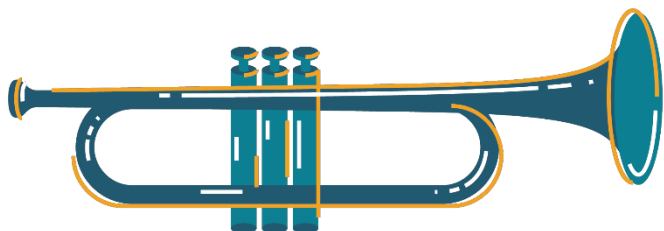


THE NAACCR NARRATIVE



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President's Message



Winny Roshala, BA, CTR
NAACCR President

Hello Everyone! I hope you are enjoying the Spring season, a time for rebirth, hope, and reaffirmation. As we reflect on all these things, let us reaffirm our commitment to the cancer surveillance community. To our dedicated colleagues who persevere and strive to provide high quality data and our researchers who analyze the data, seeking to answer critical questions to increase our knowledge of this disease, we thank you all!

Congratulations to registrars as we celebrate National Cancer Registrars Week! You are the cornerstone of the cancer data collection system and we appreciate the unique, high skillset required to perform the critical work you do! There would be no cancer surveillance system without you!

We also want to acknowledge and congratulate our public health colleagues in celebrating National Public Health Week!

Please join me in congratulating the following newly elected NAACCR Board members: Treasurer (second term): Kevin Ward, PhD, (GA), Representatives at Large: Joshua Mazuryk, Cancer Care Ontario, Bozena Morawski, PhD, (ID), Sarah Nash, PhD, (IA). The Nominating Committee for 2023-2024 includes: Heather Stabinsky, MSEd, CTR, (NJ), Carrie Bateman, BS, (UT), and Mona Highsmith, BA, (MN). Congratulations to all elected Board members and Nominating Committee members, as we welcome you and look forward to an exciting year ahead!

The Board and the Steering Committee Chairs, in collaboration with the Strategic Management Plan Work Group have been working diligently to

develop metrics to monitor the Strategic Management Plan (SMP) as we transition from a Management Plan to a Strategic Plan. The initial first year results will be shared with the membership in June. Kudos to everyone involved for positioning NAACCR to establish a strategic visionary path for our future!

Lastly, we invite and encourage you to attend the 2023 NAACCR Conference, in New Orleans, June 20-23, 2023. Yes, we are actually having an in-person conference

again this year! Come, learn, connect and network with your colleagues! It's been a long time since our last in-person conference experience and the Program Committee is working hard to offer robust, relevant, and diverse educational content. You won't want to miss it!

Wishing you all a healthy, safe and beautiful Spring season! Thank you for all the work you do!

Spotlight on Registries: Jetty Alverson, Michigan Cancer Surveillance System

Spotlight on Registries is a relatively new feature for the *NAACCR Narrative* and presents a series of articles that highlights a registry's special activities or achievements. This edition spotlights the Wyoming Cancer Surveillance Program's (WCSP's) 2021 NPCR Success Story. It describes their partnership with the neighboring Utah Cancer Registry (UCR) involving the transmission of electronic pathology laboratory (ePath) reports from Utah to Wyoming. Because many Wyoming patients cross into Utah for diagnosis and treatment, many of these ePath reports represented cancer cases that were not reported by any other healthcare provider. These new cases contributed toward increasing WCSP's overall case completeness. WCSP encourages other state cancer registries experiencing a significant number of residents crossing state lines for diagnosis and treatment to pursue similar partnerships with registries in neighboring states.

To see the original 2021 NPCR Success Story, [click here](#). 

This project was the result of UCR's decision to start sharing ePath reports in addition to regular NAACCR XML files as part of their regular interstate data exchange. For DxYear 2018, nearly 82% of the cases UCR sent went to the three neighboring states of Idaho (39%), Wyoming (22%), and Nevada (20%). You can read more about this project here: [Journal of Registry Management, 2021, vol. 48, no. 2, p. 59-63.](#)

Julia Espinoza from Wyoming Cancer Surveillance System and author of the Success Story spoke with the *NAACCR Narrative* recently about their experience. Some responses were edited for clarity.

NAACCR Narrative (NN): What do you think was your greatest challenge in implementing this new procedure of receiving ePath reports of WY residents from UT?

Ms. Espinoza: I don't feel that there were any real challenges on the part of the Wyoming Cancer Surveillance Program (WCSP) in implementing this process, as the WCSP had the infrastructure to process the HL7 ePath reports received from the Utah Cancer Registry (UCR). The biggest challenge prior to receiving HL7 ePath reports from UCR was that many Wyoming residents travel outside of the state to receive care for their cancer diagnosis, and the WCSP has no way of tracking these residents outside of the state. Many of the cases found through ePath are not found during routine interstate data exchange. With UCR being proactive and alerting the WCSP (with the ePath reports), the WCSP is now able to have much more complete data.

NN: What do you think was your greatest success in this implementation?

Ms. Espinoza: The greatest success of this implementation was the ability to obtain data that the WCSP didn't even know existed. The extra data from the ePath reports not only creates a more robust database for the WCSP, but a more comprehensive look of what is really happening with cancer in Wyoming.

NN: Do you have anything else you would like to share with the NAACCR community as part of this article on your Success Story experience?

Ms. Espinoza: I would like to say, thank you to the UCR staff on behalf of the WCSP. The UCR's innovative thinking and sharing of ePath reports with the WCSP has helped WCSP to continue to be a successful registry.

Welcome to New Ohio Registry Manager, Emily Bunt



Please join us in welcoming Emily Bunt to the NAACCR community. She is the new Registry Manager for the Ohio Cancer Incidence Surveillance System (OCISS) at the Ohio Department of Health. Emily previously worked as a researcher and evaluator for Ohio's Comprehensive Cancer Control Program and Breast and Cervical Cancer Project. She has used OCISS data to plan, implement and evaluate these programs, recently providing leadership for the revision of Ohio's Cancer Plan. She has worked with a team to write reports on Ohio's cancer incidence, including Cancer Stats & Facts for Ohio, a series of fact sheets to coincide with cancer awareness months. As Registry Manager, Emily hopes to maintain the collection of high-quality data and promote its use to reduce the burden of cancer in Ohio. Emily enjoys hiking, reading, and attending her son's and daughter's music concerts and theater productions. Emily is excited to join the team at OCISS and meet many of you at the NAACCR conference this summer!

Massachusetts Cancer Registry Releases Childhood Cancer Report (2009-2018)

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

The Massachusetts Cancer Registry (MCR) is pleased to announce the release of its latest report on childhood cancer in Massachusetts, *Childhood/Adolescent Cancer in Massachusetts, 2009-2018*, <https://www.mass.gov/doc/childhood-adolescent-cancer-in-massachusetts-2009-2018/download>. This is the MCR's third report on childhood cancer spanning thirty years. The data were analyzed by four age groups (0-4, 5-9, 10-14, 16-19), sex, and race/ethnicity. Childhood cancers are coded according to the International Classification of Childhood Cancer (ICCC) which is based on the type of tissue affected (histology or morphology). The current version of ICCC is ICCC Recode Third Edition ICD-O-3/IACR 2017 (<https://seer.cancer.gov/iccc/iccc-iarc-2017.html>). Some findings from the MCR report include:

1. The overall incidence rate was 207/1,000,000. The incidence in males was 218/1,000,000 which was significantly higher than females 195/1,000,000.
2. There were no significant trends in the incidence of childhood/adolescent cancer from 2009-2018 for either the four age groups or the four race/ethnicity groups.
3. The age-specific incidence rate of childhood cancer was highest for Massachusetts males 0-4 and for females 15-19.
4. For incidence leukemia ranked highest among the youngest age group while central nervous system (CNS) tumors ranked among the top two cancers for all age groups.
5. From 2008-2018 cancer was ranked the fourth most common cause of death for Massachusetts children aged 0-4, the most common for children aged 5-9 and 10-14 and the fourth most common for adolescents aged 15-19.

6. Asian, non-Hispanics (NH) had the highest mortality rate for all cancer deaths, but it was not significantly elevated. This elevation was driven by Asian, NHs having a significantly higher mortality rate of CNS cancers compared to the other groups.
7. CNS cancer was the leading cause of cancer deaths among Massachusetts children and adolescents from 2009-2018, followed by leukemia, cancers of the soft tissue, bone, and adrenal gland.
8. Childhood/Adolescent cancers have stable incidence and mortality rates from 2009-2018. In the MCR's prior report for 2000-2009, incidence rates increased due to slight though significant increases in leukemia and Hodgkin lymphoma. Mortality rates were stable for the 2000-2009 report.

Thanks to Richard Knowlton, MS, epidemiologist at the MCR, for all his work on this report. As a participant in the National Childhood Cancer Registry (<https://nccexplorer.ccdi.cancer.gov/>), the MCR looks forward to contributing to research and to improved outcomes for children diagnosed with childhood cancers.

Succession Planning – Using the 3-Legged Stool Model

You are a cancer registry manager, and your data analyst of 24 years tells you he is planning on retiring. He does quite a lot of different tasks for the registry, such as processes incoming data files, performs a myriad of file linkages (such as Virtual Pooled Registry, state mortality, SSDI, NDI, IHS, and the state breast & cervical screening program), installs cancer software, conducts database deduplications, runs GenEdits, generates state statistics, processes and sends the Call For Data file, conducts cancer studies for communities with concerns about pollution and illnesses, among other things. He has developed routines and systems for all these tasks, and you have no idea what they are. What are you going to do? This is exactly what is happening in our registry in Alaska with my planned retirement. Change is always a constant in any cancer registry, and even long-timers like me eventually move on. This is why succession planning is such an important subject. Registries should be prepared for changes in staff with as little disruption of operations as possible. This is one of the reasons why it is the subject of this year's Birds of a Feather session at the annual NAACCR conference in New Orleans.

In Alaska we are using the "3-Legged Stool" approach to succession planning for my position. Maybe you haven't heard of this model before? That's because I just made it up. This is how the model works:

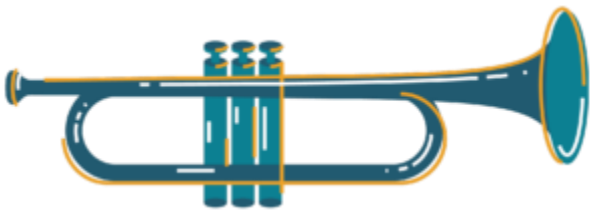
- **Advanced notice:** This is the seat of the stool, since if you don't have this part, you don't have anything to which to attach the legs. Once the staff member knows they are leaving, they should give as much advance notice to their supervisor as is practicable. If you don't get enough advanced notice, then you don't have enough time to accomplish the next three tasks. In my case, I was the only person in the registry that did data processing and analysis, so I had a lot of information to pass on. I decided to give my supervisor an entire year notice so they could start planning early. Admittedly this is unusual, and I imagine the majority of employees give a standard 2two-week notice. But the longer the period of advanced notice, the better chance you have of creating and attaching the three legs.
- **Document all tasks in great detail:** All our registries are required to have an Operations and Procedures manual. They are very helpful, especially to new staff. But they are usually not cookbooks, just a general outline of processes. That's why it's very important for the person who is leaving to take the time to document all the tasks they do using a lot of detail. In my situation, the tasks I perform are often rather complicated so I decided to start documenting them about two decades ago so I wouldn't forget how to do them. The way I do these tasks often changes due to advances in technology or updates in the data, so I have to constantly update the documentation to keep it current. I have a master task document that briefly lists the tasks I do each week, each month, and then for each month of the year. For each task I have a link to a separate document that describes how to do each of those tasks.

- Hire a successor before employment separation: If a successor can be hired before the staff member leaves, then the new staff member can get some great hands-on experience right from the source. This “double fill” hire situation can often be difficult to accomplish. It is more often the case that the position is not filled until the staff member has already left. Some states may have special rules that prevent the previous staff member from being hired as a contractor to train the successor, especially when the previous staff member is receiving a state pension.
- Train coworkers: This final leg of the stool is especially important if it doesn’t look like a “double fill” hire situation is going to happen. The staff member who is leaving can train coworkers or (in my case) colleagues who don’t work in the cancer registry but work in the same section as the cancer registry and have availability to perform cancer registry tasks. And if there wasn’t a lot of overlap between the incoming and outgoing staff member or no overlap at all, the trained staff members can help the new staff learn their job.

I hope you find this “3-Legged Stool” approach to succession planning helpful in maintaining the operation your registry in the midst of change.

NAACCR 2023 Conference Extras

Sound the Trumpets! The NAACCR Annual Conference is going to New Orleans, Louisiana



[There is still time to register!](#)

Join us Thursday, June 20-22, 2023

New Orleans, Louisiana

The Roosevelt Hotel

Birds of a Feather: Succession Planning

Join other NAACCR 2023 conference goers in-person on Tuesday, June 20, 2023, from 5:15- 6:15pm (Salon V-Mezzanine Level) for a lively discussion on the challenges and potential solutions presented. Stimulating topics in the area of how organizations handle succession planning.

Moderators: Dr. Sarah Nash, State Health Registry of Iowa; Wendy Aldinger, Pennsylvania Cancer Registry; and David O’Brien, Alaska Cancer Registry

Exhibitor Showcase and Attendee Social

Monday, June 19, 2023

5:00 PM – 6:30 PM

Roosevelt Ballroom (Mezzanine Level)

Meet our sponsors and vendors, meet up with your friends, have a nibble, and maybe even win a prize! Cash bar. Everyone welcome!

Opening Reception

Tuesday, June 20, 2023

6:30 PM – 9:00 PM

Crescent City Ballroom (Mezzanine Level)

Join us for the opening welcoming reception. Make new friends, re-connect with old friends, and socialize with excellent NOLA style music. Heavy appetizers will be available with cash bar. Entrance is complimentary with Full Conference Registration fee. Extra tickets will be available for purchase on the conference registration site.

Pre-Dinner Social

Wednesday, June 21, 2023

5:00 PM – 6:30 PM

Blue Room (Lobby Level)

Join conference attendees in the historic Blue Room before you head out for dinner with friends. There will be conversation, light appetizers, cash bar, cash coffee bar, and light entertainment. Raffles and give-aways will happen periodically between 5:15 PM – 6:15 PM

Closing Social Gathering with Trivia

Thursday, June 22, 2023

4:30 PM – 5:30 PM

Roosevelt Ballroom (Mezzanine Level)

All conference attendees are invited to gather for a light snack and beverage after the final session as we depart New Orleans. This will be a cash bar event with light appetizers in a casual stand-up gathering. Join us along with Randi Rycroft and Chuck Wiggins in a lively game of Trivia.

Highlights from the Program Manager of Standards



Lori Havener, CTR

Program Manager of Standards

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NAACCR Data Standards and Data Dictionary v24 Implementation:

The High-Level Strategic Group (HLSG) voted on the proposed revisions for 2024 implementation, HLSG approved changes are listed below. The Uniform Data Standards Work Group (UDS WG) is currently working to update the NAACCR Data Standards and Data Dictionary, v24 to meet the July 1st release deadline.

The following is a list of changes approved by the HLSG for 2024:

- Retired data items:
 - Birthplace [250]
 - Place of Death [1940]
 - Name–Maiden [2390]
 - Ln Status Femoral-Inguinal, Para-aortic, Pelvic [3884]
 - CRC Checksum [2081]

- Revised data items:
 - Location of Radiation [1550]
 - IHS PRCDA [194]
 - UHIO [284]

- UHIO City [285]
 - Tobacco use smoking status [344]
 - EDP MDE Link Date [530]
 - EDP MDE Link [531]
 - SEER SSF#1: HPV [3700]
 - SSDI Brain Molecular Markers [3816]
 - New SSDI Schema: P16 [3956] – Vulva
- Revised surgery codes:
 - Breast
 - Colon
 - Lung
 - Pancreas
 - Thyroid
- New Data Items
 - Derived Summary Grade
 - Geocoding Quality Code
 - Geocoding Quality Code Detail
 - Rx Hosp – Recon Breast
 - Rx Summ – Recon Breast
 - Brain Primary Tumor Location

NAACCR Data Standards and Data Dictionary (Volume II) Version 24 Implementation Timeline

Activity	MLTG Deadlines	Comments
Proposed requests for new data items and revisions to existing data items that require field testing submitted to the Mid-Level Tactical Group (MLTG).	2023-07-01	Data items approved by MLTG will be sent to the Uniform Data Standards Work Group (UDS WG) for preliminary review
Field testing initiated.	2023-10-01	
Proposed requests for changes to existing data items that do not require field testing submitted to MLTG. Other planned changes (e.g., staging, ICD-O-3.2, SSDI schemas, etc.) reported to MLTG.	2023-10-01	MLTG may elect to require field test on changes*
MLTG informs the High-Level Strategic Group (HLSG) of all planned changes for 2025.	2024-01-01	
MLTG transmits proposed revisions to UDS WG.	2024-01-01	UDS will review all information provided
Field test results reported to MLTG.	2024-03-01	MLTG votes on proposed revisions and makes recommendation to HSLG.
HLSG reviews/approves changes to be implemented in 2025.	2024-04-01	
HLSG/MLTG transmits new standards approved for implementation to UDS WG	2024-04-01	NAACCR Data Standards and Data Dictionary is updated.

Standard setters provide their requirements for the Data Standards and Data Dictionary Required Status Table and the Reportability table.	2024-05-01	
UDS WG final review and approval of the Data Standards and Data Dictionary.	2024-06-01	
UDS WG submits NAACCR Data Standards and Data Dictionary, V25 to the Standardization and Registry Development Steering Committee for review/approval.	2024-06-15	
NAACCR Data Standards and Data Dictionary, V25 Released.	2024-07-01	

*Changes to existing data items that result from experience in collecting the data, questions received from registrars or reliability studies generally will not require field testing. However, changes to codes made for other reasons may require field testing to ensure that the new codes and coding instructions can be accurately applied in registry settings. Change requests made in October that the MLTG determine need to be field tested may postpone the implementation year.

NAACCR Education and Training Program Update



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

NAACCR Education and Training (NET) Site

NET is the name of the NAACCR Learning Management System (LMS). If you haven't visited for a while, it is time to check it out! We have been working with our software vendor to upgrade the look and feel of the site and improve some of our processes.

<https://education.naaccr.org/>

NAACCR Monthly WEBINAR SERIES

The price of the NAACCR Monthly Webinar Series is going up next year. The base price of a 12-webinar series is going up to \$2000. Even at that price, it is still a bargain.

For that base price you still get a live 3-hour webinar each month presented by the best trainers in the industry. That's 36 hours of high-quality training for you and your staff. You can have up to 5 of your staff view the live sessions remotely for no additional charge with the base package. You will still get a copy of the recording that can be kept in your training library and can be viewed as often as you or your staff like.

The new schedule and pricing options will be available in early June. The first webinar of our new season will be presented on October 5, 2023.

Speaking of next season, I'm excited about how the new schedule is coming along! Participants seem to like dedicating multiple sessions to a single topic. In the current season we are dedicating two sessions to breast and two sessions to colon. Next season we will dedicate two sessions to lung and two sessions to one other topic. We also have a great mix of speakers we have used in the past and some new speakers!

More information about the 2023-2024 Monthly Webinar Series page at <https://education.naaccr.org/next-year-webinar-series>

2022-2023 Monthly WEBINARS (current season) AT A GLANCE

- Breast 2022 Part 1 10/06/22
- Breast 2022 Part 2 11/10/22
- Esophagus 2022 12/01/22
- Head and Neck 2023 1/12/23
- Data Item Relationships 2/2/23
- Boot Camp 2023 3/02/23
- Prostate 2023 4/06/23
- Lower GI 2023 Part 1 5/04/23
- Lower GI 2023 Part 2 6/01/23
- IT Worked for Me: In“FUN”matics in the Cancer Registry 7/13/23
- Melanoma 2023 8/03/23
- Coding Pitfalls 2023 9/07/23

NAACCR CTR PREP AND REVIEW

The CTR Prep and Review Series for the June testing period started on May 2, 2023. There have been significant changes made to the content of the exam this year and we have been busy updating our materials to reflect these changes.

Additional information is available at <https://education.naaccr.org/ctr>.

NAACCR TALKS RECORDINGS

Recordings of all NAACCR Talks can be found at: <https://education.naaccr.org/freewebinars>.

PRINCIPLES OF CANCER REGISTRIES

Our latest educational product is titled *Principles of Cancer Registries*. These asynchronous training modules are targeted at international registries. The first module looks at sources of cancer data and the process for collecting cancer data. The second module focuses on Assessing the quality of data collected within a cancer registry. A third module will be posted this summer. It will review the basic registry operations that occur once data is submitted to a central registry.

The modules are available at <https://education.naaccr.org/international>.

As always, if you have any questions about the plethora of NAACCR Education and Training products don't hesitate to contact [Jim Hofferkamp](#) or [Angela Martin](#)!

Spring 2023 Education and Training Calendar



Angela Martin, CTR
NAACCR Trainer/Project Coordinator
amartin@naaccr.org

June 2023

- 06/01/2023 NAACCR Webinar Series: Lower GI 2023 Part 2
- 06/06/2023 NAACCR CTR Exam Prep and Review Webinar Series Session 6
- 06/13/2023 NAACCR CTR Exam Prep and Review Webinar Series Session 7
- 06/20/2023 NAACCR Annual Conference – New Orleans, LA
- 06/21/2023 NAACCR Annual Conference – New Orleans, LA
- 06/22/2023 NAACCR Annual Conference – New Orleans, LA
- 06/27/2023 NAACCR CTR Exam Prep and Review Webinar Series Session 8

July 2023

- 07/13/2023 NAACCR Webinar Series: IT Worked for Me: In"FUN"matrices in the Cancer Registry

For more information about NAACCR education and training opportunities, or to register online, go to the Education and Training site <https://education.naaccr.org/upcomingevents> or contact [Angela Martin](#)

Spring 2023 Research & Data Use Update



Recinda Sherman, MPH, PhD, CTR
NAACCR Program Manager of Data Use and Research
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I am looking forward to seeing many of you at our Annual Conference in New Orleans in June. I am also eager to eat a big ole muffuletta from Central Grocery & Deli. But in between the eating and the catching up, there will be some excellent presentations.

For instance, RDU has two workshops on Wednesday June 21st:

NAACCR Data Confidentiality & Data Release Recommendations

This workshop will present an early look at the draft NAACCR Data Release Guidelines, under development by the Data Security & Confidentiality Workgroup. This workshop will be a targeted discussion forum on three topics related to data release: issues related to patient contact studies, release of restricted data or cases, and suppression guidelines.

Numerators, Denominators, and ABSMs – Critical Issues with Calculating Cancer Statistics

This panel discussion will provide an overview of some of the work of the Population and Area Based Social Measures (ABSM) Workgroup and describe on-going issues including population resources available, potential impact of differential privacy on the 2020 Census data, non-bridged race rate calculations, and changes to the definition of rurality by the census.

2020 Data

Overall, CiNA data showed about a 10% drop in expected cases for diagnosis year 2020, a number that is in alignment with NPCR and SEER data, including pathology reports. As mentioned in our last RDU Update, we will not use 2020 data in trend analysis.

Completeness Adjustment for 2020

Historically, the NAACCR uses a five-year Incidence to Mortality Ratio (I/M) as the comparator to estimate expected rates to evaluate the current submission year by completeness. However, as expected, this method did not appropriately capture completeness of case ascertainment for the unusual 2020 diagnosis year.

To address this issue, a NAACCR Workgroup was formed that included NAACCR, NPCR, and SEER representatives. The workgroup evaluated potential adjustments with two goals in mind: 1) do not penalize registries for decreased numbers of cancer cases *diagnosed* due to changes in medical access; and 2) do not adjust away operational issues (due to COVID-19 or other factors) that resulted in decreased number of cancer cases *collected*. To this end, the workgroup reviewed surveys of the central cancer registries on case ascertainment, evaluated multiple years of available pathology data, and assessed multiple adjustments to the standard method using submitted data. Based on these evaluations, the workgroup unanimously identified a standard method of adjustment to the 2020 submission that will be used by both NAACCR and NPCR.

NAACCR, along with NPCR, applied a “self-correcting” adjustment to the Completeness Estimate for Certification of the 2020 data. The goal was to adjust the expected case count to account for the fewer cases identified due to changes in medical care due to COVID-19, but not to adjust for registry operational issues that impacted ascertainment of cases. The adjustment was made to the underlying completeness calculation by using a single year, 2020, instead of five years for both the incidence and the mortality components of the comparison I/M Ratio. This approach was applied to all US and Canadian registries and resulted in completeness measures that aligned with historical performance as well as our understanding of current challenges within the registries.

It is important to clarify that this adjustment is for the 2020 diagnosis year only. The 2021 data will require separate evaluation for any potential adjustment.

This year, NAACCR is leading the production of the Annual Report to the Nation on the Status of Cancer with a focus on the 2020 rates as the special topic.

NAACCR Call for Data

This was a difficult year for many registries. This was reflected in the December 2022 submissions, which had a number of unexpected data quality issues that required additional attention to resolve both during and post-submission.

After applying an adjustment to the Completeness Calculation, 3 US registries and 2 Canadian registries submitted data but did not achieve any level of NAACCR Certification for the 2020 diagnosis year data. For Canada, 10 registries achieved Gold, no registries were Silver, and 2 registries did not submit data. For the US, 49 registries achieved Gold, 6 registries achieved Silver, and all US registries submitted data.

Certification results and associated data assessments, including the Tableau visualizations, were provided to registries in April through the Call for Data Portal. Registries will receive their certificates and public recognition during our annual meeting—in person!

Tumor-level Deduplication with Match*Pro for December 2023 CFD

NAACCR provided training on the new tumor-level deduplication protocol using Match*Pro in March. We solicited feedback from registries on the protocol and used their input to finalize a graduated approach for incorporating tumor-level deduplication into the NAACCR CFD submission requirements.

Registry feedback was used to inform our approach to duplication for Certification. The NAACCR Board voted and approved the following roll-out approach for deduplication for NAACCR Certification using Match*Pro.

CFD December 2023

- 100% Patient-level deduplication resolution on full submission (1995-2022)
- Gold = 5 years of tumor-level resolution (2017-2021); <.1% tumor-level duplicates (match run on all cases diagnosed 2007-2021)
- Silver = 1 year of tumor-level resolution (2021); <.1% duplicates (match run on all cases diagnosed 2007-2021)

CFD December 2024

- 100% Patient-level deduplication resolution on full submission (1995-2023)
- Gold = 2007+ tumor-level resolution; <.1% tumor-level duplicates (match run on all cases diagnosed 2007-2022)
- Silver = 5 years of tumor-level resolution (2018-2022); <.1% tumor-level duplicates (match run on all cases diagnosed 2007-2022)

CFD December 2025

- 100% Patient-level deduplication resolution on full submission (1995-2024)
- Gold = 2007+ tumor-level resolution; <.1% duplicates (match run on all cases diagnosed 2007-2023)
- Silver = 2007+ tumor-level resolution; <.2% duplicates (match run on all cases diagnosed 2007-2023)

At this time there is no intention of resolving tumor-level duplicates on cases prior to 2007. Patient-level deduplication will be assessed based on the honor system, and we will collect information in the CFD Portal similar to last year. However, tumor-level deduplication will be assessed on your submission file. We are currently working on the procedure for registries to identify cases that were reviewed and determined to not be duplicate tumors.

NAACCR Special Edition of JRM

This edition of the Narrative has an article describing the contents of our 3rd Annual NAACCR JRM collaboration with NCRA available here: <https://www.naacccr.org/jrm/>.

I am pleased to announce that articles from our edition won both “Best Paper” and “Honorable Mention” Awards. This year, article submissions are due October 3rd, 2023. We encourage registries to submit short reports or editorials, in addition to research articles.

As always, if you have any questions, concerns, revolutionary ideas, or new projects that might get us an Ig Noble Prize in the NAACCR Research and Data Use area, please contact me rsherman@naaccr.org.

Winter Edition of JRM NAACCR Special Edition

The Winter 2022 edition of the Journal of Registry Management is the third year of this collaboration between NAACCR and NCRA and can be found on the NAACCR website (<https://www.naacccr.org/jrm/>).

This year's NAACCR JRM Special Edition includes nine original articles covering a range of topics of relevance to the cancer surveillance community. Three of these papers come out of the New York State Cancer Registry. Zhang *et al.* use claims data to help explain the 10% decrease in 2020 than expected ("The Case of the Missing 2020 Cancers: Using Claims Data to Investigate a Deficit in Incident Cancer Case Reports to the New York State Cancer Registry in 2020"), with results that indicate the drop in case load may be the product of fewer cancer diagnoses during 2020. In a second study, Zhang *et al.* used claims data to characterize early COVID-19 hospitalizations among patients with a history of cancer ("Early COVID-19 Hospitalizations Among New York State Residents with a History of Invasive Cancer"), and concluded that cancer patients had higher risk of COVID-19 hospitalization and higher risk of death during hospitalization compared to the general population of New York State. Risk also varied by race/ethnicity, region of residency, and age at diagnosis. In the third paper from New York, "Identifying Factors Associated with Loss to Follow-up Among Patients Reported to the New York State Cancer Registry," Qiao *et al.* elucidate that 60% of loss to follow-up occurs within one year of diagnosis, and that it is differential by sex, race/ethnicity, place of birth, insurance status at diagnosis, age, and geography, and discuss the need to ensure the highest quality possible identifiers across all patient sub-groups.

In an NCI-lead publication, Tatalovich *et al.* assessed interstate residential mobility of SEER patients using LexisNexis address history ("Assessment of Interstate Residential Mobility of SEER Patients: SEER and LexisNexis Residential Address Linkage") and demonstrated that mobility patterns vary by race/ethnicity, patient age at diagnosis, and geographic area – but that cancer patients demonstrate less mobility than the general population.

"Improving Precision of Do Not Contact Codes: Results of a Manual Review to Inform Coding and Case Contact Procedures" by Lawson-Michod *et al.* described the results of the University of Utah and the Utah Cancer Registry's efforts to manually review discrepancies in "Do Not Contact" (DNC) codes and improve appropriate inclusion/exclusion of cancer patients in research. It also allowed Utah to update DNC codes definitions, which could be applicable to other U.S. registries. Hernandez *et al.* describe efforts to integrate screening data into regular cancer surveillance in Florida using the Florida Breast and Cervical Cancer Early Detection Program data in "Integration of Cancer Screening Data into Routine Cancer Surveillance Systems: A Florida Pilot Project."

Researchers using CiNA data may be interested in "Determining Fitness for Use of SEER Cause-Specific Cause of Death in Analyses of Cause-Specific Survival" by Morawski *et al.*, which discusses cut-points that should be used to determine if a registry or other sub-population's data are sufficiently complete to be used in cause-specific cause of death analyses. "Current and Emerging Informatics Initiatives Impactful to Cancer Registries" by Rollison *et al.* describes areas of notable activity at the intersection of cancer surveillance and informatics, including 12 informatics projects with implications for cancer registries, as identified by NAACCR's Cancer Informatics Advisory Group (CIAG).

Finally, Ostrom *et al.* have published an updated description of clinically relevant groupings of brain and central nervous system (CNS) tumors for analysis in the NAACCR CiNA data, as well as by individual central cancer registry groups ("The Central Brain Tumor Registry of the United States Histopathological Grouping Scheme Provides Clinically Relevant Brain and Other Central Nervous System Categories for Cancer Registry Data"). In addition to the peer-reviewed article in this edition of JRM, the authors have provided a write up highlighting important points around the new grouping system, "Rethinking CNS Tumor Reporting: A Novel Histopathology Grouping for Brain and Other Central Nervous System Tumors," which can be found in this edition of the NAACCR Narrative.

This year's NAACCR JRM Special Edition also includes award winning posters from the June 2022 NAACCR Virtual Forum, "Participation Rates and Characteristics of Participants and Nonparticipants in Cancer Patient Contact Studies in New York State" by Gates Kuliszewski *et al.*, "Racial/Ethnic Disparities in COVID-19 Infection Among Working-Age Women

with Precancerous Cervical Lesion” by Hsieh et al., and “New Hampshire Childhood Cancer Survivor Study: A Qualitative Study” by Ricci *et al.*

NAACCR thanks the authors of these informative studies and looks forward to your submissions to next year’s NAACCR JRM Special Edition.

Rethinking CNS Tumor Reporting: A Novel Histopathology Grouping for Brain and Other Central Nervous System Tumors

Corey Neff

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Central Brain Tumor Registry of the United States

Brain and other central nervous system (CNS) tumors are a diverse collection of tumors comprising over 100 unique International Classification for Diseases, Oncology, 3rd edition (ICD-O-3) histopathology codes, yet they are often reported in local and national cancer statistics as a single category. Moreover, among brain and other CNS tumors, non-malignant neoplasms are rarely included in overall statistics describing the epidemiology of tumors of the brain and other CNS despite being more common and their collection being mandated since diagnosis year 2004.¹ In order to provide an accurate and comprehensive account of the burden of these tumors, the use of a clinically relevant histopathology grouping scheme is necessary. Starting in June 2023, a grouping developed by The Central Brain Tumor Registry of the United States (CBTRUS) will be available in NAACCR Cancer in North America (CiNA) datasets.

The Central Brain Tumor Registry of the United States (CBTRUS) was founded in 1992 to address this limitation.² The CBTRUS aggregates incident cancer cases from the Centers for Disease Control and Prevention’s (CDC) National Program of Cancer Registries (NPCR) program and the National Cancer Institute’s (NCI) Surveillance, Epidemiology and End Results (SEER) program yearly for use in annual reports and publications.³ Since its inception, the CBTRUS has regularly collaborated with neuropathologists to develop and maintain a clinically relevant histopathology grouping that accounts for the numerous unique histopathology codes used in the diagnosis of brain and other CNS tumors. This tumor grouping scheme, most recently updated in 2021 to align with the 2016 WHO Classification of Tumors of the CNS, groups all brain and other CNS tumors into 31 distinct histopathology groups irrespective of tumor behavior.⁴

There are several notable differences in the definition of brain and other CNS tumors between different reporting groups, which should be noted when using site-specific recodes. SEER, NAACCR, and NPCR define brain and other CNS tumors as tumors located in the brain, meninges, and other central nervous system tumors (ICD-O-3 site codes: C70.0-9, C71.0-9, and C72.0-9), with the exclusion of lymphoma and leukemia histopathologies (ICD-O-3 codes 9590-9989) occurring at those sites. CBTRUS includes the brain, meninges, other central nervous system tumors, pituitary, craniopharyngeal duct, and pineal gland (ICD-O-3 site codes: C70.0-9, C71.0-9, C72.0-9, C73.3-5), as well as olfactory tumors of the nasal cavity (ICD-O-3 site code: C30.0, ICD-O-3 histopathology codes 9522-9523 only) and lymphomas and leukemias occurring at brain and CNS sites. The inclusion of tumors of the pituitary, craniopharyngeal duct, and pineal gland, and primary central nervous system lymphoma as CNS tumors align with the WHO classification of central nervous system tumors, but their inclusion in a site-specific recode is unique to the CBTRUS grouping scheme. CBTRUS also includes all primary brain and other CNS tumors irrespective of behavior. Brain tumors with ICD-O-3 behavior codes /0 (benign) and /1 (borderline) are referred to as non-malignant brain tumors. Many reports using the term “brain tumor” or “brain cancer” may be restricted to malignant brain tumors only, despite these tumors representing only ~30% of primary brain tumors.³

To facilitate broader use of clinically relevant histopathology groupings for tumors of the brain and CNS by the cancer registry community, CBTRUS has worked with NAACCR to provide the CBTRUS histopathology recode within NAACCR *Cancer in North America* (CiNA) datasets, including CiNA Public Use Data. The CBTRUS grouping was evaluated against the existing SEER brain and other CNS grouping using the CiNA dataset. The results of this initial evaluation were promising, motivating NAACCR to include this recode in all further releases of the CiNA dataset beginning June 2023.⁵ As incidence, survival, and clinical features all vary significantly by histopathology for tumors of the brain and other CNS, the CBTRUS grouping delivers a more robust, clinically-driven representation of the burden of brain and other CNS tumors. We encourage the use of the CBTRUS variable not only for neuro-oncology research but across the whole cancer registry community for the production of more detailed, comprehensive, and clinically relevant cancer statistics.

A detailed description of the comparison between the CBTRUS and SEER brain and other CNS groupings can be found in the article by Ostrom *et al.*, “The Central Brain Tumor Registry of the United States Histopathological Grouping Scheme Provides Clinically Relevant Brain and other Central Nervous System Categories for Cancer Registry Data,” published in the 2023 Winter NAACCR Special Edition of the Journal of Registry Management, which may be found here:

<https://www.naacccr.org/jrm/>.

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College of American Pathologists (CAP) PERT Update

Mignon Dryden, CTR

NAACCR Liaison to CAP PERT

A joint meeting with CAP PERT and CAP Cancer Committees was held virtually as well as in-person in San Antonio, Texas on Saturday, February 4, and Sunday, February 5, 2023. Highlights of the joint sessions included:

- **Updates on the Biomarker Workgroup** which is working to seamlessly transfer cancer biomarker test results from a 3rd party reference lab electronically into structured CAP cancer synoptic biomarker reports. The reporting variation across reference laboratories and the data complexities present challenges. An initiative is underway to assess how the CAP electronic Cancer Protocols can provide a framework for direct mapping of this data coming from the reference labs into the corresponding CAP cancer biomarker synoptic report data elements using the Ckeys without an intermediary template. Meetings and discussions with several different reference laboratories and LIS vendors continue to take place regarding this project with the objective of developing a working prototype that will be shared with the Biomarker Workgroup to obtain feedback.

- Cancer Surveillance: How the Cancer Registry and CAP Intersect – Mildred Jones, CTR, NCRA Liaison to the Cancer Committee gave an excellent presentation describing the various types of cancer registries, the data collected, and the importance of the pathologist as the cornerstone of the patient’s diagnosis and treatment. She delved into the challenges faced by registrars with new and evolving therapies, tumor markers, diagnostic tests, and surgery techniques and the sheer volume of data elements collected by the different standard setters. She noted that NAACCR published 782 available fields effective 1/1/2023 and listed the number of required, derived, and supplemental or recommended fields per each standard setter. She ended her presentation with a look to the future with NLP (Natural Language Processing) and automation allowing registrars to focus on other aspects of data collection and she reiterated that cancer registrars rely on CAP templates and the pathology reports for complete and accurate data collection.
- 2023 Release (Updated March 22nd) – the following protocols were updated with some of these required for accreditation (marked with *)
 - **Thyroid** – reflects current WHO guidelines.*
 - **Breast Biomarker and Breast Invasive Resection** – includes notes for HER2neu Low Expression.
 - **Breast Invasive Biopsy** – reflects the size of largest invasive focus in the limited biopsy sample.
 - **Gynecologic Biomarker** – clarifies content elements.
 - **Ovary** – clarifies content, updates TNM modifiers, LVI visible text, and critical information in explanatory notes.*
 - **Cervix Resection and Excision** – includes content clarification, updates to LVI visible text, and TNM modifiers.*
 - **Stomach Resection** – includes changes to Histologic Grade Requirements.
 - **Adrenal Resection** – includes critical information in explanatory notes.
- TNM Classification Updates – Beginning with the final 2022 release, any protocol with TNM Classification will now receive modeling updates to these sections and changes will be rolled out over time as protocols receive other important updates. An example of this update is “Pathologic Stage Classification” section will be renamed to “pTNM Classification” to better clarify that the final pathologic staging should only be performed by the managing physician.
- Other updates and all the CAP Cancer Protocols can be found on the CAP Website. ([Cancer Protocol Templates | College of American Pathologists \(cap.org\)](https://www.cap.org/Cancer-Protocol-Templates))

Iowa Cancer Registry celebrates 50 years with special anniversary report

Sarah Nash

Jan Krev

Iowa Cancer Registry

The Iowa Cancer Registry releases an annual report projecting the numbers of new cancer cases and cancer deaths among Iowans estimated from data that includes death certificate figures provided by the Iowa Department of Health and Human Services. Many of you have received an electronic version of this report through the NAACCR listserv or have received a hard copy of this report! As an original SEER-9 registry, we are celebrating our 50th Anniversary and focused [this year’s report](#) on the trends in cancer that we’ve recorded since 1973.

The report highlights successes and opportunities to reduce the burden of cancer through cancer prevention and control efforts employed by public health partners and the citizens of Iowa. We’ve had many achievements; for example, cancer mortality has decreased over time, due to decreased smoking, increased cancer screening and advances in treatment. We provided a timeline of the last fifty years of cancer surveillance, control, and prevention, in which we highlight the 2007 increase to the Iowa state cigarette tax from \$0.36 to \$1.36. This tax increase contributed to decreasing our cancer

mortality, as we observe in recent lung cancer mortality trends. Yet, while lung cancer screening is now widely available across Iowa for people ages 50-80 years with a 20 pack-year or greater smoking history, prevalence of screening is still low (as we reported in our [2022 report](#), which focused on screening). Studies indicate detecting lung cancer at earlier stages can lead to improved survival, which is why increasing lung cancer screening prevalence will be critical to decreasing the burden of this disease among Iowans. We've also seen increases in cancer survival over the last 50 years: in the 70s, less than 75% of people diagnosed with invasive breast and prostate cancer survived at least five years (Figure 1). Today, over 90% survive at least five years. Improvement in breast cancer survival is attributable to screening with mammograms to detect cancer at an earlier stage, as well as advances in treatment. Improvement in prostate cancer survival is largely due to advancements in treatment.

There is still work to be done to reduce the burden of cancer for Iowans. This year's report also highlighted many challenges we still face; key among these, Iowa has the second highest overall cancer incidence in the U.S. Alarmingly, Iowa is the only state with a statistically significant increase in cancer incidence from 2015-2019. There are also several cancer sites where Iowa ranks among the highest among states. For example, Iowa ranks first among all 50 states for rates of new cases of oral cavity and pharyngeal cancer, the biggest risk factors for which are persistent HPV infections, tobacco, and alcohol use. Iowa also ranks in the top five for leukemia and melanoma. Our high incidence of leukemia may be linked to our important role as an agricultural powerhouse, as pesticide exposure may increase risk of both childhood and adult leukemia. Most cases of melanoma can be prevented by reducing sun exposure, using sunscreen and avoiding tanning beds. We also have cancer disparities that need to be addressed (as we detailed in our [2021 report](#), and revisit this year): Iowa has the second highest cancer incidence rate and the third highest cancer mortality rate for all cancers combined in our Black population. Iowa also has one of the greatest differences between the rate of cancer deaths between Black and white people. Addressing inequities, particularly those that result in prostate, breast and uterine cancer disparities, is critically important and is a focus of University of Iowa researchers, in collaboration with the Iowa Cancer Registry.

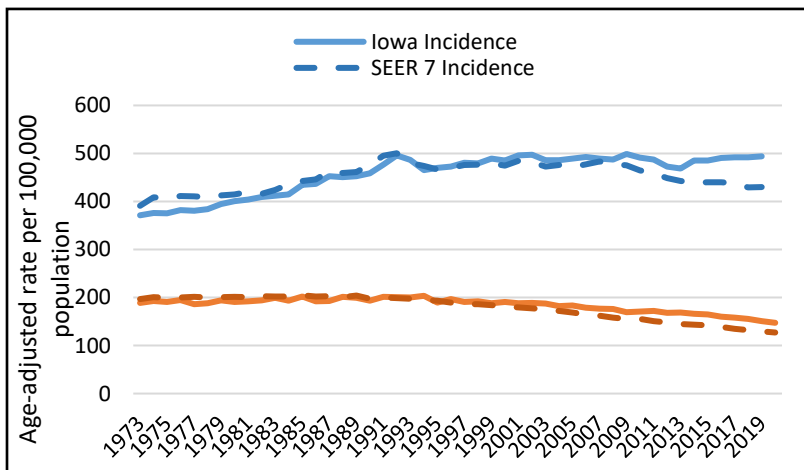
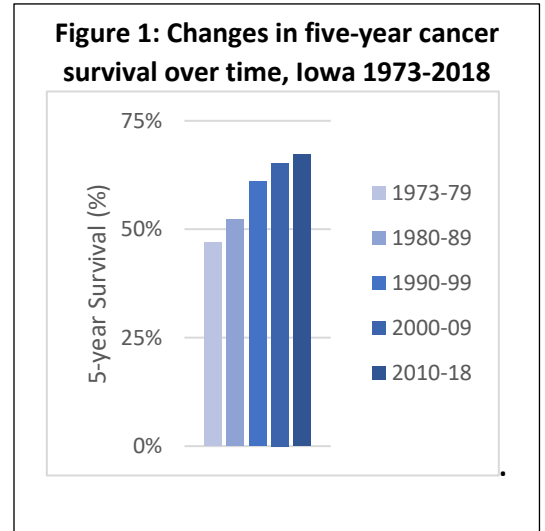


Figure 2. Cancer incidence and mortality rates comparing Iowa to the U.S., 1973-2019

*Iowa is excluded from the SEER 9 analyses; as is Detroit, which is no longer part of the SEER Program

This year's report has generated a lot of [public and media interest](#), which may be due to our 50th Anniversary or more likely because of the surprising findings about our cancer incidence rates and an urgency to act as a result. Whatever the reason, we see the report as both a public service to the citizens and state of Iowa – it is our responsibility as stewards of the cancer surveillance data we all collect to use it to improve the public's health – as well as an opportunity to share the good work that our registry staff do towards that end. After all, we remember that each data point we collect represents a person, and the story of their cancer journey. We hope that you all also enjoy reading the report and look forward to chatting with you at NAACCR 2023 in New Orleans about how you share your surveillance data with your communities.

Help the NAACCR Walkers raise funds to fight cancer



For many years, a group of dedicated NAACCR members have participated in marathons to raise money for the Jimmy Fund Walk. This year they were back in person at the Boston Marathon. The members include Jane Braun, Amy Kahn, Susan Capron, Annette Hurlbut, Susan Gershman, Cynthia Boudreau Canister, and Nancy Weiss. This year they walked in memory of their beloved friend and fellow walker, Frances Ross. To read more about this group of walkers and their mission, see their team page at: [2023 Boston Marathon Jimmy Fund Walk: NAACCR Walkers's Fundraising Page – Boston Marathon Jimmy Fund Walk.](#)



Recognize a colleague with a NAACCR Board Resolution

Reminder: If you would like to recognize an outstanding long-term member of your staff, consider nominating them for a Board Resolution. We will prepare a certificate to be presented to the individual and will post the resolution on our website. Please include some career highlights in your nomination and submit via email to mthornton@naaccr.org.

View past Board Resolutions: <https://www.naaccr.org/board-resolutions/>.

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