Hello NAACCR members!

I trust you are all working diligently on your NAACCR Call for Data. As a reminder, NAACCR did not change its Call for Data deadline – all files are due by December 3, 2019. And please do include any 2018 data you have with your file submission. As you know, NAACCR has been surveying its members regarding the effects of 2018 implementation delays and having these data will aid in the ongoing evaluation.

I had the privilege of traveling twice to Atlanta in October – once to attend the in-person meeting of the Comprehensive Cancer Control National Partnership (CCCNP) and once to attend the Year 2 grantees kick-off meeting for CDC’s cooperative agreement with NAACCR. The CCCNP is a great partner for NAACCR and they are committed to using data – including cancer registry – to inform and evaluate their work and they consistently encourage state cancer coalitions and state cancer control programs to do the same. The CDC kick-off meeting went well too and had representation from all three grantees organizations: NAACCR, CoC/AJCC, and the College of American Pathologists (CAP). One of NAACCR’s deliverables under this cooperative agreement is to provide education and training for each state’s Education and Training Coordinator. CDC is very complimentary of Jim Hofferkamp’s efforts in providing that training.

With Thanksgiving right around the corner (and in the recent past for our Canadian colleagues), I would like to express my thanks to all of you for the exceptional work you continue to do and for your participation in NAACCR. I leave you with a couple of Thanksgiving jokes fitting for this crowd: What did the turkey say to the computer? Google, Google, Google!

What do you get if you divide the circumference of a pumpkin by its diameter? Pumpkin pi, of course.

All my best to you and your families!

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Fall 2019 NAACCR Narrative
NAACCR Research and Data Use Update

Recinda Sherman, MPH, PhD, CTR
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Research & Data Use
Hello! The holidays are creeping up on us, and I am speculating if I am brave enough to tackle the “Hot Cheeto” Turkey recipe. If you have not seen it, google the Amiri King recipe. It is my kind of internet sensation. You may be amazed. You may be horrified. You may be both simultaneously... as a preview, this year’s version includes 2 lbs. of melted cheese in a turkey!

Call for Data Update
Regardless of what type (if any) turkey you may have this November (or had in October for the Canadians), we all have Call for Data looming. We introduced our new Call for Data Submission site last year and have made some upgrades for 2019. The biggest difference this year is the ability to access your registry specific Data Assessment Reports on-line. Historic DQI, CINA Submission Summary, and Certification reports from 2016-2018 are currently available. And we will release 2019 assessments here rather than via email. We are interested in other types of data quality reports your registry would find useful. Please let me know if you have any suggestions.

NAACCR*Prep has seen an overhaul with the goal to make creation of submission files easier. NAACCR*Prep can process fixed width or XML input files and output files are in XML format, fields not required for submission are blanked, multiple submission files can be output based on one input file, and the new Configuration Files store the submission settings to ensure standardized submission. NAACCR*Prep also calculates the ABSMs (area based social measures) and NHAPIIA. New this year are the Yost Quintiles and Race-Based Poverty Percentages. These data items are critical for assessment of cancer risk by social conditions. The Race-Based Poverty Percentages will be sued to develop appropriate race/ethnic based poverty cut-points to enable research on minority groups. However, these variables are still in the evaluation period. They will be evaluated for confidentiality and Fitness for Use in cancer surveillance research. At this point, none of these new ABSMs will be released for use by outside researchers.

For a stress-free (relatively) submission, please access the system early and update new personnel or positions long before the submission date. Contact me if you have any trouble accessing the system. And don’t forget to review your data for the CaRRI database. If you completed CaRRI last year, you only need to review your data for accuracy and changes.

NAACCR Call for Data: Submission due December 3, 2019 (Tuesday)
www.naaccr.org/call-for-data
New CiNA Volume 5: Prevalence

NAACCR Members have produced the inaugural *CiNA Volume 5: Prevalence* monograph. It is currently under scientific review and will be available later this month. Registries whose data qualify for inclusion in *CiNA Volume 4: Survival* are included in the Prevalence Volume. Special appreciation for Chris Johnson of the Cancer Data Registry of Idaho for spearheading this new publication. Look for it here in a few weeks: [https://www.naaccr.org/cancer-in-north-america-cina-volumes/](https://www.naaccr.org/cancer-in-north-america-cina-volumes/). In subsequent years, the Prevalence Monograph will be released with the other Volumes around the time of our Annual Conference.

Annual Conference Abstracts

We are now accepting NAACCR 2020 Pre-Conference Workshop Proposals and Abstracts! Both will be submitted through our Conference Submission Portal. You will need a MyNAACCR account to access the Submission Portal. If you do not have a MyNAACCR account, you can follow the directions on our Conference Landing Page to set one up: [www.naaccr.2020.org](http://www.naaccr.2020.org). Once you access the portal, ensure that your profile is up-to-date including your Bio. We rely on this information for program listings as well as introductions by the Session Moderators and depend on you to provide accurate affiliations and other details.

Data Request Tracking System

We had anticipated a beta-version of the Data Request Tracking System to be released this fall. This system will be used by outside researchers to request CiNA data as well as by the NAACCR community to request access for their own their delay-adjusted data, survival data, or data needed for NAACCR workgroup or taskforce work. This system will handle the Public Use File requests. However, this project is currently on hold and work will resume in 2020. Despite the delay, the ability for registries to track CiNA data consents and for researchers to apply for the CiNA Data on-line will be coming!

NAACCR Education and Training Program Update

Jim Hofferkamp, BA, CTR
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NAACCR Education and Training (NET)
[https://education.naaccr.org/](https://education.naaccr.org/)

If you haven’t done so already, check out the recently revamped NET page.
From this site you can:

- Browse through the Education and Training Calendar.
- View recordings of previous NAACCR Talks.
- Complete the Understanding Central Cancer Registries training modules.
- Discover the international training resources.
- Access the 2019-2020 webinar series and CTR Prep and Review.

It’s your one stop shop!

**NAACCR Webinar Series**


The 2019-2020 NAACCR Webinar Season is here! The first webinar in the series was a review of staging and coding of breast. Wilson Apollo as our guest speaker and did an excellent job of breaking down the rules for coding radiation. Wilson will return in December to participate in our head and neck webinar. For more information on this webinar and the rest of the webinars in the 2019-2020 season click the link above!

**CTR Prep**


The next series will start in mid-January. Registration will open in mid-December. Once again we are fortunate to have Dr. Shirley Jordan Seay as our co-host.

**NAACCR Talks**

Keep a close eye on the upcoming events page in NET for information about upcoming NAACCR Talks. Check out the upcoming webinars at: [https://education.naaccr.org/upcomingevents](https://education.naaccr.org/upcomingevents).

If you aren’t able to join us for the live presentation, the recordings are available at: [https://education.naaccr.org/freewebinars](https://education.naaccr.org/freewebinars). No fees are associated with the NAACCR Talks, but you will need a MyNAACCR account to access them.

If you do not have a MyNAACCR account, all you need to do is click on the link below:


It’s quick, easy, and everyone is eligible to sign up for a MyNAACCR account.

If you have any questions about upcoming training events, please contact Angela Martin or myself!

Angela Martin
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Jim Hofferkamp
[jhofferkamp@naaccr.org](mailto:jhofferkamp@naaccr.org)
NAACCR 2019 Education and Training Calendar

Angela Martin, CTR
NAACCR Trainer/Project Coordinator
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Upcoming Webinar Presentations

11/07/2019  NAACCR Webinar Series: Bladder
12/05/2019  NAACCR Webinar Series: Base of Tongue
12/11/2019  NAACCR Talk: Interstate Data Exchange
01/08/2020  NAACCR Webinar Series: Prostate
02/06/2020  NAACCR Webinar Series: SSDIs: An In-Depth Look

Virtual Pooled Registry Update

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Phase II Pilot Testing

We are excited to share that VPR-CLS pilot testing of Phase II will begin this Fall. Phase II of the VPR-CLS supports a streamlined process of applying for release of individual-level cancer data on matched cases identified in the Phase I linkages. When complete, The Phase II functionality will include use of a web-based Templated IRB/Registry Application (TIRA), a dedicated Central IRB to review minimal risk linkage studies, and a robust and comprehensive tracking system. While the Central IRB is not yet available, the upcoming pilot testing with the Childhood Cancer Survivor Study and the Transplant Cancer Match Study will include use of the TIRA in 33 of the 38 participating registries.

Templated Data Use Agreement (DUA) Task Force

Seven individuals with registry, research, and legal perspectives have been meeting twice a month to develop a Templated DUA that can be adopted by registries participating in VPR minimal risk linkage studies. This small but mighty Task Force has been diligently reviewing existing DUAs, discussing common requirements, and identifying areas where new language is needed to facilitate approved data sharing and publication of results. Once finalized the Templated DUA will be vetted with registries for review and feedback.
Data Sharing Workgroup Volunteers

NAACCR is seeking volunteers to contribute insights and solutions regarding secondary sharing of de-identified study data that includes registry information. According to the final NIH Statement on Sharing Research Data (February, 26, 2003), “Data should be made as widely and freely available as possible while safeguarding the privacy of participants, and protecting confidential and proprietary data.” Within this succinctly written goal is a complex interplay between Federal mandates and State law, regulations, and registry policies:

- NIH Data Sharing Policy (effective October 1, 2003) states that applicants receiving NIH funding of $500,000 or more annually must make de-identified data available to other investigators.
- State laws or registry Data Use Agreements may limit, or not address, such re-release of registry data outside the originally approved study.

The NAACCR Data Sharing Workgroup will seek to better understand the registry context and concerns regarding data sharing, explore the intent/extent of the NIH policy, and develop a plan that will support the NIH Data Sharing Policy while protecting the registry data. Individuals interested in participating can contact Castine Clerkin (cclerkin@naaccr.org).

As always, please contact me if you have any comments or questions!

Steering Committee Corner

Strategic Alliances

Chair: Nan Stroup, Co-Chair: Randi Rycroft

- NAACCR joined NCRA and One Voice Against Cancer (OVAC, http://www.ovaonline.org/) on Tuesday, October 22, 2019, for a special Hill Briefing on “Cancer Research: Challenges, Progress and the Role of Cancer Registries.” OVAC hosted a panel of speakers, including Dr. Vicki Benard from the CDC, who talked about how cancer registries are pivotal to cancer control and prevention, cancer research, and public health. This activity follows OVAC’s consensus agenda to educate policy makers on the importance of cancer registries and increase funding to NIH, NCI, and CDC NPCR.

- NAACCR and Cancer Informatics for Cancer Centers (CI4CC, http://www.ci4cc.org/) teamed up during the CI4CC’s conference in Napa, California, for their Fall 2019 Symposium & Workshop October 14-16, 2019, “Intersections between informatics, data science and population science.” Isaac Hands, NAACCR Representative-at-Large, and Eric Durbin, both CI4CC members, worked with conference organizers to highlight NAACCR and solicit volunteers to serve on the new NAACCR Cancer Informatics Advisory Group, which is co-chaired by Gary Levin (FL) and Eric Durbin (KY). Thus far, five CI4CC members have volunteered to work closely with NAACCR on transformative informatics projects to be determined in the coming year. Marta Induni, PhD (CCR) and Lynne Penberthy, MD, PhD (NCI) also gave presentations spotlighting cancer surveillance data and the opportunities to collaborate with other organizations: “Using the Trees to See the Forest: Leveraging Central Cancer Registry Data for Near-Term and Operative Data Needs” (Induni) and “A Paradigm Shift in Surveillance to Represent Real World Data” (Penberthy).
• Randi Rycroft, NAACCR President, has been an active member of the Comprehensive Cancer Control National Partnership (CCNP, https://www.cccnationalpartners.org/). The CCNP mission is to assist comprehensive cancer control coalitions to develop and sustain implementation of cancer control plans. NAACCR’s role is to ensure that cancer control efforts nationwide are using data to drive cancer control strategies. Randi attended an in-person meeting in October and there was one topic in particular from that meeting that may be of interest to NAACCR members. The CCNP has an interest in rural cancer control, either as a new standalone focus area or weaving this through other existing focus areas (e.g., colorectal cancer screening in rural areas). NAACCR can be prepared to support this focus area by supplying data and perhaps helping to standardize definition(s) for rural in this context.

• Betsy Kohler, Executive Director and many NAACCR members continue to work closely with the CDC NPCR and the National Association of Chronic Disease Directors (NACDD, https://www.chronicdisease.org/) improving registry operations and timeliness of cancer registry data. A meeting was held on October 4, 2019, where NAACCR reviewed findings from the work conducted in partnership with NAACCR registry members, and plan for next steps.

• Randi Rycroft and Jim Hofferkamp attended a meeting with NPCR CDC, AJCC and CAP on October 24 to discuss our ongoing collaborative cooperative agreement. The Strategic Alliances Steering Committee has established meetings later this fall with these partners to discuss areas of mutual interest.

NAACCR Call for Nominations

Greetings to All NAACCR Members!

Have you been looking for a new challenge? Are you seeking a new way to contribute to the cancer surveillance community? Would you like to contribute to NAACCR decisions in a new way? If you answered “yes,” or even “maybe” to any of these questions – keep reading – we can help. This time of the year is very important time for our organization as we start the process of identifying volunteers to serve on the NAACCR Board. The NAACCR Nominating Committee is seeking nominees to run for election in five key leadership roles in 2020: President Elect, three (3) openings for Representative-At-Large, and a Sponsoring Organization Representative. NAACCR has been a unique and innovative partner in the cancer registration world for over 30 years and volunteers have been a mainstay of our organization’s success. One of the many important ways that volunteers contribute to NAACCR is by serving on the Board of Directors. Through guiding existing programs and identifying future opportunities, Board members play a pivotal role in governing NAACCR affairs and moving the organization forward. NAACCR recognizes that it is fortunate to have knowledgeable, dedicated, and progressive members who volunteer each year to serve on the Board. These members of the NAACCR community generously contribute their time and expertise, allowing NAACCR to make significant, valuable contributions to cancer surveillance. Please consider recommending a qualified colleague for one of the four 2020 vacancies. You can also nominate yourself! In fact, self-nomination is the most popular method of nomination. For additional information on duties and eligibility, please click here. If you have issues with this form please contact Tyler Scott (tscott@naaccr.org). The deadline for receipt of nomination forms is 5:00 PM, Monday, December 9, 2019. Nominating Committee Members: Chandrika Rao (Chair), Jetty Alverson, Sarah Nash, Kyle L. Ziegler.
In Lima-Peru there are two types of cancer registries, one population, the Cancer Registry of Metropolitan Lima and Callao - RCLMC and another hospital, that of the National Institute of Neoplastic Diseases - INEN, which because it is a hospital specializing in cancer receives cases from all over Peru.

In 18 years of epidemiological observation, the INEN hospital cancer registry shows continuous records of new cases seen between 2000 and 2017.

In an analysis of averages, prostate, stomach and cervical cancer show positive trends higher than the rest of the cancer.

However, if we make the simple subtraction between the first observation and the last one, the cancer that tends to grow the most is thyroid cancer and cervical cancer would not appear on that list.

Trend analysis, accompanied by data on the clinical stages and age distribution of each type of cancer, could help significantly reduce the cancer burden, redistributing efforts and preparing new strategies to efficiently manage the near future.

The Population Registry of Cancer of Lima Metropolitan and Callao - RCLMC, has a different distribution of cancer, does not have an annual registry, on the contrary it presents cases by period, cases that will serve to build the incidence and mortality rates for a population of just under 10 million inhabitants distributed in 43 districts of Lima and 6 of Callao.

In Lima and Callao, the most frequent cancers for RCLMC are breast and prostate, perfectly comparable with the INEN hospital registry, because new cases would be compared per year. For INEN, the most frequent are cervix and breast.
The valuable thing about population-based cancer registries is to calculate standardized rates by age, with prostate cancer having the highest rate with respect to others.

**Conclusion:**
The analysis of the average tendency for cancer, which we have carried out in the INEN hospital registry coincides with the standardized age rate of the RCLMC population cancer registry, only in the first place, which is prostate cancer, therefore it does not coincide with the other neoplasms. Thus, briefly demonstrating the different nature of both important cancer registries.
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- American Cancer Society
- American College of Surgeons Cancer Programs
- Canadian Partnership Against Cancer
- Centers for Disease Control and Prevention
- National Cancer Institute
- National Cancer Registrars Association
- Public Health Agency of Canada