Hello from smokin’ hot Boise, Idaho! We just concluded a stretch of over 100-degree days which I am hopeful are over for the year. And the gift of 2020 keeps on giving – COVID hot-spots aside, Boise is still experiencing aftershocks from the 6.5 magnitude earthquake Idaho experienced in March. The original quake and this latest aftershock have permanently altered the peaks of the Sawtooth mountains. Thankfully, there were no reported injuries.

All the forces of 2020 have not deterred NAACCR from continuing its work. First, I would like to congratulate our new Board members who officially took office in June! Winny Roshala will serve as President-Elect and we have two newly elected Representatives at Large: Monique Hernandez from Florida Cancer Data System and Mary Jane King from Cancer Care Ontario; Angela Meisner from New Mexico Tumor Registry was re-elected. The continuing Board members are Maria Schymura (NY), Treasurer; Isaac Hands (KY), Rep at Large; Lorraine Shack (AB, Canada), and Kevin Ward, Rep at Large (GA). Lori Swain from NCRA seamlessly transitioned from her elected position as Sponsoring Member Organization Representative to an Advisory Board Member per our newly adopted bylaws. For our next round of elections, please consider running for the Board. We have a newly formed Nominating Committee — April Austin (NY), Chair; Deb Hurley (SC); and Kim Vriends (PEI, Canada) — who may be reaching out to you!

I trust most of you were able to attend the virtual annual conference in June. We had record attendance from many countries and from audiences we do not ordinarily reach. We were thrilled to receive overwhelmingly positive feedback. I’m sure we all prefer to meet in person, but June was an incredible success under the circumstances. Plans are just beginning for the annual conference in Palm Springs next year – what it will finally look like is anyone’s guess at this point but rest assured, NAACCR will find a way to bring you the highest quality content possible.
Finally, NAACCR forges ahead with developing a new Strategic Management Plan (SMP) covering 2021-2026. I hope each of you had the opportunity to complete the SMP survey – your feedback is important to us as we develop the new strategic plan which will guide our organization over the next five years. If you did not have the opportunity to complete the survey and you have some thoughts to share about the future direction of NAACCR, please feel free to reach out to me directly and I can share them with the Strategic Management Plan Work Group.

Until the next NAACCR Narrative, I wish all of you continued health and safety and smooth sailing especially as we move into data submission season. As we navigate the last four months of the year, I leave you with something I heard recently — “I’m going to stay up on New Year’s Eve, not to ring in the new year, but to make sure this one leaves!”

2020 NAACCR Virtual Annual Conference
Summer 2020 NAACCR Narrative

Stephanie M. Hill, MPH, CTR
Associate Director
shill@naaccr.org

During a year of unpredictable turns and unprecedented firsts, the cancer surveillance community came together at the first-ever virtual NAACCR Annual Conference. While we were all disappointed to not convene in Philadelphia as planned, the live virtual plenary sessions and the ongoing presentation of concurrent session topics at NAACCR talks have allowed us to reach a broader, more diverse audience than ever before. More than 2,000 people from around the world attended the virtual plenary sessions held on June 23 – 25, many of them hospital registry staff for whom this was their first NAACCR Conference experience.

The feedback we have received from the conference evaluations has been overwhelmingly positive, with more than 95% of attendees “satisfied” or “very satisfied” by the virtual experience, and all 19 plenary speakers rated 5/5 for quality of content.

NAACCR would like to thank the plenary speakers who so smoothly and willingly transitioned their presentations to the virtual format and who made the conference an engaging and educational event; the 2020 NAACCR Annual Conference Program Committee, co-chaired by Nan Stroup and Wendy Aldinger, for all of the hard work they put into planning the agenda and recruiting speakers; the NAACCR community for their patience and support over these tumultuous few months; and, most of all, the more than 2,000 attendees who took the time out of their busy schedules to turn out for the virtual sessions!
Recordings of all virtual plenary sessions as well as posters are available on the NAACCR web site. For a schedule of NAACCR Talks covering additional topics from the annual conference, please visit https://education.naaccr.org/upcomingevents.

NAACCR Awards Press Release
Summer 2020 NAACCR Narrative

The North American Association of Cancer Registries Bestows Prestigious Awards

Annually the North American Association of Central Cancer Registries recognizes members and volunteers who have made significant contributions to the field of cancer surveillance. The Calum S. Muir and the Constance Percy awards recognize individuals who have made significant contributions to the field, while the NAACCR Member Recognition Awards recognize members who have contributed in many ways to the mission of NAACCR. Poster Awards are given each year at the Annual Conference in two categories: Data Collection and Operations and Data Use and Epidemiology. All posters may be viewed online at (https://www.naaccr2020.org/posters). Awards were also given to students who presented their work in a special webinar setting this year. Congratulations to all those who were recognized by NAACCR with these awards.

Calum S. Muir Award
Chuck Wiggins, PhD

The Calum S. Muir Award is to honor someone who has made substantive and outstanding contributions in cancer registration. Preference is for the recipient to be an active member of NAACCR with a long term commitment to the organization. The award is bestowed each year at the annual conference.

Chuck serves as a keen mentor to those new (and old!) to the field of cancer surveillance, and has a long history of teaching, both at UNM, as well as the Summer Research Training Institute for American Indian and Alaska Native Health Professionals in Portland, Oregon. He has a long-held interest in cancer among underserved populations, and is an outspoken advocate for American Indian and Alaska Native peoples. In his research, he has worked extensively to characterize and address cancer burden among indigenous peoples, particularly in the southwest, but also to address methodological challenges that keep us from understanding these issues nationally. In collaboration with Dr. David Espey at the CDC, Dr. Wiggins pioneered the now-regular practice of linking cancer registries to the Indian Health Service to reduce racial misclassification. He is also highly engaged in and skilled at sharing cancer registry data with non-scientists, which he practices through his extensive community engagement work in New Mexico and beyond. Finally, he has a long history of service to the NAACCR community in various roles, culminating in the presidency from 2015-2017. He currently serves as one of the North American representatives to the International Association for Cancer Research. Over the course of his career, Dr. Wiggins has coauthored over 110 publications using cancer registry data, supporting a wide range of investigators and mentees to use registry data in a variety of creative and informative ways.
The Constance L. Percy Award for Distinguished Service has been established to recognize an individual who contributed exceptional volunteer service to NAACCR during the past 12 months, or sustained, current, and long-term contributions to the organization.

Annelie Landgren, MPH, PMP

Martha Linet, MD, MPH

During their time with the Radiation Epidemiology Branch of NCI’s Division of Cancer Epidemiology and Genetics, both Dr. Linet and Ms. Landgren generously engaged in feasibility testing of the Virtual Pooled Registry (VPR) concepts and provided thoughtful input that has led to significant enhancements to the current VPR Cancer Linkage System.

As the PI for the long-standing U.S. Radiologic Technologist (USRT) study with decreasing survey response rates, Dr. Linet volunteered to have the USRT cohort data linked with 45 registries as part of the VPR feasibility testing. These linkages resulted in 24,235 matched cases and hinted at the potential for increasing cancer case ascertainment among the USRT cohort. So impressed with the outcome, Dr. Linet identified Ms. Landgren to spearhead the process of individually applying to all 45 registries for approval to release data on the matched cases. Together, they determined key pieces of information to track throughout the process as a way to assess the benefits of registry linkage.

During this 3-year commitment that eventually resulted in receipt of data from 43 registries, Ms. Landgren diligently captured detailed information on the application, data release, and continuing review process, as well as the time and cost associated with such activities. Ms. Landgren shared her knowledge with a various VPR workgroups, including the technical group responsible for designing the VPR system for to streamline the application and tracking process across multiple registries. Ms. Landgren’s insight greatly contributed to a more comprehensive and user-friendly product.

After receipt of the data, Dr. Linet identified a skilled statistician to assess cancer incidence ascertainment by population-based cancer registries versus self-report and death certificates in the USRT cohort. This large-scale analysis confirmed the value of linking with U.S. cancer registries to comprehensively ascertain cancer incidence, thereby lending support for creation of the VPR.

NAACCR Recognition Awards

Established in 2004, the NAACCR Member Recognition Award Series is designed to acknowledge the contributions of all of our dedicated volunteers. Without the support of volunteers across North America, we would not be able to achieve our mission and goals for cancer surveillance and the reduction of the burden of cancer. Active members earn points for various activities and awards are given once a member reaches a specified point level.
The Merit Award is awarded after an individual has earned 100 member points.

The Achievement Award is awarded to an individual who has earned 200 total member points.

The Leadership Award is presented to a member who has earned a total of 300 member points.

Merit Awards:
Fran Maguire
Sarah Nash
Angela Meisner

Leadership Awards:
Baozhen Qiao, PhD
Jennifer Ruhl, MSHCA, RHIT, CCT, CTR

2020 NAACCR Poster and Oral Submission Awards

Student Oral Presentation Awards
1st Place:
Uriel Kim, Case Western Reserve University
Describing and Assessing a New Method of Approximating Individual-Level Income in Cancer Registries

2nd Place:
Janet Chu, University of California, San Francisco
Evaluating the impact of social and built environments on health-related quality of life among cancer survivors

Data Collection & Operations Poster Award
1st Place:
Tongyang Liu, ICF International; Xing Dong; Yuan Ren, ICF International Inc.; Kevin Zhang, ICF; Olga Galin, ICF International; Reda Wilson, Centers for Disease Control and Prevention
Using Python and SAS to Efficiently Process Cancer Incidence Data in NAACCR XML Format
2nd Place:

Kevin Zhang, ICF; Shailendra Bhavsar, ICF; Yuan Ren, ICF International Inc.; Jon Stanger, ICF; Jing Guo, ICF; Reda Wilson, Centers for Disease Control and Prevention; Manxia Wu, Centers for Disease Control and Prevention; Mary Elizabeth O'Neil, Centers for Disease Control and Prevention

*Modernizing Cancer Surveillance through an On-line Tracking System: Development of Data Monitoring System for the National Program of Cancer Registries*

Data Use & Epidemiology Poster Award

1st Place:

Baozhen Qiao, New York State Cancer Registry; Maria Schymura, New York State Cancer Registry; April Austin, New York State Cancer Registry; Amy Kahn, New York State Cancer Registry

*Identifying risk factors associated with subsequent breast cancer diagnosis among breast cancer survivors in New York State*

2nd Place:

Renata Abrahao, University of California, Davis Division of Hematology/Oncology

*Late effects following non-Hodgkin lymphoma in HIV-uninfected and HIV-Infected adolescents and young adults: a population-based study*

3rd Place:

Feng Guo, German Cancer Research Center

*Use of Polygenic Risk Scores to Select Screening Intervals After Negative Findings From Colonoscopy*

Highlights from the Program Manager of Standards

Summer 2020 NAACCR Narrative

Lori Havener, CTR
NAACCR Program Manager of Standards
lhavener@naaccr.org
Data Standards and Data Dictionary, Volume II, Version 21:
The cancer surveillance community is diligently working towards timely releases of the various products for 2021 implementation. NAACCR ListServ announcements will be sent out as the products are released.

NAACCR Data Standards and Data Dictionary (Volume II) Version 22 Implementation Timeline
It may seem early to be thinking about version 22 but the deadline to submit requests for new data items is quickly approaching, see v22 timeline below.

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<th>Activity</th>
<th>NAACCR Deadlines</th>
<th>Considerations/suggestions to meet NAACCR deadlines</th>
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| Proposed requests-for-change for new data items requiring field testing  | July 1, 2020      | • Complete request-for-change forms and submit to the MLTG by July 1, 2020<br>  
• Data items approved by MLTG will be sent to UDS for preliminary review<br>  
• Standard setters should have plans to conduct field testing within the timeframe required for final approval |
| Field testing initiated                                                  | September 3, 2020 | • For items that require field testing, testing to be initiated by September 1, 2020  
• Testing of newly proposed SSDI data items and “yc” data items and concept  
• NCI with support from IMS and NCRA will facilitate testing  
• All Standard Setters invited to participate |
| Proposed requests-for-change for changes to existing data items that do  | October 1, 2020   | • Complete request-for-change forms for changes to existing data items that do not require field testing and submit to the MLTG by October 1, 2020.  
• MLTG may elect to require field test  
• Note: MLTG to develop a request-to-change form for items that do not require field testing |
<p>| not require field testing submitted to MLTG for final review. *         |                   |                                                                                                                    |
| MLTG informs HLSG of all requests for change received from standard setters | December 31, 2020 | • HLSG to be informed at the group 4th quarter meeting (Oct-Dec 2020) on all changes under consideration |</p>
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| MLTG transmits new proposed standards to UDS WG for final review and approval | January 1, 2021  | • This will ensure HLSG can initiate dialog with standard setters, ask technical questions as deemed necessary  
• UDS will not consider standards received after January 1, 2021, for NAACCR volume II version 22  
• UDS will review all information provided by the standard setter, and may require additional information as necessary  
• UDS will review all information (including available field-testing results) provided by the standard setter. However, UDS will not require final report from field testing |
| UDS WG Transmits new data standards to MLTG                               | April 1, 2021    | • No standards submitted for MLTG evaluation and HLSG approval will be assessed after April 1 deadline.  
• MLTG evaluates information received from UDS and final feasibility testing results from standard setters, makes recommendation to HLSG  
• HLSG approves/rejects new data standards |
| HLSG/MLTG transmits new standards approved for implementation to UDS      | May 1, 2021      | • UDS updates NAACCR Volume II Standards according to new standards approved by HLSG  
• Under request from HLSG/MLTG, UDS may implement additional adjustments and corrections to new standards  
• MLTG to ensure that the standard setter provides a set of proposed edits to accompany the new approved data items; edits transmitted to the NAACCR Edits group |
| Convene NAACCR 2022 Implementation Guidelines Task Force                | May 1, 2021      | • Materials for the Data Standards and Data Dictionary must be in final format for the Task Force to develop the implementation guidelines.  
• Final versions of mapping and/or conversions. |
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</table>
| UDS submits NAACCR Standards for Cancer Registries Volume II, Version 22 to NAACCR Board for review/approval | June 1, 2021 | • UDS final review/approval at their May meeting.  
• MLTG recommends that UDS plans two meetings for May 2021 to ensure that all changes approved by HLSG for implementation will be included in the NAACCR Standards for Cancer Registries Volume II by June 1, 2021, deadline. |
| NAACCR Standards for Cancer Registries Volume II, Version 212 Released | July 1, 2021 |  |
| NAACCR 2022 Implementation Guidelines Released | August 1, 2021 |  |
| EDITS metafile release | August 1, 2021 | • EDITS Work Group will have begun development of edits metafile by April 2021. |
| Education and training | Ongoing as material becomes available | • Develop training materials by October 1, 2021, and provide adequate training opportunities before January 1, 2022. |
| NAACCR Standards for Cancer Registries Volume II, Version 22 effective date | January 1, 2022 |  |

**NAACCR Research and Data Use Update**

Summer 2020 NAACCR Narrative

*Recinda Sherman, MPH, PhD, CTR*

**NAACCR Program Manager of Data Use and Research**

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

**Research & Data Use**

Hindsight is 20/20 is an astute proverb, but perhaps it needs updating to reflect that many of us will be grateful to see 2020 in hindsight. But despite current excessive heat warnings and a recent fire tornado
out here in California, and the fact that we are bracing for the onslaught of political ads that come with an election year in the US (not to mention that pesky pandemic), we all are still chugging along like the public health rocks stars we are.

Some of the work we are chugging along with on the national-level is familiar to the cancer registries because registries actively participate. For instance, the Camp Lejeune Cancer Incidence Study is well underway with many US registries already complete with the cohort linkage. But cancer registry data also support efforts which do not require direct registry participation, including the projects for which we ask consent to include registry data at the time of our Call for Data. For example, the American Cancer Society Facts & Figures publications have been produced for decades and more recently the American Lung Association uses CiNA data for the cancer incidence section of their annual State of Lung Cancer Report. And there is of course the Annual Report to the Nation. But I would like to highlight a study some registries may be less familiar with, the Medullary Thyroid Cancer (MTC) Study.

We have a long-term collaboration with United BioSource to support post market surveillance to evaluate the potential of GLP-1 agonists, drugs used to treat Type-2 diabetes, to increase the risk of MTC. MTC is a rare type of thyroid cancer that arises from the C cells of the thyroid gland (cells which make the hormone calcitonin). The more common types of thyroid cancers arise from the follicular cells (cells with make the thyroid hormones T4 and T3). GLP-1 agonists are drugs that mimic glucagon-like peptide 1 (GLP-1), a hormone that enhances insulin secretion; thereby reducing blood glucose levels. These drugs have been effective in treating diabetes, but, in rodent studies, long-term exposure to stimulating the GLP-1 receptor has been associated with MTC. Because diabetes is a significant public health problem with an estimated 10% of the US population diabetic, the FDA has approved the use of the drugs because they are an important tool for treating diabetes. However, the FDA has also required a post-market study to properly evaluate the potential risk of MTC. And our registry data is an integral part of that surveillance. Additional information on the study is available here.

Geocoder Update
In July, we released a new version of the NAACCR Geocoder. From a registry user perspective, the upgrade to this new version likely went unnoticed. But there was a great deal of backend improvements made to this version which results in increased reliability and speed. This version also fixed a few known bugs and increased security based on recommendations from a recent, rigorous security vulnerability test.

Call for Data
The December 2020 CFD due date is on schedule for Tuesday, December 1, 2020. Our annual CFD webinar will be Wednesday September 16 at 2pm EST. And the CFD website is “under construction” now, but will be complete before the webinar: https://www.naaccr.org/call-for-data/. In the meantime, users can still log in to the CFD site (via the Submit Tab) and access their data assessment reports, view the new Data Visualization tool for their data, and submit any updates or changes to the CaRRI database.
**NAACCR Talks**

While our on-line version of the NAACCR Annual Conference was presented in June, we still have some Annual Conference programming coming up. We were able to present eight (8) concurrent sessions as NAACCR Talks. Look for the ListServ once registration is open but here is the list, and you can get the heads up from our education calendar of events:


As always, if you have any questions or concerns, please contact me at [rsherman@naaccr.org](mailto:rsherman@naaccr.org).

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**NAACCR Education and Training Program Update**

**Summer 2020 NAACCR Narrative**

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

Have you seen the NAACCR Education and Training Calendar lately? It looks like it is going to burst!

The NAACCR Education and Training Calendar is located on the Upcoming Events page. Here you will find dates for all of the upcoming NAACCR Talks, CTR Prep and Review, and monthly webinars. See Upcoming Events at [https://education.naaccr.org/](https://education.naaccr.org/).

**NAACCR Talks**

NAACCR Talks are free webinars targeting central registry and cancer surveillance professionals. We have more NAACCR talks schedules over the next three months than we’ve ever had in a three months’ time span! Many of the NAACCR Talks presented during this time are based on topics that would have been presented during breakout sessions at the NAACCR Annual Conference. Topics range from Coding the Grade data items, the Virtual Pooled Registry, to a two-part series on Social Determinants of Health. You can see them all at [https://education.naaccr.org/upcomingevents](https://education.naaccr.org/upcomingevents).

In addition to the topics already on the calendar we plan on hosting webinars on Changes to SSDIs for 2020 and a webinar on ICD-O 3.2 and changes to the Solid Tumor Rules. Both webinars will be presented before the end of the year.
**NAACCR Webinar Series**

Subscriptions are now available for NAACCR 2020-2021 Webinar Series! We have another exciting line-up of topics presented by professional trainers at the top of their game! For more information or to subscribe see the NAACCR 2020-2021 Webinar Series page at [https://education.naaccr.org/2020-2021-webinar-series](https://education.naaccr.org/2020-2021-webinar-series).

### 2020-2021 Webinars at a Glance

- Prostate 2020 10/01/20
- Lung 2020 11/05/20
- Thyroid 2020 12/03/20
- Treatment 2021 1/07/21
- Lymphoma 2021 2/4/21
- Abstracting and Coding Boot Camp 2021 3/04/21
- Larynx 2021 4/01/21
- Pancreas, 2021 5/06/21
- Kidney 2021 6/17/21
- Quality in CoC Accreditation 7/08/21
- Breast 2021 8/05/21
- Coding Pitfalls 2021 9/02/21
- Click for [Full Webinar Description](#)

**NAACCR CTR Prep and Review**

Session 1 of the NAACCR CTR Prep and Review starts September 1, 2020. We’ll meet 8 times to go over various topics covered on the CTR Exam. For more information or to register see [https://education.naaccr.org/ctr](https://education.naaccr.org/ctr).

**NAACCR 2020 Virtual Conference**

Did you participate in the NAACCR Conference this last June? If not, or if you would like to view a few of the sessions again, the recordings are available free of charge at: [https://education.naaccr.org/products/naaccr-2020-virtual-conference-june-23-june-25](https://education.naaccr.org/products/naaccr-2020-virtual-conference-june-23-june-25).

*Recordings of all NAACCR Talks can be found at: [https://education.naaccr.org/freewebinars](https://education.naaccr.org/freewebinars).*

As always, if you have any questions about the plethora of NAACCR Education and Training products don’t hesitate to contact [Jim Hofferkamp](mailto:) or [Angela Martin](mailto:).
NAACCR 2020 Education and Training Calendar
Summer 2020 NAACCR Narrative

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

Upcoming Webinar Presentations

August 2020
08/26/2020  Grade Review and Updates Webinar
08/28/2020  Revised Common Rule Webinar

September 2020
09/01/2020  NAACCR CTR Exam Prep & Review Webinar Series Session 1
09/02/2020  NAACCR Talk: The Virtual Pooled Registry…and Beyond!
09/03/2020  NAACCR Webinar Series: Coding Pitfalls
09/08/2020  NAACCR CTR Exam Prep & Review Webinar Series Session 2
09/09/2020  Utility, Strengths, and Limitations of Cancer Registry Data for Firefighter Cancer Research Webinar
09/10/2020  NAACCR CTR Exam Prep & Review Webinar Series Session 3
09/15/2020  NAACCR CTR Exam Prep & Review Webinar Series Session 4
09/16/2020  NAACCR Call for Data Webinar
09/24/2020  NAACCR CTR Exam Prep & Review Webinar Series Session 5
09/29/2020  NAACCR CTR Exam Prep & Review Webinar Series Session 6
09/30/2020  Operations to Enhance Data Use & Research Webinar

October 2020
10/01/2020  NAACCR Webinar Prostate 2020
10/06/2020  NAACCR CTR Exam Prep & Review Webinar Series Session 7
10/07/2020  Focus on Survival Webinar
10/08/2020  NAACCR CTR Exam Prep & Review Webinar Series Session 8
Happy Summer Everyone! Hope you are all finding time to relax and enjoy! It’s been a warm one here in New Hampshire and we are looking forward to a little beach vacation before navigating the upcoming school year. Progress continues on the VPR-CLS, with the below activities taking center stage over the next few weeks.

**Recruitment for new VPR participating registries**

We are excited that a number of additional registries have already signed on to join the VPR-CLS and participate in upcoming linkage studies. This will bring the total number of participating registries up to 45! For many registries, funding will be available from the NCI (via NAACCR) to support your participation in 3-4 linkage studies over the coming year, including the newly initiated National Childhood Cancer Registry (NCCR). Through our VPR pilot testing with the initial 38 registries, we have worked out the kinks so the linkage and data request process is really quite easy, and funding will be made available through a simple and straightforward mechanism. If there are additional registries who wish to join the VPR-CLS, please reach out to me (cclerkin@naaccr.org)!

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**Virtual Pooled Registry Update**

*Summer 2020 NAACCR Narrative*

*Castine Clerkin, MS, CTR*

NAACCR Program Manager of Virtual Pooled Registry
cclerkin@naaccr.org

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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](https://education.naaccr.org/upcomingevents) or contact Angela Martin (amartin@naaccr.org)
**Templated Data Use Agreement**

As mentioned in the last newsletter, the NAACCR Templated DUA Task Force has spent the past year spearheading development of a Templated DUA. Designed to minimize the volume and complexity of DUAs across registries involved in VPR linkage studies, the Templated DUA incorporates key elements from registry DUAs and builds on the foundation provided by the well-vetted Federal Demonstration Partnership Data Transfer and Use Agreement: [http://thefdp.org/default/committees/research-compliance/data-stewardship/](http://thefdp.org/default/committees/research-compliance/data-stewardship/), which has been adopted by many universities. The Templated DUA will be finalized very soon and then vetted with registries and their legal teams for feedback this month.

**Webinar of VPR Concurrent Session**

In the absence of the 2020 NAACCR Annual Conference, the planned VPR Concurrent Session will be presented as a NAACCR Talk on Wednesday, September 2, from 2-3:30. A NAACCR ListServ to register for the webinar was sent out on August 11. Presentation content includes the following VPR-related topics:

- *Where are we now? Virtual Pooled Registry Cancer Linkage System pilot testing progress.*
- *Making the VPR Work: How registries adapted their review/approval process to support VPR minimal risk linkage studies and use of the Templated IRB/Registry Application.*
- *Towards a new paradigm in data sharing: A pilot study of remote access to cancer registry data.*

All the best!

Castine Clerkin, NAACCR VPR Program Manager

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**Steering Committee Corner**

**Summer 2020 NAACCR Narrative**

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

News to share with the NAACCR Community:

- If you have work to promote or information you would like shared with the NAACCR membership, please don’t hesitate in contacting the Communications Steering Committee Chair at nan.stroup@rutgers.edu

Professional Development Steering Committee (PDSC)
Co-Chairs: Carrie Bateman and Andrea Sipin-Baliwas

Committee Highlights since last Narrative:

- Andrea Sipin-Baliwas and Carrie Bateman began chairing the committee in July with the help of Mignon Dryden.
- Identified new objectives to include in our strategic management plan. A selection of those objectives are below.
  - Work with other interested organizations to develop a university-level CTR curriculum.
  - Work with other Steering Committees to develop Researcher Toolkit on how to use our data.
  - Build an IT/Informatics Toolkit.

If you are interested in working with Professional Development on these important projects or would like more information, please contact Andrea Sipin-Baliwas (asipin@usc.edu) or Carrie Bateman (carrie.bateman@hsc.utah.edu).

Recent Reports/Publications:

- Cancer Registrar Training Guide added to the Recruitment and Retention Toolkit under Grow your Own CTR. [https://www.naaccr.org/recruitment-retention-toolkit/](https://www.naaccr.org/recruitment-retention-toolkit/)

Training/Education:

- Corpus Uteri 2020 will be on 8/6/2020
- Revised Common Rule will be 8/14 and 8/28/2020
- Grade coding webinar will be 8/26/2020
- Virtual Pooled Registry...and Beyond will be 9/2/2020*
- Coding Pitfalls will be on 9/3/2020*
- 9/11 Firefighters will be on 9/9/2020*
- Call for Data will be on 9/16/2020
- Prostate 2020 will be on 10/1/52020
- Focus on Survival will be on 10/7/2020*
- Social Determinants will be on 10/21 and 10/28/2020*
- Focus on Brain Tumors 11/4/2020*
- Lung 2020 will be on 11/5/2020
- Advanced Data Collection 11/11/2020*
- Thyroid 2020 will be on 12/3/2020

*would have been breakout sessions at the NAACCR Conference in Philadelphia
Other News to share with the NAACCR Community’ PAN interests:

- If you are interested in working with Professional Development on these important projects or would like more information, please contact Andrea Sipin-Baliwas (asipin@usc.edu) or Carrie Bateman (carrie.bateman@hsc.utah.edu).

Research and Data Use Steering Committee (RDUSC)

Co-Chairs: Sarah Nash and Jeff Dowden

Committee Highlights since last Narrative:

- The Committee welcomed a new Co-chair: Jeff Dowden, clinical epidemiologist, Newfoundland Cancer Registry.
- Sarah Nash and Recinda Sherman provided a PowerPoint presentation on the “Impacts of the 2020 Census Differential Privacy Procedures on Cancer Surveillance” to the NAACCR Board of Directors.
- RDU Committee members will provide reviewer support for the NAACCR coordinating of the Journal of Registry Management Fall 2020 edition.
- Mentoring/Networking Initiative in process for researchers wishing to use CiNA data but unfamiliar with cancer surveillance data.
- Hannah Weir will be coordinating a rare cancers workgroup. If you are interested in joining, contact Hannah at hbw4@cdc.gov

Training/Education:

Virtual Pooled Registry...and Beyond! Wednesday, September 2, 2020, at 2:00pm EST

Utility, Strengths, and Limitations of Cancer Registry Data for Firefighter Cancer Research Wednesday, September 9, 2020, at 2:00pm EST

Operations to Enhance Data Use & Research, Wednesday September 30 at 2pm EST

Focus on Survival, Wednesday October 7, 2020, at 2pm EST

Social Determinants of Health Sessions Part 1, October 21, 2020, at 2pm EST

Social Determinants of Health Sessions Part II, October 28, 2020, at 2pm EST

Focus on Brain Tumors, Wednesday November 4, 2020, at 2pm EST

Advanced Data Collection, Wednesday November 11, 2020, at 2pm EST

Standardization and Registry Development Steering Committee (SRDSC)

Co-Chairs: Lori Koch and Wendy Aldinger

Committee Highlights since last Narrative:

- Distributed the third 2018 Readiness Survey to all central registries and currently tabulating and analyzing results for distribution. Preliminary results were shared with S&RD Steering Committee members, the Mid-Level Tactical Group and the High-Level Strategic Group.

Convened a new task force to determine case ownership for cases identified in more than one state. The task force has met and is finalizing the task force charter and work plan.

S&RD co-chairs represented NAACCR on the Mid-Level Tactical Group.

**Training/Education:**

If you’re interested in volunteering to serve on this task force or want more information about the task force, please send an email to either Winny Roshala at WRoshala@erge-cancer.org or Lori Koch at Lori.Koch@Illinois.gov.


**Susan T. Gershan**  
Massachusetts Cancer Registry

**NCRA-NAACCR Liaisons**  
Summer 2020 NAACCR Narrative

Partnerships provide organizations opportunities to share their voice.

NAACCR and NCRA have had a long history of partnering on all things related to registrars and education. Here are two ways that we continue to keep the lines of communication open:

NAACCR Liaison to NCRA Board of Directors

Heather Stabinsky, MS.Ed, CTR, was appointed in June 2020 to serve a 2-year term as a NAACCR Liaison to the NCRA Board of Directors. In this volunteer position, Ms. Stabinsky serves as the contact for NCRA membership regarding NAACCR issues, refers NCRA Board questions or concerns to NAACCR, and advocates on behalf of NCRA members to NAACCR. Ms. Stabinsky currently serves on the NAACCR 2021 Implementation Guidelines Task Force and the NAACCR Uniform Data Standards (UDS) Work Group. She is a senior supervisor at the New Jersey State Cancer Registry and is New Jersey’s Education and Training Coordinator. When asked what she hopes to bring to the table or accomplish in her new role, Ms. Stabinsky stated, “The advancement of cancer registry data has never been more
important to researchers and medical professionals. My goal is to provide a necessary link between standard setters and NCRA members to continue building a common understanding and a trust between cancer registrars and the groups that establish our guidelines.”

Advisory Board Member on NAACCR Board of Directors

Lori Swain, MS, is the Executive Director of NCRA. Although she has served a number of years on the NAACCR Board of Directors as a Representative for the Sponsoring Member Organizations, she effectively transitioned to her new role as NAACCR’s first Advisory Board Member in June of 2020. In her new role, Ms. Swain will provide in-kind expertise, as needed to effectively implement the Strategic Management Plan or other priorities of NAACCR; offering her insight from NCRA’s perspective. When asked what she hopes to bring to the table or accomplish in her new role, Ms. Swain, stated, “Hospital registrars needs and interests are interrelated towards much of the work of NAACCR. I will work with NAACCR to understand opportunities to broaden our relationship and try to launch those efforts for the good of both organizations.”

Thank you, Heather Stabinsky and Lori Swain, for agreeing to serve in these important positions.

Antoinette Stroup, PhD
New Jersey State Cancer Registry

1 See Updated NAACCR Bylaws, effective June 2020: https://www.naaccr.org/bylaws-policies-standing-rules/.

Calling all Registrars!
Summer 2020 NAACCR Narrative

Elizabeth Ward, PhD
Co-Chair, Site Specific Data Item Work Group

Have you ever wished that a standard setter had asked your opinion on codes and coding instructions before releasing a new data item? Or wanted to give feedback on problems in coding an existing data item? Or asked you how available a data item was before implementing a new data item? If yes, now is your opportunity to speak up!
In 2019, the NAACCR Mid-Level Tactical Group (MLTG) mandated that any new data items that were going to be introduced into the registry needed to go through a field study. The purpose of a field study is to test proposed data items, including codes and coding instructions. This was not the first time that field studies had been discussed though. This was a long-term desire by the Cancer Surveillance Community. The problem continued to be how to conduct a field test.

Then Kathy Cronin, the Deputy Associate Director for the Surveillance Research Program at SEER, asked a question that would change everything. While SEER staff were discussing how to implement a field study, Kathy asked about SEER’s Reliability Website. After further discussions, it was agreed by SEER and IMS that it would be possible to modify the Reliability Website to meet the needs of the field study and the proposal to use the SEER Reliability Website was shared with AJCC/CoC, NPCR, NCRA, NAACCR and Canadian Registries. It was agreed upon by all the partners that the SEER Reliability website would be used for the field test in 2019. A small team was put together to gather all the needed information and the process was started. The team was led by Jennifer Ruhl from NCI, and included Nicki Schussler from IMS and Carmela Groves from Westat.

The first step to any field study is getting actual cases from hospitals or central registries. A call for cases goes out with the data items being tested, and the specific information, including sites and/or histology, that are needed. The cases are then received and reviewed by technical experts, in the previous field study that was Jennifer and Carmela. Cases are chosen based on if they contain the needed information, and the difficulty level. Then proposed answers and rationale are developed by the experts and then reconciled. Once Jennifer and Carmela came up with preferred answers, another group of CTR experts were provided by NCRA, who also reviewed the cases, the preferred answers and rationale. During this process, there was also discussions with the SSDI work group, AJCC physicians and pathologists. Finally, the preferred answers and rationale were determined, and the cases went off to IMS, where Nicki did her magic, along with help from some of her IMS colleagues.

For the 2019 Field Study, we tested seven new SSDIs, the new yc data items from AJCC (multiple choice questions only) and SEER’s neoadjuvant data items (multiple choice questions only). Approximately 300 registrars participated in the field test, the majority of them from hospital registries. There were five groups of cases. For the SSDIs, each group had a different medical record, each record with a slightly different way of how the biomarkers (which were being tested) were recorded in the medical record. With this type of approach, it helps those developing the data items get a wider view of how things may be documented and how the instructions should be developed.

For the field test process, registrars entered their answer and immediately were given the “preferred” answer and the rationale for that answer. Registrars were then able to comment on that particular data item or question. Through those comments, we were able to determine where the problem areas were with the data items and make some adjustments to the proposed data items before they were released. Not only did we get comments directly related to the new data items, we also received feedback that is helping the SSDI work group enhance other SSDIs. It is this feedback that is so valuable to us.

It is the goal of the MLTG that at least 500 registrars participate so that we can get more feedback. This year, there will be one proposed new data item and eight existing data items under review. The SSDIs that are already being collected and included in this field study are ones that frequently have questions in the CAnswer Forum, and where clinical changes may be occurring. We are hoping by field testing these, that we may be able to determine where the major issues are and make some adjustments to these SSDIs that will help registrars in the future. For one of the SSDIs, major changes have already been made and
we are testing those changes. We are also including cases on Grade. The Grade instructions for the 2021 updates had some major changes and we will be testing those changes as well. (Note: Updated SSDI and Grade manuals will be available in September 2020. Changes to software will not be available until later in 2020).

The call for cases has gone out through a NCRA in a special news flash and also the NAACCR Listserv. We are encouraging all registrars, in particular, hospital registrars to submit cases. These cases are critical to successful field study. Also, having cases from different facilities helps to develop an overall picture of how these data items are documented in different facilities.

The SEER Reliability Website for the Field Study will be open on October 15, 2020, for account creation and registration. Shortly before that, an invitation to participate will also be sent out through NCRA, NAACCR and SEER. The study will be open November 1 -December 15 for participants to complete their cases. And don’t forget, we want and need your feedback (post your comments in the Field Study). One comment can make a huge difference. This happened several times with the 2019 Field Study and we are so appreciative of those registrars.

Participants are asked to complete at least one set of cases. They will have the opportunity to complete all five sets of cases. CE credits will be available for each set completed.

In addition, we will also be having another section this year, which will focus on data items that Cancer Surveillance is considering collecting. We are looking to see if the information is available, and how often it is available. You may be asked to look at the last several cases of a particular primary site to see if certain information is available. This will help Cancer Surveillance determine if something is widely available enough to consider as a new data item.

We know how busy everyone is but really hope that you will take the time to participate in this important effort to improve the process of implementing new data items that are emerging as important for cancer treatment and prognosis.

CAP and IARC Collaborate to Enhance Cancer Reporting
Summer 2020 NAACCR Narrative

Joseph B. Schramm
College of American Pathologists

College of American Pathologists and International Agency for Research on Cancer collaborate to enhance cancer reporting

The College of American Pathologists (CAP) and the International Agency for Research on Cancer (IARC), part of the World Health Organization (WHO), recently signed a memorandum of understanding (MOU) to strengthen the collaboration on their respective resources that are used in cancer classification, reporting, and ultimately, patient care.
The WHO Classification of Tumours Series (also known as the “WHO Blue Books”), for the histological and molecular classification of tumors, and the CAP Cancer Protocols are essential resources in the classification and reporting of cancer cases.

As part of the MOU, IARC allows the CAP to use the classification structure of the WHO Blue Books in the Cancer Protocols and electronic Cancer Checklists (eCCs). Timely access to this content is critical to ensure that pathologists have the most up-to-date content when reporting on cancer cases. The Cancer Protocols and associated eCCs provide guidelines for collecting the essential data elements for complete reporting of malignant tumors and optimal patient care.

“We understand the importance of the CAP having access to the most current versions of the WHO Blue Books classification structure,” said Ian Cree, BMSc, MBChB, PhD, FRCPATH, head of the WHO Classification of Tumours program at IARC. “We are delighted to collaborate and exchange information and resources for the betterment of cancer reporting and patient care.”

In addition, the CAP and IARC will nominate representatives to each organization’s group that is responsible for maintaining and updating its resources: the CAP Cancer Committee and the WHO Classification of Tumours Editorial Board, respectively.

IARC has named Dr. Cree as its representative to the CAP Cancer Committee. Joseph Khoury, MD, FCAP, chair of the CAP Cancer Committee, will be nominated to the WHO Classification of Tumours Editorial Board.

“This is a big step forward and will take the collaboration between IARC and CAP to a new level by further strengthening the alignment of our respective publications, which are among the most critical resources to physicians who diagnose and treat patients with cancer,” said Dr. Khoury. “We will work closely together to share progress on timelines for new editions and updates to each organization’s publications.”

About the College of American Pathologists
As the world’s largest organization of board-certified pathologists and leading provider of laboratory accreditation and proficiency testing programs, the College of American Pathologists (CAP) serves patients, pathologists, and the public by fostering and advocating excellence in the practice of pathology and laboratory medicine worldwide. As a 501(c)(6) membership organization, the CAP is the only entity representing pathologists with unrestricted advocacy capability and a political action committee, PathPAC. For more information, visit yourpathologist.org to watch pathologists at work and see the stories of the patients who trust them with their care. Read the CAP Annual Report.

About the International Agency for Research on Cancer
The International Agency for Research on Cancer (IARC) is part of the World Health Organization (WHO). Its mission is to coordinate and conduct research on the causes of human cancer, the mechanisms of carcinogenesis, and to develop scientific strategies for cancer control. The Agency is involved in both epidemiological and laboratory research and disseminates scientific information through publications, meetings, courses, and fellowships.
Synchronization of Registry Plus Applications
Summer 2020 NAACCR Narrative

**Brian Knox, Developer**  
**John Sammerson, DBA**  
*North Carolina Central Cancer Registry*

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**The Problem**
For years the North Carolina Central Cancer Registry had been dealing with the dynamic nature of keeping track of facility contacts. Each liaison registry staffer, IT, supervisors; we all had their own way of keeping track. Can you say Excel confusion boys and girls? You see that info was needed in creating account (VPN and application), who to notify, what type of facility was it, were some facilities reporting for others, was the contact performing an RCA role, an abstractor, a contractor, a CTR, an HIM, etc. And of course, how could we keep all this info manageable and in sync Registry Plus and all those involved?

**Contact/Facility (CFAC) Management Tool was born**
All facility/contact data was merged, validated and a SQL database was created. This Contact/Facility (CFAC for short) RegistryPlus Management tool ties Contact data to Contacts, Contacts to Facilities, and Facilities data to WebPlus, PrepPlus and CRSPlus. CFAC is equipped with a web-based user interface that enables NC CCR staff to login and view, add and update facilities and their contact information.
This data can also be viewed and exported in a tabular form into Excel.

<table>
<thead>
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<th>Facility Name</th>
<th>Reporting Facility</th>
<th>Reporting Facility Status</th>
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</tr>
</thead>
<tbody>
<tr>
<td>ACOE - UNC Hospital</td>
<td>Carolina Medical Center</td>
<td>Active</td>
<td>ACOE - UNC Hospital</td>
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Facility Management
The users are able to manage data pertinent to facilities such as, are they a COC hospital, are they under a managed umbrella, what was the old facility number if it had been changed, the type of facility, the software being used, the NC CCR staff assigned to that facility, just to name a few. This application keeps a history of the changes made. Users can also maintain text related that facility, such as, why their case numbers are running low.
Contact Management

One of the problems we are attempting to resolve is the facility contact’s current status. The fluidity of staffing at some facilities has posed a problem on occasion. Our staff is able to search and identify facilities and their contacts/users (active or otherwise).

To create or modify users for a Facility, registry users must select a Reporting Source. Once a Reporting Source is selected, a listing of all users is displayed to them. Registry users can then make contact with facilities to ensure each contact’s information is correct.
Information from this user screen is used for registry processes, and in the future, will be used to create and update user’s information in the Registry Plus application(s) based on their reporting sources numbers. For example, users’ initial login credentials can be populated in WebPlus and an email generated to the users. Like with the Facility Management section, a history of notes related to the Contact can be maintained here.

End Goal
While it is true, the Registry Plus applications do have some of this information but having one place to update the data was part of our goal. On the outside, this tool keeps our staff up-to-date with all the changes to facilities and their contacts in one place. On the inside, this tool enables synchronization of Registry Plus applications, other registry processes and automatic notifications to respective staff and contacts.
What NAACCR Means to Me
Summer 2020 NAACCR Narrative

Jeannette Jackson-Thompson, MA, MSPH, PhD
Director Emeritus, Missouri Cancer Registry and Research Center
Research Associate Professor, Dept. of Health Management & Informatics, University of Missouri (MU)
School of Medicine
Core Faculty, MU Institute for Data Science & Informatics

As readers of the NAACCR Newsletter know, the North American Association of Central Cancer Registries (NAACCR) is a professional organization that develops/promotes uniform data standards for cancer registries; provides education/training; certifies population-based; aggregates/publishes data from central cancer registries; and promotes the use of cancer surveillance data to reduce the burden of cancer in North America. But NAACCR is more than just a collaborative umbrella organization for cancer registries, governmental agencies, professional associations and private groups in North America interested in enhancing the quality and use of cancer registry data. It is an organization whose staff, Board and members willingly share knowledge, materials and ideas and reach out to embrace members in need of support, consolation and prayers. I am a 24-year NAACCR member who will never forget the many words of support I received via cards, emails, texts and phone calls or the many kindnesses that came my way – flowers, food, memorial gifts, virtual hugs, etc. – following the death of my husband of 50 years, Richard C. Thompson, PhD, on 30 June 2020.

A Brief Word about Richard’s Involvement with NAACCR
Having decided to become a chemist at the age of 9 (he declared he was a Brooklyn Dodgers fan at the age of 8), Richard selected the University of Chicago for his undergraduate studies. Four years after obtaining his A.B. in Chemistry (1961), he was awarded a PhD in Chemistry from the University of Maryland (1965). After one year as a post-doctoral fellow at Argonne National Laboratory and a year teaching at the Illinois Institute of Technology, Dr. Thompson joined the inorganic chemistry faculty at the University of Missouri-Columbia, where he spent the next 35 years, becoming director of graduate studies and associate chair. He retired on 31 December 2002 at which time he was granted the title of professor emeritus. To learn more about his life, go to https://www.columbiamissourian.com/obituaries/missourian_life_story/richard-thompson-a-true-scientist-had-a-passion-for-travel-and-food/article_a6aaace6-c7a8-11ea-9d2d-ff00838b6cda.html.

In addition to being a dedicated scientist, Richard was an avid traveler with a keen interest in American history and Native American culture. He was also a lifelong learner. His first trip after retirement in January 2003 was to accompany me to a cancer surveillance workshop in San Jose, CA. He became a regular attendee at NAACCR meetings and meetings of the Union for International Cancer Control (UICC)/World Cancer Congress (WCC). His last trip was to accompany me to the 2019 NAACCR Annual Conference in Vancouver, British Columbia.
My Involvement with NAACCR

I became director of the Missouri Cancer Registry (MCR; now the Missouri Cancer Registry and Research Center (MCR-ARC)) in May 1996, too late to attend the 1996 annual meeting in Minneapolis. Five MCR staff members (our registry manager, database administrator and three CTRs) did attend and brought back valuable information. From the 1997 meeting in Boston – the last meeting to which we were able to send 5 staff – to the 2019 meeting in Vancouver, I attended every annual meeting.

It only took one meeting for me to realize the value of attendance at annual meetings and how active participation throughout the year could benefit us. As director, I encouraged MCR staff to volunteer to serve on NAACCR committees and work groups and to submit abstracts for presentation at annual meetings. Submission of an abstract opened the door to send additional staff if funding was available. Between 1998 and 2019, 10 MCR staff gave over 50 presentations at annual meetings; had they not been presenting, 8 of the 10 would not have been able to attend the annual meeting that year. Between 2002 and 2019, 8 students and 1 post doc gave 13 presentations, none of whom would otherwise have received support. After annual conferences, presentations (oral and poster) are uploaded to our website ([https://medicine.missouri.edu/centers-institutes-labs/cancer-registry-research-center/resources/presentations](https://medicine.missouri.edu/centers-institutes-labs/cancer-registry-research-center/resources/presentations)) and posters are displayed on MCR-ARC walls.

All NAACCR annual meetings have benefited attendees and, through reports made at regularly scheduled meetings, other staff and students. Over the years, follow-up contact with presenters has brought improvements to registry operations. Highlights for me and for MCR-ARC include:

1997 (Boston): Twenty minutes after 5 MCR staff landed at Logan Airport, the airport closed for more than 24 hours due to a snowstorm that dropped over 2 feet of snow on the city, disrupting the opening day schedule. Two staff members and I – all looking like drowned rats after walking back to the conference hotel from Charles Street (antique shops) – had our photo taken with John Young, DrPH, CTR, former director of the California Cancer Registry (1989-1995) and of NAACCR’s Cancer Surveillance and Control Program (1996-1998). This encounter subsequently led to the opportunity for MCR to acquire a customized version (Mo-CRIS) of the software system used by the University of California-Irvine (Cancer Registry Information System (CRIS) for the regional registry they operated; without this system, we would have had a great deal of difficulty meeting NPCR requirements and NAACCR standards. Throughout the 1997 meeting, I met NAACCR, agency and central cancer registry (CCR) staff and experienced the generosity and camaraderie of NAACCR members.
1998 (Vancouver, British Columbia): This meeting offered an opportunity to renew acquaintances and build relationships that have endured for more than 20 years. I gave my first presentation (“Collaboration and constituency building: A central cancer registry forges relationships for the 21st century”) at a NAACCR meeting. As director of MCR, I realized the importance of our staff and students being actively involved in NAACCR, not just being members of the organization and encouraged them to submit abstracts and serve on committees.

1999 (Chicago, IL): An MCR staff member, Iris Zachary, CTR (now Iris Zachary, PhD, MSHI, CTR and, since January, director of MCR-ARC) gave a presentation (“Moving towards the 21st century: A central registry Strives for quality”). While at the conference, I received a message from my supervisor that the Missouri Dept. of Health (now the Missouri Dept. of Health and Senior Services (DHSS)) had agreed to outsource day-to-day operations of MCR to the University of Missouri (MU) and he instructed me to draft a contract immediately and fax it to him. I knew that the Florida central registry, located at the University of Miami, operated under a contract with the Florida health department. Jill Mackinnon, PhD, CTR, then director of the Florida Cancer Data System (FCDS), generously agreed to contact the Florida Dept. of Health and a copy of their contract was faxed to me at the Palmer House. I crossed out names, inserted appropriate new names and faxed the amended contract back to the Missouri health department. Twenty-one years later, MCR is still operated as a joint endeavor of MU and DHSS, using the same one-year contract format; in 2002, all operations were outsourced to MU.

2001 (Miami, FL): Although MCR had been a population-based registry since 1985, we had never conducted death clearance and follow-back until 1996. We knew we didn’t meet NAACCR certification standards, so we did not submit data for certification until 2001 for 1998 data. At the 2001 meeting, we received our first NAACCR certification – silver (death certificate only cases exceeded 3 percent). “Go for the Gold” became our motto and continues to motivate us. Data for 1999 – 2017 meet the NAACCR Gold standard.

2009 (San Diego, CA): While walking through the exhibit hall, an MCR staff member, Mary Jane King, saw a demonstration of InstantAtlas® by GeoWise data visualization software and realized that this is what MCR-ARC needed for our website. We had been relying on data tables on DHSS’s website, but the public and many health professionals who are not epidemiologists or statisticians don’t relate as well to tables as they do to graphs, charts and maps. In addition to cancer incidence data, we now display cancer mortality data, behavioral risk factor data and other types of data important to the surveillance community (https://medicine.missouri.edu/instantAtlas/areaHealthProfile2015/atlas.html).
2011 (Louisville, KY): Scrolling through the photos of past conferences on the NAACCR website, I found a photo of Jim Martin (then director of the Virginia Cancer Registry) and me presenting NAACCR Student Awards (https://www.flickr.com/photos/naaccr/albums/72157626961281247/page2/). We set up the Student Award Sub-committee in 2010 under the Data Use and Research (DURC) Standing Committee. We wanted to encourage students to become involved with NAACCR (catch them young and keep them!), an idea that has been supported by the NAACCR staff and Board.

2016 (St. Louis, MO): For the first time ever, the annual meeting was held in Missouri! We chose St. Louis rather than Columbia for the convenience of participants and collaborative relationships with faculty at Washington University in St. Louis and St. Louis University. Plenary sessions built on our theme – “Gateway to Cancer Discoveries” – and included: Gateway to Results; … to Implementation; … to Diversity; … to Information; … to Scientific Discovery; and … to Patient Centeredness and Patient Perspectives. It was a great honor to host the annual meeting, one I will always cherish. I will also long remember the 2016 St. Louis Susan G. Komen Race for the Cure, which was held on the Saturday preceding the meeting. MCR-ARC sponsored a team; Richard and I participated in it, along with Shari Ackerman, the MCR-ARC staff member responsible for opening ceremony entertainment and a special NAACCR rate for a St. Louis Cardinals game, and Adam Bouras, a department staff member and PhD student.

2019 (Vancouver, British Columbia, Canada): This, my second NAACCR conference in Vancouver, was combined with the International Association of Cancer Registries’ (IARC’s) annual conference. It was the last trip Richard and I made together.

Closing Thoughts
This has been a year of changes, for me and for MCR-ARC. After nearly a quarter century as director of the Missouri Cancer Registry, on 1 January 2020 I became director emeritus and Iris Zachary became the director. Dr. Zachary came to MCR more than 20 years ago; we recruited her from
a hospital in St. Louis to join our quality assurance unit as a certified tumor registrar (CTR). While working full time at MCR, she earned a master’s degree in health informatics and a PhD in the same field. This was the culmination of succession planning that began more than 5 years ago. I hope to continue working with Iris and other members of the MCR-ARC team – and to be an active NAACCR member – for several years to come.

An unplanned change was closure of the university due to COVID-19. We have had short- and long-term telecommuting policies in place for more than a decade. Thanks to NAACCR for asking if our policies could be included in a manual, I had reviewed and updated our material in January. Only one MCR-ARC staff member was not already set up to work from home (with permission of her/his supervisor) and it took our software support analyst only 3 hours to get her set up. To maintain morale and keep in touch, Iris convenes a weekly Zoom meeting with all staff. Other weekly, monthly and quarterly meetings continue as Zoom rather than in-person meetings.

The unplanned change with most impact on me was Richard’s death on 30 June. I will be forever grateful that he was able to come home on 27 June and (with assistance from Compassus Hospice and Integrity Home Care) to have one day (the 28th) where he could gaze around my study from his hospital bed and see the artifacts we’d collected over 50 years of marriage, then be wheeled out on our patio to smell the flowers and look at my tomato plants. My husband enjoyed a taste of 16-year-old Lagavulin less than 5 minutes before he took his last breath, never complaining and still holding my hand. He was a scientist to the end, donating his body to the School of Medicine’s Gift of Body program.

In addition to the support of family and friends, I have been blessed to have the support of MCR-ARC staff, NAACCR staff and Board members and NAACCR members around the country and across the border. Your support has brought me the strength to go forward, to grieve but to continue to carry out my MCR-ARC responsibilities. In time, I hope to acknowledge each of you individually. In the meantime, know that your thoughts, prayers and actions have carried me through the darkest of days and given me hope for the future.

Jeannette Jackson-Thompson

2. 2019 NAACCR Annual Meeting (Vancouver, British Columbia, Canada): Reunion in Vancouver – Richard Thompson, Jeannette Jackson-Thompson, Angela Martin (former MCR Education Coordinator, now NAACCR trainer/project manager) and Chester Schultz, MCR-ARC Senior Statistician

3. 2016 NAACCR Annual Meeting (St. Louis, MO): The MCR-ARC team (Shari Ackerman, Jeannette Jackson-Thompson, Richard Thompson and Adam Bouras) take a break during the Susan G. Komen Race for the Cure


5. 2014 NAACCR Annual Meeting (Ottawa, Ontario, Canada): Jeannette Jackson-Thompson proposing a toast to NAACCR

6. 8 July 2020, Columbia, MO: Flowers from NAACCR staff and Board
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