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| **Research & Data Use Steering Committee****November 23, 2021** |
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| **Attendance**  |
| **Members Present:**Jeff Dowden (co-chair)Heather Zimmerman (co-chair)Keisha Musonda | Lorraine ShackChris JohnsonSarah NashBrenda Hofer | Angela MeisnerManxia WuDeb Hurley | Xiaocheng WuSusan GershmanMaggie Gates | **NAACCR Staff Present:****Recinda** Sherman |

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| **AGENDA ITEM** | **ACTION/FOLLOW-UP** |
| 1. Roll – Heather/Jeff
2. **Approval of October minutes**
3. **Call for new agenda items/any other business**
4. **Questions on Short Updates?**
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| 1. Board Liaison Update – Sarah
* There will be an in-person Board/Chair meeting, details to be determined.
* There was a discussion at the last Board meeting regarding individual memberships. Specifically, the criteria for individual membership was discussed at length. The website currently states for access to NAACCR data you must become an NAACCR Individual Member or work with a current member. However, in the NAACCR Bylaws it states individual membership should have some other way of investing in the organization. The NAACCR Board would like to know from RDU:
	+ Is it indicated in the DART application that if you do not have a NAACCR member on your group, then just apply for the data?
		- Recinda said no, from the data release perspective, the use is better if someone knows what they are doing. They are encouraged to connect with their state registry or another NAACCR member.
	+ How can we, as RDU, facilitate networking or put in place some kind of formal process for those who don’t have a membership or network with a member registry to gain data access if they are not interested in being an active member of this organization?
		- Wu asked why would we want to make it more difficult to use the data when it benefits NAACCR to have the data used.
		- Maybe they should have a sponsor from a member so it is not necessary to become a member. Recinda suggested a fee be associated.
 | * + - NAACCR Individual Membership specifications will be added to the January agenda for discussion.
		- See text at the end of this document for review.
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| 1. Items for Communications SC – Heather/Jeff
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| 1. Monthly RDU Workgroup update:
2. **GSADD, Geospatial Analysis and Resources – Heather/Recinda**
* This group will be renamed Geospatial Analysis and Resources and focus on updating the GIS resources on the NAACCR website. Need to determine is this group would be a task force or work group.
* There was a proposal 6 months ago to create a map story as a de3monstration project of how cancer surveillance data could be used and promote NAACCR data use. The Board did not approve this project. The direction is now focused on highlighting the use of map stories in cancer surveillance. Christian had an example of a story map and wants to identify other map stories to help demonstrate the tool. This is still a work in progress with the hopes of doing a NAACCR Talk in the future.
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| 1. Indemnification and Data destruction document approval – Heather/Recinda

The final drafts of these documents were sent out last week with the agenda. Heather presented the current version of the documents. * The Indemnification document will be included on the NAACCR Confidentiality Issues web page. The next step is to have more pieces focusing on subject areas that we have in data use agreements. This document is meant to help registry staff understand what the legal term means.
* The NAACCR Data Destruction Primer is intended to be a loose guidance document on things to think about regarding destruction of analysis data sets or cohort files from researcher.
	+ Keisha and others agreed more detail regarding general cloud storage would be good. In order not to delay this version, include the cloud information in subsequent version or additional document.
 | * Both documents were approved and can move forward.
* Recinda will let David know the group’s decision to add more information regarding cloud data destruction in future version of this document or included in a separate document.
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| 1. Other Business/Open Discussion – Heather/Jeff
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| **Next Meeting – January 25, 2021, 1:30pm EST** |

**Section 1. Classification of Membership**
The five classes of membership shall be:

1. Full: Full member organizations are central registries in the United States (Territories) or Canada (Territories), which are, or have the potential to become, population-based registries.
2. Individual: Individual members are those persons who are not currently working in a member organization who have demonstrated career and professional commitments and interests that are consistent with or complementary to those of NAACCR. Candidates for Individual Membership must be able to demonstrate involvement or activity in one or more of the following areas: cancer surveillance or registration, cancer epidemiology, patient care, cancer control, professional education, research, and biostatistics. Each candidate must make a commitment to support NAACCR through active participation in the activities of the Association. Individual members shall be entitled to participate and vote as a member of committees. Individual members may chair subcommittees. Individual members may not chair a committee, vote on matters brought before the Membership at the Annual Meeting, nor vote for or hold an elected position in the Association.
3. Sponsoring: Sponsoring member organizations are national professional or national governmental organizations primarily involved in any of the following areas: cancer surveillance or registration, cancer epidemiology, patient care, cancer control, professional education, research, or biostatistics. Each sponsoring member organization shall be entitled to one vote on each matter submitted to membership vote. No action taken by the Association shall be construed as committing any sponsoring member organization to a prescribed course of action. Each sponsoring member organization may designate one or more representatives from such organization to participate in the Association’s affairs on behalf of such organization. Representatives of sponsoring member organizations may be a member of and chair a committee. Only one representative of a sponsoring member organization shall be entitled to cast that organization’s vote.
4. Sustaining: Sustaining member organizations are organizations interested in promoting the purposes of the Association. No action taken by the Association shall be construed as committing any sustaining member organization to a prescribed course of action. Each sustaining member organization may designate one or more representatives from such organization to participate in the Association’s affairs on behalf of such organization. Sustaining member organizations shall not be entitled to vote, and their representatives shall not be entitled to hold office. Representatives from sustaining member organizations may be a member of and chair a committee.
5. International Membership: This membership is available to individuals or organizations from countries other than the United States (Territories) and Canada. Candidates for International Membership must be able to demonstrate involvement or activity in one or more of the following areas: cancer surveillance or registration, cancer epidemiology, patient care, cancer control, professional education, research, and biostatistics. Each candidate must make a commitment to support NAACCR through active participation in the activities of the Association. International members shall be entitled to participate and vote as a member of committees. International members may chair subcommittees. International members may not chair a committee, vote on matters brought before the Membership at the Annual Meeting, nor vote for or hold an elected position in the Association.