



## MESSAGE FROM THE PRESIDENT



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

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

This issue of the NAACCR Narrative is full of updates on several important initiatives including the 2018 data changes and the release of both NAACCR Standards Volume II v.18 and the 2018 Implementation Guidelines, education, and other Steering Committee updates. The XML Data Exchange Work Group invited registries to **an informational webinar titled “Guiding the Way to XML Data Exchange Implementation” last Thursday, April 26, 2018.** There were 26 registries that submitted in XML as part of the last call-for-data and we hope that providing more information through this webinar gave others an opportunity to learn more, ask questions, and prepare for the next submission. More details are [here](#).

There is still time to [register for the #NAACCR2018 Annual Conference, June 9-14, 2018, Pittsburgh, PA.](#) Early registration ends TODAY April 30, 2018. The [Preliminary Program for the #NAACCR2018 Annual Conference](#) has also been updated. Here are a few of the highlights ICYMI<sup>[2]</sup>:

- Our first ever [NAACCR Cancer Informatics Hackathon: Forging Solutions for Cancer Control](#) will be held just prior to the conference from Saturday, June 9<sup>th</sup>, to Monday, June 11<sup>th</sup>. The goals for the hackathon are to (1) Introduce informatics professionals and students to cancer control and data science; (2) Recruit talented, motivated, innovative people into the cancer informatics workforce; and, (3) Gather the brightest informatics minds in the Pittsburgh area for 3 days to hack out solutions to major cancer control problems. [Registration](#) is free and open to all informatics professionals and students (NAACCR membership not required!). There will be prizes for the best hacks!! Presentations and judging will be held on Monday, June 11<sup>th</sup>. See the [#NAACCR2018 Program](#) for more details.
- Our **keynote speaker is Matt Jones**, a 3-time cancer survivor, who will share his story and inspire us to achieve personal and professional success. Join us for his talk: “Life is a Marathon” at #NAACCR2018 Day 1, Tuesday, June 12<sup>th</sup>. For more information about Matt, visit <http://www.matthewdjones.com/>.
- Our lineup for **concurrent sessions** features topics on developing and emerging cancer surveillance initiatives, including Natural Language Processing (NLP), collection and use of residential histories, XML data exchange standards, Virtual

Pooled Registry (VPR), biomarkers and tissue repositories, patient-reported outcomes, data visualization, and more!

- If you don't have to rush off to the airport, new this year is a **post-conference networking opportunity**, which will be held at the end of Day 3, Thursday, June 14<sup>th</sup>, from 5:30pm – 6:30pm. Stop by to chat about conference highlights, speak to colleagues about future collaborations, or just wish everyone safe travels.

Also note that for #NAACCR2018, some of our usual meetings have moved around a bit:

- **Birds of a Feather** will be held in the late afternoon on Day 1, from 5:30pm – 6:30pm on Tuesday, June 11<sup>th</sup>.
- Our **Business Meeting** will be held in the early morning of Day 2 from 8:15am – 8:45am on Wednesday, June 12<sup>th</sup>.
- And, **committee meetings** will be held on Monday, June 11<sup>th</sup> **and** Wednesday, June 13<sup>th</sup>. See the #NAACCR2018 **Program** for more details.

Don't forget to follow us @NAACCR on Twitter and send us highlights using #NAACCR2018. See you in Pittsburgh!

[1] "Hafa Adai" is pronounced ha-fa-day and means "Hello" in my native Chamorro language.

[2] In case you missed it (ICYMI)

---

## MESSAGE FROM THE EXECUTIVE DIRECTOR



**Betsy A. Kohler, MPH, CTR**  
NAACCR Executive Director  
[bkohler@naaccr.org](mailto:bkohler@naaccr.org)

As you will see in this issue it has been a busy season at NAACCR. We have been working on finalizing tools with the major standard setters for 2018 implementation, responding to proposals, working out processes for the Virtual Pooled Registry, preparing and presenting educational materials, and of course getting ready for the Annual Conference in Pittsburgh. In addition, the Board of Directors and Steering Committee Chairs experienced a March blizzard in Princeton, NJ at our mid-year meeting. Nonetheless we worked on new ideas to strengthen NAACCR and improve services to members.

In June the NAACCR Board will welcome Kyle Zeigler (CA), Wendy Aldinger (PA) and Angela Meisner (NM) as new Representatives-at-Large, and Frank Boscoe (NY) will become President-elect. We will greatly miss the leadership of Chuck Wiggins NM (Past President),

Heather Stuart-Panko (SK), and Chris Johnson (ID) who will rotate off in June. It is never too early to consider running for the Board of Directors, please speak to a Board member (past or present) at the Annual Conference to find out more about Board Membership.

The Steering Committees will be meeting prior to the Annual Conference in Pittsburgh—please plan to attend if you are a member. The Annual Conference is also a good opportunity to volunteer for a work group or task force to work on a NAACCR initiative. Please let us know if you would like to work on a project. There is always lots of work to do!

See you in June!

---

## **HIGHLIGHTS FROM THE PROGRAM MANAGER OF STANDARDS**



**Lori Havener, CTR**

NAACCR Program Manager of Standards

[lhavener@naaccr.org](mailto:lhavener@naaccr.org)

## **STANDARDS VOLUME II, VERSION 18**

The NAACCR [Data Standards and Data Dictionary](#), Version 18 was released March 2, 2018. There have been several changes since the initial release of the Data Standards and Data Dictionary, Version 18. All of the changes since the release are documented in the change log that is available on the same website as the Data Standards and Data 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.

## **2018 IMPLEMENTATION GUIDELINES**

A draft of the NAACCR 2018 Implementation Guidelines (IG) document has been posted to the NAACCR [2018 Implementation Information webpage](#). This draft version includes compiled information provided by the standard setting agencies, NAACCR stakeholders, relevant committees, work groups and task forces. The sections (7.1 and Appendix B) for which information is pending are identified with a placeholder. These sections will be updated as information becomes available.

Some of the links to key references are not included in this draft; however, they will be included in the final document version. For example, when the Site-Specific Data Item Manual is final the link to the manual will be added to the IG.

Beyond the addition of the missing sections, the IG Task Force members do not anticipate any substantive changes. The final IG version will be reviewed by the Standardization and Registry Development Steering Committee and NAACCR Board prior to being posted to the NAACCR Implementation Guidelines page on the NAACCR web site.

We wish to thank all the members of the IG Task Force for their hard work and countless hours to produce this draft version. We hope that this draft is informative and useful, until such time that the final IG version is posted.

## XML DATA EXCHANGE FORMAT

The XML Data Exchange Work Group is hosting a webinar, *Guiding the Way to XML Data Exchange Implementation*, on April 26<sup>th</sup> at 2:00 pm ET. Isaac Hands, XML Data Exchange Work Group Chair, will discuss the XML data exchange standard giving a brief history and the reasons we are moving to XML, a review of the XML software tools and libraries, and the implementation timeline.

A plan to implement the XML data exchange standard was approved by the NAACCR Board. The NAACCR [Plan to Implement XML](#) is posted on the NAACCR website.

## STANDARDS VOLUME II, VERSION 19:

NAACCR is advocating to keep 2019 changes to a minimum. However, it is imperative that folks review the 2019 Implementation Timeline below if there are any planned changes for 2019.

Activity	NAACCR Deadlines	Considerations/suggestions to meet NAACCR deadlines
Proposed requests-for-change (new and changed data items) submitted to the Change Management Board (CMB)	October 1, 2017	1. Complete request-for-change forms for new and changed data items; submit to the Change Management Board by October 1, 2017.
Requests-for-change final review/approval by CMB and other groups as needed (e.g., UDS)	December 1, 2017	1. Coordinate with CMB to ensure communication with stakeholders. 2. Final requests are submitted to the UDS WG for review and inclusion in Standards Volume II.

NAACCR Narrative Spring 2018

Convene NAACCR 2019 Implementation Guidelines Task Force	April 1, 2018	1. Materials for NAACCR Standards 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 Standards Volume II	May 2018	1. Assumes completion of all requests for changes to existing data items and requests of new data items.
Finalize NAACCR Standards Volume II and submit to NAACCR Board for review/approval	June 1, 2018	1. UDS final approval at May 2018 UDS meeting.
NAACCR Standards Volume II Released	July 1, 2018	
NAACCR 2019 Implementation Guidelines Released	August 1, 2018	
EDITS metafile release	September 1, 2018	1. EDITS Work Group will have begun development of edits metafile by February 2018.
Education and training	Ongoing as material becomes available	1. For 2019 implementation: develop and implement educational materials by summer 2018.
Implementation	January 1, 2019	

---

**NAACCR RESEARCH AND DATA USE UPDATE**



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

Cancer registration is truly a moving target. Implementation of 2018 changes implementation and attempts to stem our ever increasing workload has dominated much of the cancer registry community discussion for the past couple years. Although changes are focused on abstraction of data, the continuous advancements lead to increasing work demands extending beyond data collection.

The primary purpose of central cancer registries is to provide data-driven information for cancer prevention and control and to advise public health planning. This means registry analysts are our frontline for describing and explaining trends and distinguishing them from spurious fluctuations due to data collection changes, as well as developments in clinical diagnosis or treatment. It is not easy to keep up-to-date on of all the issues that impact current and historical trends. And this extends to an analyst's secondary role, as cancer researchers and technical advisors for shared data.

No one knows the cancer data better than we do, and our expertise is critical to ensure cancer surveillance data is used and interpreted appropriately. In order to remain relevant to outside researchers, we need to provide high quality data in a timely manner. But in order to ensure research integrity, we must also provide our expertise, which, as we know, is warranted but not always solicited. But often we are overloaded by our roles related to the primary purpose of cancer surveillance, while our secondary roles in cancer research and data sharing have to move down our priority list. Many cancer registry analysts are struggling with these competing, and ever increasing, demands.

This often results in long delays for data request fulfillment, which is frustrating for outside researchers. And, potentially more seriously, analyst overload can result in the loss of technical support from the cancer registry. Appropriate and ethical use of cancer registry data hinges on understanding the limitations of our data—including but not limited to the impact of coding changes overtime, which and when new data items meet fitness-for-use criteria, potential for bias with unknown data, using SEER Summary stage versus AJCC, how to use unconsolidated data and the limitations of specific data items in consolidated data, and how data quality initiatives and funding or staffing changes impact the completeness and robustness of our data. It is imperative that we remain timely about our data development and communicate issues fully with outside researchers to ensure the integrity of cancer surveillance research.

So what are we to do? One of the great values of NAACCR is our community network. But much of our analyst collaboration and advising is done through informal networks. As part of my role, NAACCR is moving towards strengthening and formalizing these networks. While work is progressing slower than hoped, we are developing best practice guidelines to help with analyst training and support. We are currently working on updating geocoding guidelines and will move on to other sections of an analyst job, including data dissemination and interpretation.

We also have technical data on our website related to data quality and interpretation focused on CiNA, which we will be augmenting. Regarding data quality, the Data Assessment Work Group, currently chaired by Dr. Mei-Chin Hsieh of the Louisiana Tumor Registry, publishes data quality assessments on commonly used research variables: <https://www.naacccr.org/data-quality-assessments-and-evaluations/>. And we are currently improving our Researcher Registry Information Database which helps researchers understand fitness for use for specific research by registry: <https://www.naacccr.org/research-capabilities-by-registry/>. And, in some cases,

NAACCR works directly with central registries to fulfill data requests or consult with outside researchers.

But as our field is in constant revolution, this work is under development. If you are interested in documenting your needs or in working to develop the support and standardization tools for analysts, please contact me at [rsheerman@naaccr.org](mailto:rsheerman@naaccr.org).

---

## **NAACCR 2017 EDUCATION AND TRAINING CALENDAR**



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

---

### **MAY 2018**

---

05/01/2018	CTR Exam Preparation and Review Webinar Series Session 3
05/03/2018	Cancer Registry & Surveillance Webinar: Directly Coded Stage
05/08/2018	CTR Exam Preparation and Review Webinar Series Session 4
05/15/2018	CTR Exam Preparation and Review Webinar Series Session 5
05/29/2018	CTR Exam Preparation and Review Webinar Series Session 6

---

### **JUNE 2018**

---

06/05/2018	CTR Exam Preparation and Review Webinar Series Session 7
------------	----------------------------------------------------------

---

06/07/2018	Cancer Registry & Surveillance Webinar: Collecting Cancer Data: Thyroid & Adrenal Gland
06/12/2018	NAACCR 2018 Annual Conference: Bridging the Path to the Future of Cancer Surveillance
06/19/2018	CTR Exam Preparation and Review Webinar Series Session 8

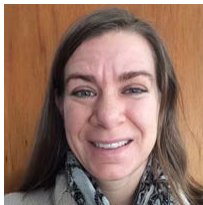
---

NAACCR recently developed an online calendar listing not only NAACCR training opportunities but also lists resources from the larger cancer surveillance community. Please see the [An Update from the NAACCR Education Committee](#) article to learn more.

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**



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

Spring has been slow to arrive at my teleworking site in New Hampshire and I truly believe that the grass is currently greener in other parts of the country! Needless to say, despite winter's grip, we have been busy as bees developing various aspects of the Virtual Pooled Registry. Below are some highlights.

NCI Central IRB and Templated IRB/Registry Application: NCI's initial solicitation to identify a Central IRB for minimal risk studies did not yield a qualified candidate and will be re-solicited in the coming months. Meanwhile, we have reviewed and incorporated registry feedback on the Templated IRB/Registry Application. Your survey responses from last fall provided a great snapshot of what each state registry and their IRB will accept in regard to streamlining the application process for release of registry data on matched cases. Currently, 31 registries can rely on the NCI Central IRB and/or use the Templated IRB/Registry Application for all aspects of their review process. Only six registries have said that they must continue to use their state IRB forms; however, three that have both an IRB and registry review process are willing to use the Templated IRB/Registry Application in lieu of their registry form.



Five of the registries are still unsure about what was possible and 11 registries did not respond to the survey. These results are very exciting!

Match\*Pro Linkage Software: IMS, Inc. has developed a great new linkage software, Match\*Pro, with alpha- and beta-testing input from various cancer registries. The resulting software can easily handle large files, runs quickly, and offers some amazing functionality. Match\*Pro will be used for all VPR linkages and will be made available to cancer registries for use with other types of linkages as well. **A Match\*Pro Workshop is being offered during the 2018 NAACCR Conference on Sunday, June 10<sup>th</sup> from 1-5 p.m.** Appropriate staff from all U.S. registries are encouraged to register here to attend this workshop: <https://www.naacr.org/conference-workshops/#Match>

Development and Testing of VPR Cancer Linkage System (VPR-CLS): The VPR-CLS is the secure portal through which all VPR requests will be managed. The VPR-CLS will support the workflow and tracking associated with two phases of VPR linkages: 1.) Initial linkage and release of match counts; and 2.) Registry/IRB application for release of data on matched cases. The infrastructure for Phase I is essentially complete, while development of Phase 2 functionality will occur over the next 6-8 months. We will be identifying a new study cohort and multiple cancer registries to participate in hands-on testing of Phase I VPR-CLS functionality in the coming months. This testing will include using Match\*Pro for the linkage, interfacing with the VPR-CLS, and providing feedback on areas for system improvement.

Thanks for your ongoing support as we work toward a single, comprehensive, user-friendly, efficient system that facilitates multi-registry linkages.

---

## **STEERING COMMITTEE CORNER**



**Susan T. Gershman, MS, MPH, PhD, CTR**  
*Massachusetts Cancer Registry*

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.

**Professional Development Steering Committee (PDSC)**

**Co-Chairs: Frances Ross and Mignon Dryden**

Committee Highlights since last Narrative:

- Work continues on the Survey Course — a series of webinars titled “Understanding Population-Based Cancer Registries” recorded and uploaded to the NAACCR Learning Management System. Paul Fearn and Marina Matatova of the SEER Surveillance Informatics Branch have agreed to develop a series of modules on Cancer Informatics for central cancer registries.
- Angela Martin, NAACCR Training Specialist, has updated some features of the LMS and will demonstrate the Learning System at the annual meeting in Pittsburgh at the NAACCR exhibit booth.
- Logistics for the Hackathon, to be held June 9-11, just prior to the NAACCR annual meeting in Pittsburgh, continue to be finalized. A web page has been created and an announcement has been sent via listServe regarding the Hackathon.
- The NAACCR Member Awards Program has been incorporated as part of the Professional Development Steering Committee activities June 2017. The newest member to our committee, Stephanie Hill, has agreed to take over responsibility for this program in 2018 from Frances Ross, who has led the program for the past 10 years.
- The committee continues work on the Action Plan for Recruitment and Retention strategies aimed at cancer surveillance personnel, specifically central cancer registrars, cancer informatics staff, student and young investigators. A survey of members was conducted last month in order to quantify and identify specific R&R needs. A presentation of the analysis of the survey results will be shared at the Annual Meeting.

**Research and Data Use Steering Committee (RDUSC)**

**Co-Chairs: Hannah Weir and Susan Gershman**

Training/Education:

- *Guiding the Way to XML Data Exchange Implementation* webinar scheduled for April 26, 2018, 2:00pm -3:30pm ET.
- SEER Tools webinar to be scheduled.

Committee Highlights since last Narrative:

- Data Confidentiality Work Group: The group had its first meeting which focused on administrative set/up goal setting. The group will split into 2 groups ( Research & Data Use and Security/IT) for the majority of work.
- Cancer Fact Sheet Work Group: State and national level data fact sheets modeled after the One Voice Against Cancer (ASC Advocacy group) handout are under consideration.
- Secondary data release of registry data ( Paul Pinsky, Eric Miller): This presentation at the MarchRDU Conference Call focused on issues with additional linkages to administrative databases, standard definition of PHI, and whether registries understand the move towards data sharing requirements for NCI funded researcher. Next step is to reach out formally to all PI/program directors at the registries to discuss the issues. Possibly reach out to registries via NAACCR Forum. Castine, Eric, & Paul will re-group and figure out next steps.

- 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)).

### Standardization & Registry Development (S&RD)

Chair: Mary Jane King and Lori Koch

Committee Highlights since last Narrative:

- Work group and task force updates presented to the committee from the SSDI TF, the ICD-O-3 WG, and the UDS WG.
- Edits Impact TF has been disbanded.
- Currently reviewing recommendations from the Registry of the Future workshop, specifically timeliness of reporting and new and emerging data sources.

Recent Reports/Publications:

- The Assessment of Central Cancer Registries Timeliness and Reporting Standards TF report has been submitted to the NAACCR Board for approval.

---

## NAACCR 2018 CONFERENCE



**Wendy Aldinger, RHIA, CTR**

Manager, Pennsylvania Cancer Registry  
*2018 NAACCR Program Chair*

We are getting closer and closer to the 2018 NAACCR Annual Conference in Pittsburgh, PA, June 9 through June 14. June is a great time of year to visit Pittsburgh. There is so much to see and do: bike rides, river boat tours, museums, inclines up the mountain, the list goes on and on. Not to mention all the wonderful dining options. Be sure to check out the [Activities](#) tab on the conference web page for more details.

You won't want to miss the opening ceremony it will be sure to get your feet stomping. Our keynote speaker will share his inspiring story and will have us reaching for VICTORY. The 2018 agenda is packed full of information. There are five plenary sessions covering advances in precision medicine, the legal side of cancer surveillance, new data and new data sources, clinical outcome improvement, and planning for the future. There are five concurrent sessions that include 27 separate tracks, plus 3 student tracks. The concurrent sessions cover such topics as Epidemiology, Survival, Natural Language Processing, National Quality

Initiatives, Timeliness, Improving Registry Operations, Biomarkers, Tissue Repositories, Data Linkage and so much more. See the full [agenda](#) on the conference web page.

If you haven't done so already, there is still time to register. Registration and conference information can be found on the [NAACCR Annual Conference web site](#).

I'll see you in the 'Burgh.

---

## **BIRDS OF A FEATHER**

**Melanie Williams PhD,**  
*Texas Cancer Registry*

## **BIRDS OF A FEATHER STILL FLOCK TOGETHER**

---

After ten illustrious years of leading Birds of a Feather at the NAACCR Annual Conference, Susan Gershman of the Massachusetts Cancer Registry and Rich Pinder of the Los Angeles Cancer Surveillance Program passed the torch to Melanie Williams, Texas Cancer Registry, and Gary Levin with the Florida Cancer Data System.

This year's discussion focuses on "Doing More with Less," a topic that reflects a less than ideal reality that many registries must deal with. As in year's past, we'd like to hear your thoughts on how you are managing professionally and personally.

Both positive and negative examples of doing more with less situations, solutions, and frustrations are welcome. We want to know, have you managed in some way to turn lemons into lemonade (without sweetener no less), or do you feel like there is nothing left to do but think "pucker!" In either case, attending the session, sharing your experiences, ideas, and support is an invaluable part of the NAACCR Annual Conference that will continue.

So be sure to join us for this interactive session where we can share, learn, and figure out new ways to flock together, and make the best out of doing more with less.

---

## **CANCER INFORMATICS HACKATHON**



**Dustin Dennison, M.MIS.**  
*NAACCR Information Technology Administrator*  
[ddennison@naaccr.org](mailto:ddennison@naaccr.org)

NAACCR will be hosting it's first ever cancer informatics hackathon in conjunction with the [NAACCR 2018 Annual Conference](#) this June 9-11 in Pittsburgh.

## NAACCR Narrative Spring 2018

The hackathon is open to anyone regardless of their affiliation with the cancer surveillance field. Please note that all of the projects for the hackathon are cancer related. There is no charge for registration and cash prizes will be awarded to the top three teams (or individuals). The deadline to [register](#) is **May 15, 2018**.

The goals for the hackathon are:

- Introduce informatics professionals and students to an exciting career in the rapidly evolving world of cancer control and data science
- Recruit talented, motivated, innovative people into the cancer informatics workforce
- Gather the brightest informatics minds in the Pittsburgh area for 3 days to hack out solutions to major cancer control problems

The hackathon will begin on Saturday, June 9, at the Herberman Conference Center on the UPMC Shadyside Campus. Participants will have two and a half days to develop solutions to one of several cancer related informatics projects

On Monday June 11, the teams will be transported to the NAACCR conference site to present their software solutions. Based on these presentations the judges will select the top three teams (or individuals). The judging will be based on multiple criteria to ensure a level playing field for all participants whether they are new to cancer informatics or are seasoned professionals.

We encourage you to share this with anyone you think may be interested in attending or competing. To learn more about the hackathon or to register please visit our website: <https://www.naacccr.org/hack>

Additional details will be added as they become available. Please email [hackathon@naaccr.causewaynow.com](mailto:hackathon@naaccr.causewaynow.com) if you have any questions about the event.

---

## NAACCR FORUMS



**Angela Martin, CTR**

*NAACCR Trainer/Project Coordinator*

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

Did you know that NAACCR has a Forums page in which you can go and ask questions or start a discussion topic, or just to view what others may be saying in regards to the cancer surveillance world?

No? Well NAACCR has created a group of forums that are open to the NAACCR community. The purpose of NAACCR Forums is to give the NAACCR community a place to discuss various topics regarding the cancer surveillance world. It is intended to be a place

for individuals to respectfully voice concerns, ask questions and solicit collaboration from NAACCR colleagues. With topics for every Steering Committee, as well as other topics such as 2018 Implementation, NAACCR XML Standard, New NAACCR Data Fields and so forth.

So how do I get involved? First, on the NAACCR website (<https://www.naaccr.org/>) scroll down to the bottom of the page. Under *Useful Links* you will find *Forums*. Click on it. This will take you to the Forums page. Next you will need to login. The login on the NAACCR website is at the very top of the page. If you don't have a MyNAACCR account or unsure if you have one, you will be given the opportunity to create one here. After that you are ready to go!

---

## **NATIONAL DATA EXCHANGE ANNOUNCEMENT**



**Susan T. Gershman, MS, MPH, PhD, CTR**  
*Massachusetts Cancer Registry*

### **Spring Has Arrived, so Enjoy the Spring Flowers and Sign-**

Forty-three state registries, the District of Columbia, Guam, Puerto Rico, and the Virgin Islands have signed the modified national data exchange agreement. For registries that are now ready to sign:

Go to [www.naaccr.org](http://www.naaccr.org). Click on Standards and Registry Operations; click on National Interstate Data Exchange Agreement; then follow the instructions below:

1. Central registry downloads agreement.
2. Central registry has proper authority review agreement and adds state-specific restrictions if needed.
3. Appropriate registry representative signs agreement.
4. Agreement is sent to NAACCR; central registry retains copy.
5. NAACCR posts states that have signed agreement on NAACCR website, including specific restrictions.
6. Registry contacts other participating states to determine the logistics of how data will be exchanged.

The registries that have signed the National Interstate Data Exchange Agreement include: Alabama, Alaska, Arkansas, Arizona, Colorado, California, Connecticut, Delaware, District of Columbia, Georgia, Guam, Hawaii, Idaho, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Mississippi, Montana, Nebraska, Nevada New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, Tennessee, Texas, Utah,

Vermont, Virgin Islands, Virginia, West Virginia, Washington, Washington DC, Wisconsin and Wyoming. Join our team so you can add another important step towards efficient registry operations!

Please fax your signed National Interstate Data Exchange Agreement to the NAACCR office at 217-698-0188. Jim Hofferkamp ([jhofferkamp@naaccr.org](mailto:jhofferkamp@naaccr.org)) provides a listserv announcement to the NAACCR community as soon as a new registry signs on.

Check our updated map at:

<https://www.naaccr.org/national-interstate-data-exchange-agreement/>

Thanks for your help.

---

## **PERT COMMITTEE UPDATE**

**Mignon Dryden, CTR**

*NAACCR Liaison to PERT*

### **College of American Pathologists (CAP) Pathology Electronic Reporting (PERT) Committee Update**

The PERT Committee met February 10-12, 2018 in Miami, Florida. The first day was a combined meeting with PERT and the Cancer Committee. The next two days PERT members covered a great number of topics, including updating the strategy and priorities of the committee. Other topics of interest to the NAACCR community included the following:

- The **Release Update** – (And future plans). In 2017 there were 7 releases in total. 2018 releases will be in January and August, and 2019 releases are planned for February and August. A list of what changes are expected for next release will be published for end users.
- **ASCO (American Society of Clinical Oncologists) CancerLinQ Update** – 135 cancer centers have signed up, but most are not live yet. New partnerships were made with Tempus and PI. QOPI/MIPS are a high priority for 2018; there is still much interest and commitment to the cancer protocols and CAP electronic Cancer Checklists (eCC), although they are not the highest priority at the moment.
- **TNM Descriptions/pTNM suffix/prefixes** – After much discussion with different modeling options, it was recommended and voted to not change the input and have the vendors modify the output as needed.
- **Structured Data Capture (SDC)** – CAP participated in a successful IHE-Connectathon in January as a Form Filler and Form Manager. The forms worked as they should. A demonstration including having those in attendance at the PERT meeting join in a live mini connectathon where it was possible to download, upload, make a selection, fill in the form and send the form took place. The committee was impressed with the SDC product.
- **Vendor Engagement** – A lively brainstorming session occurred with multiple action items decided: PERT Leadership to create a plan for vendor engagement based on this day's discussion and a previous discussion to CSA (Council on Scientific Affairs); finalize vendor survey; write articles including the benefits of structured data using

California and Cancer Care Ontario as use cases; and publish a “Top 10” list of what eCC functionality in vendor systems should be.

- **“How Standard Setters Determine Required Data Items”** – A presentation on the NAACCR layout and change management process, new data items, and the standard setter process for requiring new data items was discussed by Peggy Adamo and Mignon Dryden (liaisons to PERT from NCI-SEER and NAACCR). It was decided that a Registry project team/workgroup would be useful; goals and roles it would play are to be drafted for discussion at a later date.
  - **Presentation on Feedback from eCC Lite Version Concept Shaping & Testing** – Back in September 2016, the PERT committee decided to move forward with testing and concept shaping of an “eCC Lite” web version. This product is to provide an electronic solution to pathologists who are not using eCC or eFRM for various reasons. This presentation explained the methodology used, the concept, who the market focus group was, and the results. Follow up discussion is scheduled for the next PERT teleconference with the goal of having a recommendation of how to proceed.
- 

## **AN UPDATE FROM THE NAACCR EDUCATION COMMITTEE**

**Lynda Douglas, CTR**

*Centers for Disease Control and Prevention*

A Google calendar with links to training and dates along with some text about SEER Educate and other resources for training is now available: <https://www.naacccr.org/education-training-calendar/>. Some dates may be approximate and changes will be notified. The Education Committee is also looking at gaps in the existing training and trying to develop training webinars on these topics:

- Summary Stage 2018
  - EOD 2018
  - Grade
  - SSDI
  - ICD O 3
  - Hematopoietic and Lymphoid Neoplasm Database
  - STORE Manual and New Radiation Coding
  - Solid Tumor Manual
  - Overview of v18 Metafile
- 

## **USCS DATA VISUALIZATION TOOL**

**Lisa C. Richardson, MD, MPH**

*Centers for Disease Control and Prevention*



CDC's Division of Cancer Prevention and Control is pleased to introduce new updates to the United States Cancer Statistics: Data Visualizations tool, a user-friendly product that allows cancer surveillance data to be directly and more easily accessible by the public and cancer control planners. It now includes seven tabs:

- Overview
- Demographics
- Trends
- State/County Statistics
- Survival
- Prevalence
- Related Data

New features include:

- County statistics
- Survival estimates
- Prevalence estimates
- Display is optimized for mobile devices
- Ability to share specific selections on social media

Data displays on national and state incidence, death, and trends are available as maps and bar charts with interpretive text when users scroll over each graphic. Users can customize displays of overall and cancer-specific statistics, download data tables, and share each page via social media.

This tool, developed in conjunction with ATSDR's Geospatial Research, Analysis, and Services Program (GRASP), creates data visualizations to describe U.S. cancer burden, incidence and mortality over time, and state-specific data in comparison to national rates.

The direct link to access the application is: <https://gis.cdc.gov/grasp/USCS/DataViz.html>.

2015 cancer data are scheduled to be added this summer.

---

## **NCDB NEWS – WHAT TO DO WITH 2018 CASES**

**Kathleen K. Thoburn, CTR**

*Commission on Cancer*

### **What to Do with 2018 Cases: Abstract in NAACCR Version 16-compliant Software and Submit to RQRS!**

Due to delays beyond cancer registry software vendor control, the North American Association of Central Cancer Registries (NAACCR) version 18-compliant software upgrades will not be available until June or July of 2018 (or possibly later). Because of the prospective nature of the treatment alert function within the NCDB RQRS and the new timeliness requirements for commendation on Program Standard 5.2 that were implemented in the calendar year of 2017, the Rapid Quality Reporting System (RQRS) is currently accepting cases diagnosed in 2018 for which abstraction has begun in NAACCR v16-compliant

software and that are submitted using the NAACCR v16 file format. Although cases diagnosed January 1, 2018 and later must be completed using NAACCR V18-based software, the majority of data items can still be abstracted for a 2018 case using v16 software. The only data items that are new or revised for 2018 are related to Grade, AJCC staging, Site-specific data items, and radiation treatment:

- Grade: The current grade data item [#440] will be replaced by three separate grade data items assessed during the clinical and pathologic timeframes or for cases that had neoadjuvant therapy administered
- AJCC Clinical and Pathologic T, N, M and stage groups: The current TNM Clin T [#940], TNM Clin N [#950], TNM Clin M [#960], TNM Clin Stage Group [#970], TNM Clin Descriptor [#980], TNM Path T [#880], TNM Path N [#890], TNM Path M [#900], TNM Path Stage Group [#910], TNM Path Descriptor [#920] data items will be replaced by new, expanded data items to be used to collect AJCC 8th edition stage data.
- Site-Specific Factors 1-25: All CS site-specific factors (SSFs) will be replaced by separate site-specific data items (SSDs). Note that some CS SSFs were dropped, some have been slightly redefined, and some new site-specific data items will be required.
- Radiation Treatment: The current Rad-Regional Dose: cGy [#1510 ], Rad-No of Treatment Vol [#1520 ], Rad-Treatment Volume [#1540], Rad-Location of RX [#1550], Rad-Regional RX Modality [#1570], Rad-Boost RX Modality [#3200], and Rad-Boost Dose cGy [#3210 ] data items will be replaced by new data items to update the way phases of radiation treatment and treatment target volumes are described to better reflect modern nomenclature and practice and to enable more accurate and informative research studies.

### RQRS Reporting Requirements

There are two lists of data items required for submission to RQRS, one that delineates the absolute minimum data items required for successful submission (i.e., will not be rejected by the system), and another that delineates the data items required to successfully run measure algorithms and generate Estimated Performance Rates (EPRs) for submitted cases.

#### ***Minimum data item requirements for successful submission to RQRS:***

The following data items are required for submission to RQRS. Values must be submitted for each of these data items or the record will be rejected.

- Record Type [#10]
- NAACCR Record Version [#50]
- Sex [#220]
- Date of Diagnosis [#390]
- Primary Site [#400]
- Tumor Histology [#522]
- Tumor Behavior [#523]
- Facility Identification Number (FIN) [#540]
- Accession Number [#550]
- Sequence Number Hospital [#560]
- **Date of 1st Contact [#580] (new requirement)**
- Class of Case [#610]

**PLEASE NOTE:** The data item of **Date of 1st Contact is now required** for submission to RQRS. The system issues that were causing rejection of cases due to missing Grade [#440] have been resolved; **Grade is no longer required** for initial submission to RQRS.

The list of data items required to successfully run the measure algorithms and generate EPRs for the submitted cases has not changed and can be found at the following

URL: <https://www.facs.org/quality-programs/cancer/ncdb/qualitytools/rqrs>

### **CoC Guidelines for Abstraction of Cases Diagnosed in 2018 Using v16-compliant Software**

1. Abstract as many data items as possible using your current v16-compliant software; the overwhelming majority of data items required for 2018 cases have not changed and can be fully abstracted using v16-compliant software.
  - a. Be sure to abstract the minimum data item requirements for successful submission to RQRS.
2. Do NOT abstract the data items Grade [#440], the AJCC 7th Edition Clinical and Pathologic T, N, M, and stage groups, version 16-compliant radiation data items, or any CS Site-specific factors. Capture as much textual documentation as possible for these data items to facilitate completion of them once your registry software has been updated to v18.
3. If pursuing commendation on Program Standard 5.2, submit the partially-completed abstracts to RQRS to satisfy reporting frequency and timeliness requirements for commendation.
  - a. Cases that do not include adequate information for the measure algorithms to run will simply be assigned an incomplete status.
4. All cases diagnosed in 2018 that were abstracted and submitted to RQRS using v16-compliant software will need to be resubmitted to RQRS once your program's software has been updated to NAACCR v18-compliant software. All cases that were set to incomplete status upon initial submission in v16 will then have adequate information for the measure algorithms to run, and EPRs will be generated.

### **CoC Program Standard 5.2: Submission-related Tasks for Commendation**

**Frequency of Reporting:** Many CoC-accredited programs are striving to meet commendation on CoC Program Standard 5.2. One of the requirements for commendation with Standard 5.2 is submitting to RQRS on a monthly basis. This can be accomplished by submitting cases with the minimum required data items to avoid rejection of cases. Programs are given credit for successful submissions (i.e., not rejected) even when records are incomplete or contain edit errors.

**Timeliness of Reporting:** Another requirement for commendation on Standard 5.2 is submitting a certain percent of RQRS measure eligible cancer cases within 3 months of the Date of First Contact [#580] based on the year of diagnosis and the calendar year during which records are being submitted. For the purposes of survey, this new timeliness requirement for commendation is calculated at the end of each calendar year:

**2017:** 25% of measure eligible cases that were diagnosed and submitted in the calendar year of 2017 must be submitted within 3 months of the Date of 1st Contact.

**2018:** 50% of measure eligible cases that were diagnosed in 2017 and 2018 that were submitted in the calendar year of 2018 must be submitted within 3 months of the Date of 1st Contact.

Programs being surveyed this year (2018) that are pursuing commendation and would like to know what percent of RQRS ME cases were diagnosed and submitted in 2017 within 3 months of the Date of 1st Contact, please write to [ncdb\\_rqrs@facs.org](mailto:ncdb_rqrs@facs.org) to request this information. Please be sure to include your FIN in the communication.

**OPTIONAL Interim Solution for Calculation of Estimated Performance Rates (EPRs) for 2018 Cases Submitted using V16**

As stated earlier, cases diagnosed in 2018 that are abstracted and submitted to RQRS in v16 file format will be assigned an incomplete status, primarily due to missing AJCC 8th Edition stage information. Once programs upgrade to v18-compliant software, the new 2018 data items will need to be completed within the v18-compliant software and resubmitted to RQRS using the v18 record layout. At this point, the RQRS measure algorithms will run and EPRs will be generated.

However, some programs may not want to wait until the v18 software upgrades are available to have RQRS appropriately run measure algorithms and send prospective treatment alerts for cases diagnosed in 2018. In an effort to better serve our programs, CoC is working in conjunction with the CDC Registry Plus group on configuring an NCDB-customized version of the NAACCR Version 16-compliant CDC Abstract Plus Software that will

- include and enable abstraction of 2018 data items required for EPR calculation
- include these data items within the State/Requestor Area of the v16 NAACCR Record Layout upon export
- be accepted by the RQRS Data Submission and Processing System, which will be configured to read these data items for 2018 cases and use them to feed them into the Quality Measure Algorithms

Please Note: Use of this program is NOT REQUIRED and is COMPLETELY OPTIONAL. It is up to the discretion of each program whether or not to use this interim solution. We will be posting more details along with the NCDB-specific version of Abstract Plus to the RQRS website in the near future.

**All New RQRS Website Coming Soon!**

The NCDB is working diligently to generate an all new webpage dedicated to RQRS data submission information. Look for a communication about the release of this new site from the CoC soon.

**Standards for Oncology Registry Entry (STORE) Manual Update**

The NCDB is also hard at work taking on the monumental task of generating the all new STORE Manual. As previously announced, due to circumstances outside the CoC's control, the release of the manual has been delayed until March 2018, a deadline we are striving to meet. As a result, while we work to finalize the entire manual, we will be posting a document including only the new CoC data items to the new RQRS website so that registrars can review and comment on this information prior to its incorporation into the formal STORE manual. We will concurrently be adding a new sub-forum in the CaForum where registrars can submit comments. We will be posting this document on the new RQRS webpage as soon as it is available.

**WE ARE ALL IN THIS TOGETHER**

Change is a necessary component of forward progress; it is inevitable in the pursuit of

excellence. As we make our way adjusting to new data items and registry operations, we must always keep foremost in our minds the higher goal of improving cancer patient across the United States. The NCDB strongly encourages registrars to continue communicating questions and concerns about the 2018 standards to the CoC. When standard setters make decisions regarding new cancer data standards, they make best efforts to think globally and thoroughly through all the issues at hand. However, despite exhaustive, multiple reviews, important details may still be overlooked. As a result, the only individuals that can truly inform the standard setters are the registrars who abstract the data. The CoC can't thank our registrars enough for the perseverance and patience you put into your jobs every day. The NCDB would not exist without the diligence of cancer registrars across the nation.

As always, please feel free to submit any questions or concerns to the RQRS support desk at [ncdb\\_rqrs@facs.org](mailto:ncdb_rqrs@facs.org).

---

## **NCI SEER RELEASES NEW CANCER STATISTICS REVIEW AND LATEST SEER DATA**

**Patricia Murphy**

*National Cancer Institute*

### **SEER Releases New Cancer Statistics Review (CSR) and Latest SEER Data**

The SEER Cancer Statistics Review (CSR), 1975-2015, published by NCI's Surveillance Research Program, was released on April 16, 2018. The updated Cancer Statistics Review presents the most recent cancer incidence, mortality, survival, and prevalence statistics.

New materials posted include:

- [Cancer Statistics Review 1975-2015](#)
- [Cancer Stat Fact Sheets](#)
- [SEER\\*Explorer](#)
- [Fast\\*Stats](#)
- [The Cancer Query Systems](#)
- [Cancer Statistics Animator](#)
- [SEER Incidence Data, 1973-2015](#)
- [Specialized Databases](#)

The Surveillance Research Program [website](#) has also been updated to reflect the new statistics, including new versions of Joinpoint and DevCan software.

All material in the SEER CSR report is in the public domain and may be reproduced or copied without permission; however, [citation](#) of this source is appreciated.

Since the early 1970s, the Surveillance, Epidemiology, and End Results ([SEER](#)) Program has been an invaluable resource for statistics on cancer in the United States, tracking and reporting trends in incidence, mortality, survival, and prevalence. Researchers at NCI and around the country continue to rely on SEER for the most accurate cancer statistics.

[Follow SRP on Twitter!](#)

## **HAPPY RETIREMENT**

### **Junhie Oh**

#### *Rhode Island Cancer Registry*

The Hospital Association of Rhode Island Cancer Information Systems is the Rhode Island Department of Health (RIDOH)'s three decade-long partner (contractor) for the Rhode Island Cancer Registry operation.

Mr. David Rousseau, the Director of Cancer Information Systems recently retired, and Rhode Island Cancer Registry would like to recognize his dedicated public health service and extensive contributions. During his tenure since 2005, the Rhode Island Cancer Registry has always met the Gold Standard accredited by NAACCR, and received the Registry of Excellence awarded by the CDC NPCR.

David started his career in the field of cancer registration 40 years ago, and he has been a leader, role model, teacher, and friend of cancer registrars and healthcare providers. He has been a driving force to constantly innovative and advance quality cancer data collection and reporting. His influence does not stay in Rhode Island, but resonates to the cancer surveillance field nationwide.

Foremost, we all remember his warm and kind heart, having proudly and tirelessly served for the cause to save more Rhode Islanders' lives from cancer.

The photo below was taken in the Statewide Cancer Registrars' Meeting, Feb 22, 2018 when David received the RI Governor's Citation Award.



From left: Carol Hall-Walker, Associate Director, Division of Community Health and Equity, RIDOH, David Rousseau, Hon. Teresa Paiva Weed, President, Hospital Association of Rhode Island, Junhie Oh, Cancer Registry Manager, RIDOH.