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| **Research & Data Use Steering Committee**  February 27, 2024 | | | |
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| **AGENDA ITEM** | **ACTION/FOLLOW-UP** |
| 1. Roll - Angela |  |
| 1. **Administrative/Housekeeping – Jeff/Angela/Recinda**     1. **Call for new agenda items** – No new items.    2. **Review/Approve Minutes** – January meeting minutes were approved.    3. **Questions on Short Updates** |  |
| 1. **Board Update – Board Liaisons**   Bozena provided updates on the upcoming board meeting in March, a resolution in honor of Susan Gershman's retirement, approved Certification Task Force Charter, and the position announcement for Betsy's replacement was posted. |  |
| 1. **DS&G WG: Data Release Document – Bozena/Lauren**    1. **Vote for approval**   Lauren discussed the data security confidentiality work group's data release documents, which were circulated for review and will be voted on today to forward to the NAACCR Board. Xiaocheng raised a question about the necessity of requesters signing confidentiality agreements for completely de-identified data. Lauren confirmed that requesters should sign such agreements. Bozena explained that the rationale is to ensure that data users agree to not reidentify individuals and to publish in accordance with certain guidelines. She suggested that best practice would be to ask requesters to agree to follow certain criteria, such as not reidentifying patients and using the data only for stated purposes. The participants discussed the challenges of contacting patients for multiple studies, which can lead to confusion and inconvenience. Bozena highlighted that the document under discussion was intended as a living document to be updated based on feedback. Xiaocheng raised a question about the need for confidentiality agreements when releasing de-identified data for AI projects, to which Bozena and Xiaocheng agreed, suggesting the need for a separate section on the topic in the document moving forward. Angela has a section on AI/ML/Big Data which would be very useful to add in the future. Bozena mentioned that the document would be reviewed annually as part of their workflow. | * The guidelines were approved for sending to the board, with minor corrections and clarifications to be incorporated. * Recinda and Bozena agreed to send the guidelines to the board, from RDU (including where it will go in the future), giving the team a week to submit any final comments. |
| 1. **RDU Work Plan 2024/25-26/27 – Recinda/Jeff/Angela**    1. **Social media WG**   The group is now focused solely on cancer awareness, is seeking participation from both seasoned analysts and newer ones, particularly students.   * 1. **CiNA Research Writing WG**   This group is being restructured to be topic-driven and will focus on promoting the use of CiNA data. The group is also aiming to increase the research capacity within their cancer surveillance community. Recinda also mentioned that while some basic work might fall under the CiNA Editorial, the research writing work group could potentially cover more specific topics. While all members of the work group wouldn't be co-authors, the group would provide more opportunities for collaboration and paper writing. | * Recinda will update the charters for the Social Media and CiNA Research Writing workgroups and present them for review in March. |
| 1. **NARRATIVE Update – Recinda/Jeff/Angela**   The team discussed the structure and content of the new NARRATIVE.   * 1. **What content would you like to see?**   Previously Recinda would submit status of Call for Data, Certification and Journal Registry of Management. Angela suggested publishing the Short Reports.   * 1. **General Feedback**   They considered whether the updates were important to people and if the structure was effective. Jeff proposed the idea of a poll email to gather more feedback. | * All please review the new NARRATIVE format and content. * A poll will be emailed regarding NARRATIVE feedback. |
| 1. **Other Business – Recinda/Jeff/Angela**    1. **Next TF/WG Meeting July 23rd (90 minutes)**   It was decided to have another meeting with task force and work group chairs, possibly biannually, with the next one slated for July. |  |
| **Next Meeting – March 26, 2024, 1:30pm ET (90 minutes)** | |