# Standardization and Registry Development Steering Committee
# August 25, 2022

| Attendance | | | | | |
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| **Members Present:** | Rich Pinder | Valerie Yoder | **Board Liaisons Present:** | **NAACCR Staff Present:** | **Guest:** |
| Peggy Adamo | Winny Roshala | | Lori Koch | Jim Hofferkamp | Lois Dickie |
| Jenna Deniaud | Randi Rycroft | | Wendy Aldinger | Karen Knight | Joshua Mazuryk |
| Sandy Jones | Heather Stabinsky | | | | Alex Goel |

| AGENDA ITEM | DECISION | ACTION/FOLLOW-UP |
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| **1. Roll** | | |
| **2. Review minutes/action items from May and June minutes** | Approved | |
| **3. Discussion Items** | | |
| **a. ICD-O-3 WG report – Lois**<br>On July 6, 2022, the annotated ICD-O-3 update was emailed to vendors and the guidelines and tables were posted August 2022. An announcement was released using the NAACCR listserv and SEER registrar listserv. To date, WHO has released only one 5th edition update on urinary sites. The participation on the WG has stabilized and in good shape. Currently the WG is running parallel with the Cancer Path Chart activities. | | |
| **b. Volume V WG report – Joshua/Sandy**<br>This group is changing from a TF to a WG. The name is changing to Pathology Reporting WG. They are working to finalize Volume V, Version 5.1. The WG requested funds for a HL7 specialist. One of the tasks will be to review Volume V, Version 5.1, and the examples within Volume V. They are waiting to hear from Board on whether they can get an HL7 specialist. Sandy has solicited new central registry volunteers to participate on the WG from NH, RI, FL, and LA. There are activities to move towards FHIR; however, HL7 v2 structure will need to be maintained as the WG works on FHIR. | | |
| **c. IHE SDC on FHIR IG HL7 Ballot – Sandy**<br>CDC has been working with CAP and Lantana on HL7 FHIR since 2019. HL7 FHIR implementation guidelines are being developed for the Integrating the Healthcare Enterprise (IHE) Structured Data Capture (SDC), the CAP cancer checklists, and is currently out for ballot. These guidelines provide guidance to pathology laboratories on how to map the CAP checklists to FHIR observations. This is not for central registries; it is for pathology laboratories and how to implement FHIR. CDC has consultants working on this initiative. For example, someone is mapping the CAP checklists questions and answers to SNOMED. Lantana is packaging the HL7 FHIR implementation guidelines for the Cancer Pathology Data Sharing implementation guide. The Office of National Coordinator is pushing the use of HL7 FHIR, so CDC has been working on a framework to get better data from pathology laboratories into the electronic health record. The HL7 ballot closes September 12th. The HL7 ballot was presented to the CIAG, and it was decided since this is for pathology laboratories it would be confusing for central registries. Sandy inquired whether it would be helpful to have a webinar for central registries to review the implementation guidelines and reassure registries that they do not need to develop something new right now. | Communicate high-level information on the HL7 FHIR activities:<br>• what's going on<br>• emphasize this ballot is for trial use and not final content<br>• who is involved<br>• impact now<br>• impact down the line<br>• central registries do not need to do anything at this time | Sandy and Alex will draft a one-page informative paper to share with S&RD SC prior to sending out via the NAACCR ListServ. |

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| **d. Minimum Data Set TF – Lori K.**<br>Need to establish the charter and workplan to convene a TF. This would be a minimum data set used primarily to calculate incidence and the concept of faster reporting.<br><br>Randi mentioned there are two concepts with the minimum data set. One being rapid case reporting and the other being the short record (e.g., path only record).<br><br>Sandy reported that NPCR is moving forward with this and there will be an incidence-type report that will be submitted, possibly for 12-month data.<br><br>CDC is working with LexisNexis to use Accurint Plus to bring in additional data sources and social determinants of health information. And approaching the Data Modernization Initiative to look at this as a service to all public health agencies at an enterprise level where data is getting reported through different mechanisms (e.g., APHL AIMS).<br><br>Sean Porter is interested in joining the TF. | The SC agreed the TF focus will be on a minimum data set to calculate incidence and not consider the concept of faster reporting at this time.<br><br>Start with basic must-have information, regardless of the source, to calculate incidence.<br>• Identify data items<br>• Define what can be unknown and still be valid.<br><br>Out of scope:<br>• Two-tiered reporting<br>• Defining minimum data set by source<br>• Edits<br><br>Next steps:<br>• Identify issues that that registries know exist<br>• Identify impact on registry operations<br>• Identify realities of two-tiered reporting | Lori K. will share the charter with the SC for review/comment.<br><br>Utilize the NAACCR ListServ to solicit volunteers for the TF.<br><br>Lori K. will update the S&RD workplan to remove “targeted” from Goal 2 Objective 6. |
| **e. Cancer Informatics Advisory Group update – Eric/Gary**<br>The CIAG discussed the IHE SDC on FHIR IG HL7 ballot on their last meeting. See agenda item above for additional information.<br><br>Karen mentioned that the Fast Data Response Questions document is being wrapped up to bring back to S&RD SC. | | |
| **f. Mid-Level Tactical Group update – Colleen**<br>No report due to lack of time. | | |
| **4. Other Business** | | |
| **5. Board liaison report – Wendy/Lori K.**<br>No report due to lack of time. | | |
| **6. Tweet worthy for Communications SC** | | |
| **7. Parking lot:**<br>**a. Need for definitions for Eternal/Ephemeral cases? – Lori K.** | | |
| **8. Next Meeting** | Thursday, September 22 at 12:00 – 1:30 pm eastern | |