

Standardization and Registry Development Steering Committee
April 26, 2018

Attendance				
Members Present:	Mary Jane King	Board Liaisons Present:	NAACCR Staff Present:	Guests Present:
Lori Koch (Co-chair)	Gary Levin	Heather Stuart-Panko	Lori Havener	Donna Rivera
Peggy Adamo	Rich Pinder	Randi Rycroft		Nan Stroup
Eric Durbin	Winny Roshala			Valentina Petkov
Sandy Jones				

AGENDA ITEM	DECISION	ACTION/FOLLOW-UP
1. Roll		
2. Review Action items from last meeting.		
3. Consent Agenda (see items in Table 1 and go to Causeway for updates)		
4. Discussion Items		
a. S&RD WG and TF team charters 1. ACCR TRS TF – Nan Stroup Unlike other workgroups or taskforces ACCR TRS work is complete and will disband after their presentation at the NAACCR Annual Conference on the work accomplished. Nan shared some of the goals achieved. Considerable information regarding timeliness was gathered through survey, analysis and focus groups. She recommended those who participated meet in future to follow-up on suggestions made about timeliness. The report has been shared with the NAACCR Board for feedback. If there is a recommendation for the S&RD group to address, the taskforce can reconvene. 2. 2018 Implementation Guidelines TF – Amy and Winny Several IT experts were added to the roster and has been a great benefit to the overall effort. This provided the ability to identify IT issues early on, making the process easier. The groups first charge of creating a concurrent abstracting document was completed in December. A working draft of the Implementation Guidelines was released on March 29 th and continues to be updated. Everyone has worked together well to accomplish this and it has gone very smoothly.		
b. SEER Linkage and Data Acquisition – Valentina and Donna Donna presented slides giving an overview of the initiative to enhance SEER data and provide new opportunities for cancer surveillance. Currently we collaborate with medical, pharmacy and genomic data. A working group is being created to look at current and future data sources. This idea came out of Registry of the Future session at the 2017 NAACCR Annual meeting. The group goals will be to asses a		<ul style="list-style-type: none"> Donna and Valentina will send their presentation slides to Peggy for distribution to this group.

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<p>decision matrix tool for evaluating new data linkages and to look at the feasibility of the linkages and focus on best practices among these groups.</p> <p>Valentina presented slides regarding genomic linkages, which she is responsible for at SEER. One group of linkages happens outside SEER data management system of the registry and the other is inside SEER DMS system. Linkages were on the back-burner due to contracts. It is expected we can continue this work beginning in May.</p> <p>Both Donna and Valentina will be making presentations at the NAACCR Annual Conference on other subjects.</p>		
<p>c. NCRA presentation, Precision Cancer Surveillance for Central Cancer Registries – Eric Eric presented slides regarding acquiring and linking data to molecular data. There is a lot research focused around precision medicine for classifying patients based on molecular changes in their tumors. My experience with the Molecular Tumor Board motivated my interest in leveraging the central cancer registries to help facilitate the decision-making process. Use cases were reviewed. Ultimately, we would like to integrate all data sources together so patient outcomes can be modeled. Also, to make the data available for research. We are increasing our access to sequence data, but it illustrates the challenge in that there is not a single standardized format for transmitting this information. My belief is this can be accomplished within a couple years.</p>		•
d. Monthly reports:		
1. 2018 Implementation and Guidelines TF - Winny		
e. Volume II Process Proposal		
f. Data Collection Model - Randi		
g. Registry of the Future Report - Randi		
5. Other business		
a. NAACCR Implementation Webinar –		
6. Tweet worthy items for Communications SC		
7. Next meeting	May 24, 2018 at 12:00 pm ET	