Standardization and Registry Development Steering Committee
September 28, 2017

Attendance			
Members Present: Lori Koch (Co-chair) Mary Jane King (Co-chair) Gary Levin Rich Pinder Winny Roshala	**Board Liaisons Present:** Heather Stuart-Panko Randi Rycroft	**NAACCR Staff Present:** Lori Havener	**Guests Present:**

AGENDA ITEM	DECISION	ACTION/FOLLOW-UP
I. Roll		
II. Review Action items from last meeting. • S&RD voted yes for the Randi Rycroft XML version. The XML was tested and approved by email vote. It was submitted to the NAACCR Board in September and was approved. It was recommended a special S&RD meeting with the XML workgroup. Mary Jane would like to include some from the Communications Steering Committee. At the October XML meeting an outline of the project will be requested. • Data Security Charter – Lori Havener was going to contact Recinda about volunteers from the Standardization Committee to participate from this work group. • Workplan S&RD to host on NAACCR web server – Dustin said it could be done, but would be very like Causeway. For us to work on the document live, it would require a very costly Microsoft license. Causeway may have this ability in the future with Word. • Mary Jane discussed the possibilities with Excel regarding a spreadsheet she is working on. • Workgroup & Taskforce Word version – Lori received the EDITS and Physician Reporting Workgroup documents still in development. Lori Havener suggested Wendy Blumenthal for the Physician Reporting Workgroup who will be joining the LOINC call next month. Issac was another suggestion for presenting		• Lori will email the steering committee inviting them to join the XML workgroup if interested. • Mary Jane will submit an article to the NAACCR Narrative. • Lori Havener will contact Recinda about volunteers from the S&RD SC to serve on the Data Security Charter. • Lori K. and Mary Jane will work on a schedule to receive 2 oral presentations for each meeting starting in October.
III. Consent Agenda (see items in Table 1 and go to Causeway for updates)		
IV. Discussion Items		
a. **LOINC – Wendy S. and Wendy B. (postponed to October):**	Postponed until October.	
b. **Data Security WG – (Lori H.) R&DU SC plans to tackle everything in the S&RD charter and their list. R&DU would like two volunteers from S&RD to participate on the group.** Recinda said that the Research & Data Use Steering Committee plans to tackle everything included in the charter, in addition to things they added. It was asked some volunteers from S&RD volunteer to participate. Those with expertise in other areas will be pulled in as needed.		• Rich and Gary volunteered to be a part of the Data Security WG group

c. SSN Unavailability issues (see S&RD SC notes-20170126 and SSN Unavailability Issues_20161219).
This was a group the steering committee had requested to discuss issues of increased unavailability of SSN. A document was developed identifying the issues and recommendations. There needs to be a standard linkage number for those cases that do not have any identification number. It is important to include background information regarding how much we think this is going to affect our ability to link. Most billing sources will be using the MBI. Lori believes it would be this committees responsibility to develop this charter, expressing our thoughts on how we see this moving forward and ask for input. Gary also felt Dr. Penberthy and Dr. Bernard should be contacted because they have a vested interest in LinkPlus and have statisticians that may be able to contribute. The group agreed this would be a great place to start. Lori noted UDS has seen and approved the MBI number that will be included in the Volume II Version 18.
 	
The following options would have their own charter:
1) Convene a group to work on a standard linkage algorithm that does not require SSN to determine best methodology. This would be a charter.
2) Convene a group to develop educational material on the importance of the SSN to central registries and how the SSN is used by central registries.
 	
This one would go to UDS first and then be given to Winny and Amy as co-chairs of the 2018 Implementation & Guidelines Group.
1. The SSN is a key matching criteria for patient case consolidation; lack of SSN may then require MBI to be included for case consolidation. Things to consider:
   a. Inclusion of both SSN and MBI in export and import of data, when available.
   b. MBI without SSN is of no benefit to consolidation when consolidated data is based on SSN.
	• It was agreed by all a group should be formed to address this including members of the IMS beta testers and then a collaborative effort taskforce could be convened.
	
	• This will be tabled until the 2018 Implementation.
		• Lori Havener will contact NAACCR staff: Castine who leads the VPR efforts and Recinda who is on the Research & Data Use Steering Committee. They could look at activities going on in this area regarding linkage algorithms that do not require a SSN.
		
		• Lori will email UDS about how the MBI will be handled if a partial MBI is collected and transmitted.

d. Standards Volume II process Lori was asked to provide a summary of discussions that took place on steering committee calls regarding the Volume II process and created a document with this information. Lori would like to see that the standard setting agencies receive a spacing within the NAACCR Record Layout that could test new data items being proposed. Registries could begin collection allowing it to be in the NAACCR Record Layout. This data item would not be assigned a NAACCR data item number and not included in the NAACCR EDITS set, until submitted as a new specific data item. This will encourage testing a data item before assigning it a NAACCR data item number. This would also help lessen the data items pushed through approval, never being used and later retired. Rich pointed out this may encourage those to use the XML.	• Propose a space for the standard setters to test new data items before making them permanent.	• Lori will write a proposal and send via email for the group to review. Once reviewed and approved by this committee it will be forwarded to the NAACCR Board for their October meeting.

e. S&RD Work Plan 2017-2018:		
i. S&RD WG and TF team charters		
1. EDITS WG The charter and workplan document was reviewed. Possibly add deliverables and status report process. The subgroups also need to be identified. Are the groups ongoing and who are the members? Wendy suggested leaving the charter more generic and then adding the specifics in the workplan every year, as they would change. Include a timeline for updates.		• Mary Jane will add the comments and suggestions discussed to the document. • Lori will forward it on to Jim.
2. Physician Reporting WG	Postponed until October.	
f. Monthly reports:		
i. CMB Loria Pollock and Laura Myers discussed revisions to the specific histologies that are excluded from AJCC TNM chapters. Most cases have been included, but not all. Jim presented TNM override flags that are necessary for 7th Edition. Those were approved and forwarded to UDS. There was also discussion regarding the burden on hospitals and registries. There is concern for the quality of data with all the new data items being rushed through and training.	• Remove ICD-O-3 Implementation Guide and ACCR-TRS TF from the agenda. Updates will be posted to the Causeway. • The 2018 Implementations Guideline Taskforce will be added to the Monthly Reports on the agenda.	
ii. ICD-O-3 Implementation Guide TF The next meeting will be tomorrow. This taskforce also makes sure the histology codes for AJCC 8th Edition are in sync. Waiting for that to be finalized and then checked for consistency with what we already have for 2018.		
iii. ACCR-TRS TF Mary Jane said a document is being developed.		
V. Other business		
VI. Tweet worthy items for Communications SC The XML implementation plan will be coming out soon.		
VII. Next meeting	Thursday, October 26, 2017 at 12:00 pm ET	