

**Standardization and Registry Development Steering Committee
May 28, 2020**

| Attendance | | | | |
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| Members Present: | Deborah Hurley Mary Jane King Peggy Adamo Wendy Aldinger Eric Durbin | Board Liaisons Present: | Kevin Ward | Guest: Liz Ward Stephanie Hill |
| | | | | NAACCR Staff Present: Lori Havener |
| AGENDA ITEM | | | DECISION | ACTION/FOLLOW-UP |
| 1. Roll . | | | | |
| 2. Review minutes/action items from last meeting | | | | |
| 3. Discussion Items | | | | |
| <p>a. SSDI WG report – Jennifer R./Liz The SSDI Workgroup completed all changes for 2021 on time according to the implementation timeline deadlines. All 7 new SSDIs were field tested, 2 additional SSDIs will be applied to additional schemas, and 1 schema discriminator was added. There were some changes to codes, code descriptions and notes in the manual based on changes in clinical practice and questions from registrars. Some changes were made to the Grade manual, most importantly the addition of yc created at the request of AJCC. Jennifer Ruhl and Jim Hofferkamp will present a NAACCR webinar in August covering basic education as well as the new grade changes. The group is currently meeting twice a month and may be able to meet once a month in the next year if the workload permits. The only new SSDI for 2021 is P16 for Cervix. With the use of XML from now on, standard setters can use their user-defined XML data dictionary to test new items or run them through a field test for approval for collection. In the future we hope to work with SEER and CoC to evaluate what SSDIs are still needed and those that can be retired. Before items are retired a list is sent to central registries to survey how many are still collecting the data item. Liz pointed out it would be helpful if the CoC were to inform the MLTG group of any changes coming so that they may have input if needed. We will continue with the current leadership structure and want to thank Jennifer Ruhl for all her dedication and attention to detail regarding the massive effort she took on.</p> | | | | |
| <p>b. COVID-19 – Stephanie Hill Stephanie informed the group 2 COVID groups have been formed to address collection of COVID issues. They came to the conclusion it is not realistic to expect the collection of complete population based data on COVID through the cancer registries. No place exists in the abstract to accommodate this, although several options were looked at. This is not to say we shouldn't consider a place for the data in the future. Then we can implement it in a thoughtful and planned manner that coincides with our existing change control. Next week some guidelines will be released on documenting COVID in text fields. Peggy suggested we may want to have fields to be able to capture data quickly in the future. Lori pointed out that XML will allow for this in the user-defined dictionary.</p> | | | | |

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| <p>c. 2018 Readiness Survey Results – Lori K./Winny This was sent out at the beginning of May and results have been received. Winny presented some preliminary analysis received from Frank Boscoe.</p> <ul style="list-style-type: none"> • More responses were received this time than last • 75% said at least one of their facilities were less than 50% complete with 2018 • 66% said they are capable of accepting NAACCR XML • 94% said they know where to find resources for the NAACCR XML Standard • 75% are aware state-specific data items need to provide an XML User Dictionary defining those items to reporting facilities and software vendors • 67% know where to find the NAACCR XML documentation and understand the NAACCR XML Data Exchange Standard requirement for v21 | | |
| <p>d. Review SC goals and objectives – Lori K./Winny Randi suggested adding to the plan the goal to have a field that can capture unexpected events impacting cancer diagnosis/outcomes in a timely manner and will be discussed at the June meeting.</p> | | <ul style="list-style-type: none"> • Add additional fields to capture special circumstances to the next meeting agenda. |
| <p>e. Cancer Informatics Advisory Group update – Eric/Gary The second meeting has taken place and the varied individuals involved in the group is impressive. Jeremy Warner at Vanderbilt University is leading one of the nation’s largest consortium of COVID-19 data and they have received 2,000 cases of cancer patients infected with COVID. Their manuscript has been accepted by Lancet. The group agreed COVID will continue to be a topic of discussion. Eric informed the group they will be sending a draft recommendation to S&RD that COVID data be collected on a state level that can perform linkages, as opposed to the registry level, as registries do not update historical data. Topics to discuss were voted on. Early data reporting and timeliness of data was at the top and will be discussed at the future meetings. Data Interoperability was considered and may be worked on in the future.</p> | | |
| <p>4. Other Business There was considerable discussion regarding registrars being furloughed and hospital administrators questioning the relevance of cancer registries.</p> | | <ul style="list-style-type: none"> • Deb is compiling materials to send the hospital regarding the importance of cancer registries and will share this with Stephanie. |
| <p>5. Tweet worthy for Communications SC</p> | | |
| <p>6. Board liaison report</p> | | |
| <p>Next Meeting – Lori will send out a Doodle poll for a June date that does not conflict with the NAACCR Virtual Annual Meeting.</p> | | |