

# Standardization and Registry Development Steering Committee

February 27, 2025

| Attendance   |               |                |               |                       |   |   |
|--|---------------|----------------|---------------|-----------------------|---|---|
| <b>Members Present:</b>  | Eric Durbin   | Mary Jane King | Rich Pinder   | <b>Board Liaison:</b> | <b>NAACCR Staff Present:</b>                | Fernanda Michels  |
| Heather Stabinsky (co-chair)   | Georgia Yee   | Peggy Adamo    | Randi Rycroft | Lori Koch             | Lori Havener                                | Ashley Knealing   |
| Jenna Deniaud (co-chair)   | Valerie Somma | Valerie Yoder  |               | Joshua Mazuryk        | Jim Hofferkamp                              |   |
| Wendy Aldinger   | Gary Levin    |                |               |                       | Stephanie Hill                              |   |
| AGENDA ITEM  |               |                |               |                       | DECISION                                    | ACTION/FOLLOW-UP  |
| 1. Roll  |               |                |               |                       |   |   |
| 2. Review minutes/action items   |               |                |               |                       |   | January minutes reviewed and approved.  |
| <b>3. Discussion Items</b><br><b>a. CROS TF report</b><br>Fernanda leads the Central Register Operation Standards TF. There are several subgroups working on various sections of CROS. Jennifer Seiffert has been hired as a consultant to review all documents to ensure clarity and accuracy. The optimal platform is being discussed with Tyler and Charlie. Fernanda gave updates on the progress of the different areas of work and the next steps. S&RD will give final approval as the sections are completed; each section will go live as it is approved. Three new subgroups will be convened in the future: one on informatics, one on training, and one on data sharing. Stephanie expressed the team's desire for a more accessible and navigable format for their project, rather than a large PDF document. Confluence was a suggested platform. The SC was encouraged to share any examples in structuring or formatting. Jenna demonstrated how Wisconsin uses Confluence.<br><b>b. Cancer Informatics Advisory Group report – Eric/Gary</b><br>Eric reported that the group is working on refining the genomic manuscript. The CIAG prepared a list of informatics priorities per the NAACCR Board request. The group is waiting to hear back from the Board. Eric also mentioned the group's anticipation of a discussion about the new administration's priorities and their potential impact on their own list of priorities.<br><b>c. Value of NAACCR</b><br>The SC discussed the value of NAACCR and updated the list. <ul style="list-style-type: none"> <li>• Having standards allow us to aggregate our data nationally</li> <li>• Virtual Pooled Registry</li> <li>• NAACCR promoting standards across registries improves quality and uniformity</li> <li>• Standardization brings efficiency and collaboration</li> <li>• Volunteer opportunities, networking, career opportunities</li> <li>• NAACCR fosters a sense of community that motivates members to participate</li> </ul> <b>d. Partial Records</b><br>The SC discussed the concept of "partial records" and its implications in their work. The meaning of a partial record was discussed at length, with some defining it as a record that lacks certain crucial information, while others viewed it as a record that is incomplete but still valuable. A partial record is different from an early incidence record as an early incidence record is a type of partial record. Valerie suggested a system where specific data items could be filled out for cases with limited information. Randi pointed out that some essential data might be unavailable from certain sources like pathology labs. All agreed that clearer definitions and use cases are needed for terms like "partial records" to improve communication. There is ongoing work with partners to develop an early incidence record. There is need to focus on how registries can PROCESS partial records (including the early incidence record and subsequent treatment records)<br><b>e. Mid-Level Tactical Group report</b><br>The voting results will be provided on the SHARE site. |               |                |               |                       |   | <ul style="list-style-type: none"> <li>• Lori H. will post the Value of NAACCR document to the SHARE site.</li> <li>• SC will provide additional thoughts on the value of NAACCR to Heather, Jenna, and Lori H. before the Board Chair meeting next week.</li> <li>• Jenna and Heather will discuss the partial records challenges at the Board/Chair in-person meeting.</li> </ul> |
| 4. Next Meeting  |               |                |               |                       | Thursday, March 27, 2025 at 12:00 – 1:30 pm |   |