

**Standardization and Registry Development Steering Committee
August 24, 2023**

Attendance					
Members Present:		Winnipeg Staff Present:		NAACCR Staff Present:	Guest:
Heather Stabinsky (co-chair)	Eric Durbin	Winnie Roshala	Randi Rycroft	Jim Hofferkamp	April Austin
Jenna Deniaud (co-chair)	Sandy Jones	Randi Rycroft	Valerie Somma	Stephanie Hill	Sean Porter
Peggy Adamo	Mary Jane King	Valerie Somma	Georgia Yee		Ann Marie Hill
Robin Harris Billet	Lori Koch	Georgia Yee	Valerie Yoder		
	Joshua Mazuryk	Valerie Yoder			
AGENDA ITEM			DECISION	ACTION/FOLLOW-UP	
1. Roll					
2. Review minutes/action items			Approved		
3. Discussion Items					
<p>a. Minimum Data Set TF report – April/Sean The Minimum Data Set TF has completed the report to outline their work and their approach to decision making. Several data items were identified as needed to process cancer incidence i.e., consolidation, these are not necessarily needed to inform incidence. Then, the TF identified a list of data items needed to inform incidence. Type of Reporting Source may help establish a quality measure to determine if a high percentage of a specific reporting source e.g., pathology reporting. Additional concerns identified by the TF are included in the report as well.</p> <p>b. Discharge and Claims Data TF report – Jenna The Discharge and Claims Data Best Practices Guide is ready for review.</p> <p>c. Pathology Reporting WG – Sandy/Joshua The WG has updated the Electronic Pathology Reporting Guide v5.1 (formerly Volume V) with several revisions and corrections to align with where transmission is going i.e., HL7 FHIR. Appendices have been separated from the document to improve usability of the document. An HL7 SME reviewed the guide, a new validation tool will be developed by APHL AIMS when the document is approved, laboratories reporting through APHL AIMS uses the current v5.0 standard and will migrate to the v5.1 standard. The WG plans to finish the document and provide it to the SC by the September S&RD meeting.</p> <p>d. Review S&RD Charter – Heather/Jenna No discussion due to lack of time.</p> <p>e. Review S&RD workplan – Heather/Jenna No discussion due to lack of time.</p> <p>f. Review WGs, TFs, and AG – Heather/Jenna No discussion due to lack of time</p> <p>g. Counting Every Case Coffee Break – Randi During the August Coffee Break the group discussed the topic of making every cancer count. There was a lack of participation in the discussion. Participants were asked if a presentation should be given at the NAACCR 2024 Conference or a NAACCR webinar; however, there was minimal feedback.</p>			<p>Investigate to see if the data items identified are available in 12-month data and how many have unknown values. Concerns of availability and completeness were discussed about the race/ethnicity and county data items. These concerns should be shared with the HLSG.</p> <p>The SC should review the best practices guide and send comments to by October 12th. Randi and Joshua will be the primary reviewers.</p> <p>Counting Every Case Coffee Break discussion should continue at next month's S&RD meeting.</p>	<p>April and Sean will share the report with the HLSG including the S&RD SC concerns with the completeness of data items e.g., race and county in an early data set e.g, 12-month data set. April and Sean will report the HLSG discussion back to the S&RD SC.</p> <p>Discharge and Claims Data Best Practices Guide comments should be submitted to Jenna and Tricia by October 12th.</p> <p>Lori H. will set up a separate call to discuss the S&RD Charter, Workplan and review of the WGs, TFs, and AG.</p> <p>Add Counting Every Case Coffee Break discussion to the September SC agenda.</p> <p>Heather and Jenna will email the MLTG report to the SC.</p>	

<p>The point was to discuss instances and scenarios of cases falling in the cracks that are not included in low-risk research projects or differing practices among registries. For example, in what instances do central registries collect or not collect state residence? Do path reports that do not have a patient address sit in limbo? Are registries counting every case they should be? There are several nuances in how registries process, or not, data that come in with no address or interstate data exchange cases. Valerie Y. was not on the Coffee Break but would have been interested in this discussion. Utah has worked on improving interstate data exchange and path reports to help improve gaps. Sandy mentioned she is aware of laboratories that send cases across the country because they prefer how a specific lab processes the case. If the case is missing address, it is sent to the state of the ordering provider. Some registries ignore these cases because they do not have the staff to follow-back on these cases.</p> <p>h. Cancer Informatics Advisory Group update – Eric/Gary No report due to lack of time.</p> <p>i. Mid-Level Tactical Group update – Heather/Jenna No report due to lack of time.</p>		
<p>4. Other Business</p>		
<p>5. Board liaison report – Lori K./Joshua No report due to lack of time.</p>		
<p>6. Tweet worthy for Communications SC</p>		
<p>7. Next Meeting</p>	Thursday, September 28 at 12:00 – 1:30 pm eastern	