Winter 2019 NAACCR Narrative

MESSAGE FROM THE PRESIDENT

Antoinetta Stroup, PhD
NAACCR President
nstroup@rulgers.edu

Ha'a fa'a-day (1)

If it’s time for the Winter Narrative, it’s time for NAACCR abstracts! Abstracts for the NAACCR-IACR Conference in Vancouver, BC, Canada for NAACCR members were due on Friday, February 1, 2019. We received more than 220 abstracts! Thank you and good luck to everyone who submitted.

Abstracts for IACR members and students are due on Friday, February 15, 2019 (11:59 pm ET) or Saturday, February 16, 2019 (4:09am UTC).

The last time NAACCR and IACR (International Association of Cancer Registries) held a combined meeting was 5 years ago in 2014 in Ottawa, Ontario, Canada. This year’s conference will be from June 8-13, 2019. We’re looking forward to coming together again as a global cancer registry community to share and learn about advances in cancer surveillance, research, and operations.

Thank you to all NAACCR voting members for casting their votes during this last election cycle. As many of you know, we held a Special Election to elect a new President-Elect. Results are still being tallied and we will announce the new, incoming President-Elect soon. The new President-Elect will assume office immediately upon certification of the election and will assume the Presidency this June 2019.

I’d like to take this opportunity to wish Frank Boscoe (NY), outgoing President-Elect, all the best as he enters into another phase in his career. Thank you for your contributions to the Board as both a Representative-at-Large and President-Elect. I am heartened to know that although Frank is stepping down as President-Elect, he has assured us that he will remain an active member of NAACCR, contributing to the many ongoing and new research, data use, and surveillance projects.

Finally, please take some time to get acquainted with NAACCR’s new collaboration workspace, SHARE. SHARE replaces Causeway and can be accessed under the Organization & Membership tab on the NAACCR website. There is a how-to video available – Thanks, Jim! – and members can log in using their MyNAACCR login and password. Remember to use NAACCR Share to access materials for all your committees. Thanks to the Communications Steering Committee, Jim, Charlie, and others at the NAACCR office, and all the NAACCR members who tested the site and provided feedback.

Don’t forget to follow us on social media platforms on Facebook and Twitter @NAACCR, Inc.

Photo: Frank Boscoe at The Andy Warhol Museum, Pittsburgh, PA. June 2018

(1) “Ha’a fa’a-day” is pronounced ha-for-day and means “Hello” in my native Chamorro language.

MESSAGE FROM THE EXECUTIVE DIRECTOR

Betsy A. Kohler, MPH, CTR
NAACCR Executive Director
bkohler@naaccr.org

Plans for the 2019 NAACCR/IACR conference in Vancouver June 9-13, 2019, are well underway. Our colleagues from around the world will be joining us for a joint meeting this year, expanding our horizons and networking opportunities in many ways. Our pre-conference workshops will focus on improving analytic skills, linkage software, collecting qualitative data, and tools for efficient operations. (See more information in this issue of the Narrative.) Plenary and keynote speakers from around the world will share their knowledge, visions and expertise with us. We are expecting a record number of abstract submissions for the conference, which means dozens of learning opportunities for all levels. Come and see how cancer registries operate in the far corners of the world! NAACCR will be looking for volunteers to help sponsored guests adapt to the Annual Conference—know it can be overwhelming! If you are interested in being paired with a delegate from another country please contact me (bkohler@naaccr.org). Foreign language skills would be helpful, but definitely not required.
HIGHLIGHTS FROM THE PROGRAM MANAGER OF STANDARDS

Winter 2019 NAACCR Narrative

Lori Havener, CTR
NAACCR Program Manager of Standards
lhavener@naaccr.org

DATA STANDARDS AND DATA DICTIONARY DATABASE MANAGEMENT SYSTEM UPDATE

NAACCR plans to update the current management system that houses the data standards and data dictionary. The data standards and data dictionary is primarily used for data translation; however, there are a variety of users with a variety of needs. If you have contacted Monica or me in the past with a request or have thought of a utility you would like added to the management system please send your wish list to Monica Thornton (mthorton@naaccr.org) by February 28th.

STANDARDS VOLUME II, VERSION 18

The NAACCR Data Standards and Data Dictionary, Version 18 was released March 2, 2018. There have been many changes since the initial release of the Data Standards and Data Dictionary, Version 18 with the most recent change release on November 7, 2018.

NOTE: All changes since the initial Version 18 release are documented in the V18 Change Log that is available on the Data Standards and Data Dictionary webpage directly under the Data Standards and Dictionary. The change log identifies the date of the change, the data item number, data item name, the field that was changed, the change that was made and a column for notes.

DATA STANDARDS AND DATA DICTIONARY (VOLUME II). VERSION 20 TIMELINE:

<table>
<thead>
<tr>
<th>Activity</th>
<th>NAACCR Deadlines</th>
<th>Considerations/suggestions to meet NAACCR deadlines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proposed requests-for-change (new and changed data items) submitted to the Mid-Level Tactical Group (previously Change Management Board (CMB))</td>
<td>October 1, 2018</td>
<td>1. Complete request-for-change forms for new and changed data items; submit to the Mid-Level Tactical Group (previously CMB) by October 1, 2018.</td>
</tr>
<tr>
<td>Requests-for-change final review/approval by Mid-Level Tactical Group and other groups as needed (e.g., UDS)</td>
<td>December 31, 2018</td>
<td>1. Coordinate with Mid-Level Tactical Group to ensure communication with stakeholders. 2. Final requests are submitted to the UDS WG by January 1, 2019, for review and inclusion in to Standards Volume II.</td>
</tr>
<tr>
<td>Convene NAACCR 2019 Implementation Guidelines Task Force</td>
<td>April 1, 2019</td>
<td>1. Materials for NAACCR Data Standards and Data Dictionary (Volume II) must be in final format for the Task Force to develop the implementation guidelines. 2. Final versions of mapping and/or conversions.</td>
</tr>
<tr>
<td>UDS Work Group reviews and updates the Data Standards and Data Dictionary (Volume II) (Jan – April)</td>
<td>May 2019</td>
<td>1. Assumes completion of all requests for changes to existing data items and requests of new data items.</td>
</tr>
<tr>
<td>Finalize the Data Standards and Data Dictionary (Volume II) and submit to NAACCR Board for review/approval</td>
<td>June 1, 2019</td>
<td>1. UDS WG final approval at May 2019 UDS WG meeting.</td>
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<tr>
<td>NAACCR Data Standards and Data Dictionary Released</td>
<td>July 1, 2019</td>
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<tr>
<td>NAACCR 2019 Implementation Guidelines Released</td>
<td>August 1, 2019</td>
<td></td>
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<tr>
<td>EDITS metafile release</td>
<td>September 1, 2019</td>
<td>1. EDITS Work Group will have begun development of edits metafile by February 2019.</td>
</tr>
<tr>
<td>Education and training</td>
<td>Ongoing as material becomes available</td>
<td>1. For 2020 implementation: develop and implement educational materials by summer 2019.</td>
</tr>
<tr>
<td>Implementation</td>
<td>January 1, 2020</td>
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</tbody>
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NAACCR RESEARCH AND DATA USE UPDATE
Winter 2019 NAACCR Narrative

Recinda Sherman, MPH, PhD, CTR
NAACCR Program Manager of Data Use and Research
rsherman@naaccr.org

Research & Data Use
If you are home having a snow day today, please know that we in Southern California are also feeling the polar vortex—we had light frost two days last week. Laugh if you will, but the low 40s do feel cold if you don’t own a proper coat. And there is my metaphor for today—we need a proper coat (resources) to do our work. One of the many strengths of NAACCR is the ability to reach out to other states for guidance as we move forward in our work. And one way to do this is through Pre-Conference Workshops.

Pre-Conference Workshops: We have a slate of workshops planned for Vancouver this year including new and improved versions of Basic and Advanced SEER*Stat and Match*Pro Training. We also have an introductory class on METRIC. METRIC is a system designed to assess relationships between health and environmental metrics, with the goal of using neighborhood-level prevention strategies to address health disparities. Two new half day courses are also available—one on collecting meaningful qualitative data for cancer research and a second on available tools and software to improve data quality and automate parts of the abstraction process. For dates and other logistics, please visit the Workshop Tab on our Conference page: https://www.naaccr.org/naaccr-lacc2019/#workshops. I hope to see you in Vancouver!

Call for Data: Call for data is a wrap, and we are moving forward with data quality reports, certification, and CINA. This year we had a total of 68 NAACCR submissions: 56 sent 12-month data, 43 sent XML (up from 26 last year), 53 sent the new County at Diagnosis—Analysis codes, and 64 sent the new Survival codes.

There are still a number of registries that have not completed the CoRRI database. The purpose of the CoRRI (Cancer Registry Researcher Information) database is to assemble information on how to access registry data across North America to, ultimately, support cancer surveillance research. This year, each registry will need to enter baseline data that used to be collected partially during Call for Data and partially through the CDC IRIS Assistance site. In subsequent years, registries will only need to review the data annually and update as needed.

SHARE: You may have heard that NAACCR has moved to a new committee on-line workspace. One of the advantages of this system, SHARE, is the ability to create user role based email distribution lists. This enables NAACCR to decrease the number of general listserv emails sent and to target relevant information to members who need it. I am currently setting up two groups—one to send out information on Call for Data and one for information on the Geocoder. I will be reaching out to registries to identify the key personnel for those lists. Please ensure the appropriate staff are included on these lists so important information won’t be missed. For more information on SHARE, please review the listserv sent from Charlie Blackburn on January 31, 2019.

NAACCR EDUCATION AND TRAINING PROGRAM UPDATE
Winter 2019 NAACCR Narrative

Jim Hofferkamp, BA, CTR
NAACCR Program Manager of Education & Training
jhofferkamp@naaccr.org

NAACCR WEBINAR SERIES
I know we are not even half way through the 2018-2019 webinar season, but I want to let everyone know that prices for next season (2019-2020) will be the same. The schedule for next season should be posted in mid-May.

I would like to say that I am thrilled with the wonderful job our guest hosts did on the January webinar! Denise Harrison and Louanne Currence presented on Testicular Primaries. The feedback we got from our participants was spectacular!

The February webinar was on colon and in March we will have our Boot Camp. Boot Camp this year will focus on the fundamentals of abstracting the new data items required for 2018. During boot camp participants will spend the majority of time completing quizzes and exercises. There will be minimal lecture.

For more information on upcoming NAACCR webinars see our website at: https://www.naaccr.org/cancer-registry-surveillance-webinar-series/.

CTR PREP
It’s hard to believe that we have already completed 5 of the 8 weeks in the 2019 CTR exam prep series. The exam will include 2018 changes. We’ve updated all of our materials to reflect the changes.

For more information see the NAACCR CTR Prep and review page at: https://www.naaccr.org/ctr-exam-preparation-review/.

The next series will start in late April.
NAACCR TALKS

Keep your eye out for information on upcoming NAACCR Prep Talks! We are working on a robust schedule for 2019. NAACCR Talks are free webinars on topics that concern the NAACCR membership. These are usually topics related to research and data use, analytic tools, and central registry functions. More information on upcoming NAACCR Talks and recordings of previous NAACCR talks are available at https://education.naaccr.org/treewebinars.

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

Angela Martin
amartin@naaccr.org
Jim Hofferkamp
jhofferkamp@naaccr.org

NAACCR 2018 EDUCATION AND TRAINING CALENDAR

Winter 2019 NAACCR Narrative

Upcoming Webinar Presentations

**FEBRUARY 2019**

02/19/2019  NAACCR CTR Exam Preparation and Review Webinar Series 2019 Session 7
02/20/2019  NAACCR Talks: Preparing Your Mortality Data to be used in SEER*Stat
02/26/2019  NAACCR CTR Exam Preparation and Review Webinar Series 2019 Session 8

**MARCH 2019**

03/07/2019  Cancer Registry & Surveillance Webinar: Abstracting and Coding Boot Camp: Cancer Case Scenarios

**APRIL 2019**

04/04/2019  Cancer Registry & Surveillance Webinar: Collecting Cancer Data: Hematopoietic and Lymphoid Neoplasms

For more information about NAACCR education and training opportunities or to register online, go to the Education and Training tab on the NAACCR website (naaccr.org), or contact Jim Hofferkamp (jhofferkamp@naaccr.org).

VIRTUAL POOLED REGISTRY UPDATE

Winter 2019 NAACCR Narrative

Casline Clerkin, MS, CTR
NAACCR Program Manager of Virtual Pooled Registry
clerkin@naaccr.org

I’m excited to welcome 2019! We found out late last year that the NCI funds intended to support registry participation in future VPR-CLS linkages were not going to be available due to budget cuts. While somewhat disappointed, we informed registries that we’d aim for funding in 2020 and quickly focused on the silver lining. This grace period allows us more time to: (1) test the full VPR-CLS functionality with additional cohorts, (2) perform registry outreach to expand acceptance of the Templated IRIS/Registry Application, (3) establish a contract for the NCI Central IRIS, and, (4) explore other key initiatives that support a streamlined application and data release process.
STEERING COMMITTEE CORNER

Winter 2019 NAACCR Narrative

WELCOME TO THE STEERING COMMITTEE CORNER!

This column will provide brief Steering Committee updates such as new reports or projects, coding changes, new data standards, requests for priority area network members for specific workgroups, and other information that NAACCR Steering Committees feel the NAACCR community should be aware of. We hope that this column helps to connect us as we continue to move forward with enhanced cancer surveillance.

Susan T. Gershman
Massachusetts Cancer Registry

PROFESSIONAL DEVELOPMENT STEERING COMMITTEE (PDSC)

Co-Chairs: Frances Ross and Mignon Dryden

Committee Highlights since last Narrative:

The Board of Directors have tasked the Professional Development Steering Committee with new charges. Recruitment for NAACCR members to join Task Forces or Work Groups has started for the projects listed below.

New Committee Charges:

1. Outline the NAACCR opportunities for Higher Education, in all aspects of central cancer registry activities: operations, surveillance, research, Informatics, etc.
2. Develop Best Practices for Recruitment & Retention, including Policies on Telecommuting and a New Registrar Training Guide
3. Global Initiatives - outline a simplified education plan for low-resource countries, with current emphasis on the Caribbean countries
4. CDC Cooperative Agreement work with Jim Hoffenkamp as he responds to NPCR’s requests for webinars. In person training sessions, and assessments of educational needs
5. Expand and promote NAACCR’s Learning Management System with tutorials on NDI linkage, Match*Pro, and other continuous use tools
6. Continue to maintain and update the Member Awards Program

If you are interested in working on Professional Development on these important projects or would like more information, please contact Frances Ross fr@bcr.dvy.edu or Mignon Dryden mdryden@cancercancer.org.

RESEARCH AND DATA USE STEERING COMMITTEE (RDUSC)

Co-Chairs: Hannah Weir and Susan Gershman

Training/Education:

<table>
<thead>
<tr>
<th>Webinar List</th>
<th>Date</th>
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<tbody>
<tr>
<td>Preparing Your Incidence Data to be Used in SEER*Stat</td>
<td>January 23, 2019</td>
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<tr>
<td>Preparing Your Mortality Data to be Used in SEER*Stat</td>
<td>February 20, 2019</td>
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<tr>
<td>XML</td>
<td>March 27, 2019</td>
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<tr>
<td>Project Description</td>
<td>Date</td>
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<td>NCI Methods and Tools for Population-Based Cancer Statistics: JoinPoint, Delay-adjustment, DevCan/Know your changes, Incidence-based mortality, MP-SIR, CanStat, &amp; Survival</td>
<td>April 24, 2019</td>
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<tr>
<td>NCI Methods and Tools for Population-Based Cancer Statistics: JoinPoint, Delay-adjustment, DevCan/Know your changes, Incidence-based mortality, MP-SIR, CanStat, &amp; Survival</td>
<td>May 1, 2019</td>
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<tr>
<td>NAACCR Geocoder</td>
<td>May 8, 2019</td>
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<td>MatchPro</td>
<td>TBD</td>
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<tr>
<td>Death Clearance</td>
<td>TBD</td>
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<tr>
<td>Annual Report to Nation</td>
<td>Waiting publication release date</td>
</tr>
<tr>
<td>California Cancer Highlights: Focus on Minorities</td>
<td>TBD April 2019</td>
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</tbody>
</table>

**Committee Highlights since last Narrative:**

- Advocacy Cancer Fact Sheets: NAACCR will distribute ACS CAN state specific and summary fact sheets when reports become approx. March 2019. ROU will work with Communications Steering Committee to provide guidance regarding how to use the fact sheets to advocate for cancer surveillance.
- If you have a suggestion for a journal club or surveillance webinar topics, please contact Hannah Woll (hwill@cdc.gov) or Susan Gershman (gershman@state.ma.us).