival and prevalence would be applied to the 7 years of incidence data that are typically used to calculate survival metrics. Bozena gave details of criteria that would stay the same and suggested changes/additions.	<ul style="list-style-type: none"> Iris suggested clarity to “meets follow up completeness” between SEER and NPCR. Mary Jane added in Canada prostate cancer is not screened in all provinces. They do ad-hoc but there are not screening programs. Monique shared in Florida has been trying for years to get the Department of Health to sign the NAACCR interstate data agreement to no avail. She has concerns with this affecting the gold criteria. The big barrier is the legal department. Randi added the rationale will be very important to add. Bozena and Josh assured her this would be added. 		
3. Review July 2nd notes – Randi		Approved.	
4. Updates from the Board – Wendy Wendy shared the Board did approve a DEIR statement and will be taking inventory of the Board policies to see which ones have DEIR aspects. Looking to identify any gaps and incorporate DEIR policies where needed.			
5. Discuss National Academies workshop on cancer surveillance – Monique/All (Link for recording https://www.nationalacademies.org/event/41759_01-2024_enabling-21st-century-applications-for-cancer-surveillance-through-enhanced-registries-and-beyond-a-workshop) Monique advised we keep an eye out for the report to identify areas that we need to address any misconceptions. Ann Marie suggested a link https://www.bing.com/videos/riverview/relatedvideo?q=lobbying+vs+advocacy+no+n+profits&mid=8DFA0AD6C48CE21AB1148DFA0AD6C48CE21AB114&FORM=VIRE to understand where the lines are as far as where you can educate and where you can't educate, because unlike some other nonprofits we do not have the ability lobby. We	<ul style="list-style-type: none"> Ann Marie had a suggestion regarding engaging with patient advocacy groups to further the mission of cancer surveillance. Karen added those facilitating/participating in the meeting were not necessarily people who understood cancer registries and the breadth of they do. Those in attendance could walk away with a misunderstanding of what cancer surveillance is and its status. SPA could address who we are, what we do and what needs advancement, with targeted audiences. 	<ul style="list-style-type: none"> Randi and Monique to resume work on the external-facing brochure. 	

<p>can educate in a general way. Monique shared the following link regarding advocacy groups https://www.curetoday.com/advocacy-groups.</p> <p>Monique suggested possibly using the development of the external facing brochure and modify it for patient advocacy groups.</p>	<ul style="list-style-type: none"> • Eric and Wendy were disappointed at the lack of registry knowledge, maybe hospital but not cancer registries. • Wendy mentioned the presenters of the meeting will have one week for a technical review. She is unsure of when the meeting report will be released. Ann Marie thought it may be a couple months until the report is released. 	
<p>6. Public comment periods for HTI-2 and USCDI+ Cancer – Karen/All The Office of the National Coordinator has two items out for comment.</p> <ul style="list-style-type: none"> • USCDI+ Cancer has a 60-day comment window and will close on September 23rd. USCDI+ Cancer is a set of standards that expand on the United States core data items for interoperability. This is a limited data set intended to capture what is absolutely essential for early incidence reporting from health IT. These were developed by the office of the National Coordinator for Certification of Health IT vendors. A life feedback session was held and went well. The HLSG Standards Alignment Task Force has drafted comments on USCDI+ Cancer registry data items and asked for feedback from their community. These will be shared with HLSG. The plan is for NAACCR to put some sort of comment in on behalf of the community, but also encouraging registries to do the same, and others in our community. • HTI-2 is the overarching policy that determines what is required for health IT vendors to become certified. The relevant part for cancer registries is they must use the Cancer Content Reporting Implementation Guide, which is an HL7 FIHR implementation for reporting from ambulatory facilities. They have added the Cancer Pathology Reporting Implementation Guide which is also an HL7 implementation guide. Sandy Jones has expressed there was so much effort to get pathology labs using NAACCR Vol. V that there is concern in shifting to this new implementation guide. This comment period closes October 4, 2024. 	<ul style="list-style-type: none"> • Eric Durbin helped facilitate the USCDI+ Cancer session. It had 280 participants and went well. Once concept regarding the challenges of consolidating is a first vs. a subsequent primary. The idea is that the early data set would be automatically transmitted from the EHR. • Stephanie shared that much of the audience was from a hospital registry background, many questions were around how the hospital registry would benefit or be involved. Again, it is important to clarify when we're talking about central vs. hospital registries. More access is not as beneficial as more structure to the data. • Randi asked if NAACCR is going to provide comment on the HTI-2 policy. Karen believes this will be discussed with HLSG and NPCR in the next couple weeks. • Karen added the comment has been shared that additional resources would be necessary to implement USCDI+ Cancer Registry and does relate to HTI-2 as well. 	
<p>7. Narrative or Social Media topics – Wendy / Eric Wendy suggested things shared in this meeting regarding advocacy including the links provided.</p>		<ul style="list-style-type: none"> • Monique and Anne Marie to draft content on advocacy for the narrative and/or social media.
<p>8. Summarize meeting for reporting to the Board – Randi/All</p> <ul style="list-style-type: none"> • The discussion around engaging with patient advocacy groups would be important to raise with the Board. • The need for educating partners and other leadership became apparent from the National Academies meeting. 	<p>Stephanie asked if there is anything being done with the effort to showcase the benefits of being a NAACCR member? Randi shared the benefits to members has been published and one for benefits to partners is in progress. Randi shared the benefits to members was published on the NAACCR website and in a NARRATIVE Article. Many agreed continuing to promote this and cross-posting would be beneficial.</p>	<ul style="list-style-type: none"> • Stephanie to review and potentially repurpose existing member benefits content for the website. • Randi and Monique to prepare for the upcoming board meeting, highlighting discussions on engaging patient advocacy groups and educating partners.
<p>Next Meeting:</p>	<p>October 1, 2024@11:30-1:00 ET</p>	