Standardization and Registry Development Steering Committee
December 5, 2024

Attendance							
Members Present:	Robin Harris Billet	Mary Jane King	Valerie Somma	**NAACCR Staff Present:**	**Board Liaison:**	**Guest:**	Isaac Hands
Heather Stabinsky (co-chair)	Valerie Yoder	Sandy Jones	Randi Rycroft	Lori Havener	Lori Koch	Mona Highsmith	
Jenna Deniaud (co-chair)	Georgia Yee	Peggy Adamo		Jim Hofferkamp	Joshua Mazuryk	Lois Dickie	
				Stephanie Hill		Recinda Sherman	

AGENDA ITEM	DECISION	ACTION/FOLLOW-UP
1. Roll		
2. Review minutes/action items		October minutes reviewed and approved.
3. Discussion Items		

a. **Unresolved Issues chapter of DD – Recinda**
Occupation and Industry and Sequence Number Central Notes
Recinda discussed the need for a more comprehensive and updated chapter on unresolved issues previously in the data dictionary. She mentioned the work of the Fit for Use Data Assessment Work Group (FUDA WG), which has been assessing variables and providing guidance. Recinda also mentioned a landing page for researchers to access and learn more about the data.
 	
    b. **Inter-registry Data Exchange TF report – Mona**
Mona discussed the progress of the task force, which convened in May and meets once a month. The TF has reviewed the charter and added some deliverables, including updating the web page for guidelines and agreement. The TF has completed an initial review of the Inter-registry Data Exchange Guidelines and plans to develop a spreadsheet for registries to track their data exchanges with states including the format they prefer information to be exchanged. There has been discussion about the minimum data items, some members have suggested that it is no longer needed for inter-registry data exchange.
 	
    c. **ICD-O WG report - Lois**
Lois provided an update on the ICD-O-4 review, stating that they had completed their review and sent their comments to Dr. Michael Eaton. She also mentioned that a specialized group will be convened to oversee the implementation of ICD-O-4. The WG will continue their review process for the Blue Books, which involves identifying new codes, changes in behaviors, and non-reportable malignancies. The SC discussed the need for funding to purchase Blue Books and Lois suggested that the online version would be cheaper. The task force is in need of more participation, due to past and upcoming retirements.
 	
    d. **XML Data Exchange WG report – Valerie Y.**
Valerie reported the WG has successfully released the XML-based dictionary and version 1.8 of the XML Data Exchange Standard in May, which introduced a date-time data type. The group is considering whether to release a version 1.9 XML data exchange standard in 2025, pending any changes in the data dictionary. Future priorities include aligning the XML standard with emerging oncology and healthcare data standards, addressing short-term data exchange needs in the NAACCR community, and expanding the capabilities of the current NAACCR XML standard format. The group also plans to review syntax changes suggested by Fabian, from IMS, in early 2025. Valerie and Isaac discussed the potential alignment with the emerging Observational Health Data Sciences and Informatics (OHDSI) data standard in the oncology space. They noted that while this standard is important, it's not yet ready for prime time and they need to wait for further guidelines.
	• S&RD metrics: The team agreed to consider these metrics further in the next meeting. The number of active vs. inactive members was discussed. Lori H. mentioned that inactive participants could be asked if they still have an interest in the group and will be able to actively participate in future meetings. Jenna proposed discussing the strategic plan in the next meeting.	• Lori H. to schedule a call with Lois, Jenna, and Heather to discuss WHO Blue Book purchasing options and complete the budget request form which will be submitted to the Board.
		• Jenna will post the discussion questions regarding partial records on the SC Share site prior to next month's meeting for the SC to prepare thoughts for discussion.

	e. Cancer Informatics Advisory Group report – Eric/Gary Lori H. reported that CIAG has been focused on completing the manuscript and prioritizing informatics initiatives for the Board, with no recent discussion on the OHDSI data standard.		
	f. S&RD Metrics – Heather Heather proposed four metrics for the S&RD initiatives and tasks: 1) State or Territory representation, 2) monitoring metafile updates and clearinghouse entries in a reporting year, 3) number of clearinghouse uploads done for a reporting year, and 4) monitoring updates to Registry Guidelines. The team discussed the importance of adequate representation on committees from central registries, standard setters, and vendors. Heather presented a spreadsheet generated by the NAACCR office that provides a breakdown of what state members of S&RD committees are coming from. They also discussed the potential for these metrics to provide valuable information for the chairs and MAP.		
	g. Partial Records – Jenna Jenna discussed the strategic initiatives and a discussion about improving timeliness through innovative approaches to data collection, focusing on the journey from source record generation to submissions and calls for data. She encouraged the team to think about what a more efficient future would look like and how to prepare central registries for partial record collection and processing. She asked the group to consider what our shared vision of a more efficient future looks like. How can we prepare central registries for partial record collection and processing? What would a timelier cancer registry mean to you? Lori H. suggested a quick assessment to understand who's doing what with partial records within central registries.		

	h. Mid-Level Tactical Group report – Jenna
	Jenna provided an update of the last MLTG meeting.
	   i. Progress of version 25 and version 26 implementation, highlighting the importance of these updates for the work groups under S&RD.
	   ii. Recruitment for the ICD-0-4 task force and the discussion about a phased approach.
	   iii. The proposed v26 changes will be discussed further and voted on in a couple months.		

	i. NAACCR Annual Conference in-person meeting – Lori H. Lori H. mentioned that Angela Martin from the office is looking at the annual conference in person meeting schedule and asked the SC to consider whether they want to meet in Connecticut in June 2025.		
4.	**Board liaison report – Lori K./Josh**		
5.	**NAACCR Narrative article worthy – Heather/Jenna**		
6.	**Other Business**		
7.	**Next Meeting**	Thursday, January 23, 2025, at 12:00 – 1:30 pm	