

# THE NAACCR NARRATIVE

## Winter 2019 NAACCR Narrative

### MESSAGE FROM THE PRESIDENT

Winter 2019 NAACCR Narrative



**Antoinette Stroup, PhD**  
NAACCR President  
[nan.stroup@rutgers.edu](mailto:nan.stroup@rutgers.edu)

Hafa Adai!<sup>[1]</sup>



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 (4:59am 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] "Hafa Adai" is pronounced ha-fa-day and means "Hello" in my native Chamorro language.

### MESSAGE FROM THE EXECUTIVE DIRECTOR

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**Betsy A. Kohler, MPH, CTR**  
NAACCR Executive Director  
[bkohler@naacccr.org](mailto:bkohler@naacccr.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, vision 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- we know it can be overwhelming! If you are interested in being paired with a delegate from another country please contact me ([bkohler@naacccr.org](mailto:bkohler@naacccr.org)). Foreign language skills would be helpful, but definitely not required!

## HIGHLIGHTS FROM THE PROGRAM MANAGER OF STANDARDS

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**Lori Havener, CTR**  
NAACCR Program Manager of Standards  
[lhavener@naaccr.org](mailto: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 transmission; 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 ([mthornton@naaccr.org](mailto:mthornton@naaccr.org)) by February 28<sup>th</sup>.

### 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:

Activity	NAACCR Deadlines	Considerations/suggestions to meet NAACCR deadlines
Proposed requests-for-change (new and changed data items) submitted to the Mid-Level Tactical Group (previously Change Management Board (CMB))	October 1, 2018	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.
Requests-for-change final review/approval by Mid-Level Tactical Group and other groups as needed (e.g., UDS)	December 31, 2018	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.
Convene NAACCR 2019 Implementation Guidelines Task Force	April 1, 2019	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.
UDS Work Group reviews and updates the Data Standards and Data Dictionary (Volume II) (Jan – April)	May 2019	1. Assumes completion of all requests for changes to existing data items and requests of new data items.
Finalize the Data Standards and Data Dictionary (Volume II) and submit to NAACCR Board for review/approval	June 1, 2019	1. UDS WG final approval at May 2019 UDS WG meeting.
NAACCR Data Standards and Data Dictionary Released	July 1, 2019	
NAACCR 2019 Implementation Guidelines Released	August 1, 2019	
EDITS metafile release	September 1, 2019	1. EDITS Work Group will have begun development of edits metafile by February 2019.
Education and training	Ongoing as material becomes available	1. For 2020 implementation: develop and implement educational materials by summer 2019.
Implementation	January 1, 2020	

## NAACCR RESEARCH AND DATA USE UPDATE

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**Recinda Sherman, MPH, PhD, CTR**  
NAACCR Program Manager of Data Use and Research  
[rsherman@naaccr.org](mailto:rsherman@naaccr.org)

### Research & Data Use

If you are at 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 abstractions process. For dates and other logistics, please visit the Workshop Tab on our Conference page: <https://www.naaccr.org/naaccr-iacr2019/#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), 55 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 CaRRI database. The purpose of the CaRRI (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 IRB 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

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**Jim Hofferkamp, BA, CTR**  
NAACCR Program Manager of Education & Training  
[jhofferkamp@naaccr.org](mailto: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/freewebsinars>

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

Angela Martin  
[amartin@naaccr.org](mailto:amartin@naaccr.org)

Jim Hofferkamp  
[jhofferkamp@naaccr.org](mailto:jhofferkamp@naaccr.org)

## NAACCR 2018 EDUCATION AND TRAINING CALENDAR

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**Angela Martin, CTR**  
NAACCR Trainer/Project Coordinator  
[amartin@naaccr.org](mailto:amartin@naaccr.org)

### 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
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#### APRIL 2019

04/04/2019	Cancer Registry & Surveillance Webinar: Collecting Cancer Data: Hematopoietic and Lymphoid Neoplasms
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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](http://naaccr.org)), or contact Jim Hofferkamp ([jhofferkamp@naaccr.org](mailto:jhofferkamp@naaccr.org)).

## VIRTUAL POOLED REGISTRY UPDATE

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**Castine Clerkin, MS, CTR**  
NAACCR Program Manager of Virtual Pooled Registry  
[cclerkin@naaccr.org](mailto:cclerkin@naaccr.org)

I'm excited to welcome in 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 IRB/Registry Application, (3) establish a contract for the NCI Central IRB, and, (4) explore other key initiatives that support a streamlined application and data release process.



**VPR-CLS Pilot Testing:** Last October we completed our first pilot test of the Phase I VPR-CLS functionality which included linkage using Match\*Pro and release of aggregate match counts to the researcher. This test between the Childhood Cancer Survivor Study and 35 registries was very successful and provided the study investigators with valuable information. In 2019, we will expand our testing to include the Phase II functionality. Phase II allows the streamlined submission and tracking of registry/IRB requests for release of individual-level data on matched cases identified during Phase I. Phase II will include use of the Templated IRB/Registry Application. We have identified five cohort studies, including the Childhood Cancer Survivor Study, that are excited to participate in the next round of testing, with 2-3 studies testing all the way through Phase II.

**Templated IRB/Registry Application:** This application compiled common questions from across over 50 registry and IRB applications and has undergone one round of vetting with cancer registries. An updated version of the Templated IRB/Registry Application was recently finalized. Over the next few weeks this document will be shared with registries for any additional feedback. I will also be talking with states that had yet to decide whether they were able to adopt this form for minimal risk linkage studies coming through the VPR-CLS. The aim is to address any concerns about the Template and expand acceptance.

**Central IRB:** NCI and NAACCR are currently holding informational calls with registries/IRBs to better understand the requirements and mechanisms necessary for a local/state IRB to cede review to the Central IRB, as well as how local context issues are to be handled. This information will help guide the inclusion of this task as a requirement within the statement of work and estimated cost for the RFP. NCI also plans to hold industry calls with commercial IRBs, entities which don't normally follow the government RFP release websites, to talk about the CIRB plans and respond to questions. The RFP will include a copy of the Templated IRB/Registry Application that the Central IRB will be asked to use. The goal is to post the RFP this spring.

**Other Key Initiatives:** Another high priority initiative is to develop a Templated Data Use Agreement (DUA) that can be used in lieu of state-specific DUAs. NAACCR is creating a Templated DUA Task Force and anyone interested in actively contributing to this important initiative can contact me at [cclerkin@naaccr.org](mailto:cclerkin@naaccr.org).

As always, I'm happy to hear from registries with any comments, questions, or concerns!

## STEERING COMMITTEE CORNER

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### 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 Hofferkamp 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 with Professional Development on these important projects or would like more information, please contact Frances Ross [fer@kcr.uky.edu](mailto:fer@kcr.uky.edu); or Mignon Dryden [mdryden@crqc-cancer.org](mailto:mdryden@crqc-cancer.org).

## RESEARCH AND DATA USE STEERING COMMITTEE (RDUSC)

Co-Chairs: Hannah Weir and Susan Gershman

### Training/Education:

Webinar List	
Preparing Your Incidence Data to be Used in SEER*Stat	January 23, 2019
Preparing Your Mortality Data to be Used in SEER*Stat	February 20, 2019
XML	March 27, 2019

NCI Methods and Tools for Population-Based Cancer Statistics: JoinPoint, Delay-adjustment, DevCan/Know your changes, Incidence-based mortality, MP-SIR, CanStat, & Survival	April 24, 2019
NCI Methods and Tools for Population-Based Cancer Statistics: JoinPoint, Delay-adjustment, DevCan/Know your changes, Incidence-based mortality, MP-SIR, CanStat, & Survival	May 1, 2019
NAACCR Geocoder	May 8, 2019
Match*Pro	TBD
Death Clearance	TBD
Annual Report to Nation	Waiting publication release date
California Cancer Highlights: Focus on Minorities	TBD April 2019

[Edit](#)

**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. RDU 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 Weir ([hweir@cdc.gov](mailto:hweir@cdc.gov)) or Susan Gershman ([gershman@state.ma.us](mailto:gershman@state.ma.us)).