Hello NAACCR members!

Happy New Year! I cannot believe it is 2020, a year that sounded so far away all my life. In honor of it being ‘2020’, let’s make this a year driven by clear vision. A few updates:

The Bylaws committee is working diligently with the help of a parliamentarian to review and tighten language in our bylaws. Look for the committee’s recommendations in the next couple of months and if any members have suggestions for bylaws changes, now is the time to submit those.

Watch for some new best practices documents from the Professional Development Steering Committee on telecommuting and recruitment and retention.

Now that data submission is done, it’s time to start thinking about the annual conference to be held June 21-25 in Philadelphia, PA. This year’s theme is “Cancer Surveillance: Keystone of Progress” and the conference is being co-hosted by Pennsylvania and New Jersey, which may be a first for NAACCR. Whether you are a Pat’s or Geno’s fan, start making your plans now to join us in Philly — all are welcome in the City of Brotherly Love! The Planning Committee (co-chaired by Wendy Aldinger and Nan Stroup) and NAACCR staff are working hard to give us yet another excellent educational and networking experience. Plus, we are hosting another hackathon this year — what brilliant solutions might the participants come up with for cancer surveillance this time? I can’t wait to find out, and I look forward to seeing you all there!

And in other annual conference news, NAACCR recently announced that the 2022 annual conference will be held here in Boise, Idaho. The Cancer Data Registry of Idaho is delighted to work with NAACCR to plan the meeting and a few extracurricular activities for your enjoyment. Remember when Frances Ross taught us all the correct way to pronounce ‘Louisville’? For Boise, you need to know that it’s pronounced ‘Boy-C’ not ‘Boy-Z’. Much more to come later...

It is my honor and privilege to work with and learn from each of you. I want to take this opportunity to encourage each of you to participate in NAACCR’s committees, workgroups, and task forces. Share your wisdom to help guide and improve the cancer surveillance community, contributing toward our ultimate mission of reducing the burden of cancer in North America. Your voice is important to NAACCR!

All my best to you and your families!
The NAACCR Office has been very busy over the past few months. There are many new projects for us on the horizon and hope that they will serve the membership and the cancer surveillance community. Nan and I paid a visit to the Philadelphia meeting site recently. It is going to be a great venue. Located just two blocks from city hall, in the heart of center city, there will be much to do within a few blocks of the hotel. The Reading Terminal Market [https://www.visitphilly.com/articles/philadelphia/best-things-to-eat-at-reading-terminal-market/] will be a great place to grab lunch between sessions. Philadelphia is a great city for art with The Philadelphia Museum of Art [https://philamuseum.org/], the Rodin Museum [http://www.rodinmuseum.org/], and the Barnes Foundation (one of the largest collections of Impressionist art) [https://www.barnesfoundation.org/] all located on a mall, not too far from our hotel.

We heard that the Phillies won’t be in town during the Conference, but tours of the stadium can be arranged in advance. Oh, and then there is the scientific portion of the meeting! We have some excellent speakers lined up – check out the preliminary program [https://www.naaccr2020.org/agenda]. We are pleased to announce that Quinn Ostrom, who won the Enrico Anglesio Prize at the NAACCR/IACR Annual Conference in 2019 published a paper based on her award-winning presentation. The paper, *Relative survival after diagnosis with a primary brain tumor or other central nervous system tumor in the National Program of Cancer Registries, 2004-2014*, was published in Neuro-Oncology Practice in December. Congratulations Quinn!

We hope you have gotten a chance to explore NAACCR’s newest publication “Cancer in North America Vol.5- Cancer Prevalence in the United States and Canada”. These statistics are the most comprehensive estimates of cancer prevalence to date for U.S. and Canadian jurisdictions, and estimate that over 8 million people in the US and 360,000 in Canada have a history of cancer diagnosis within the last 10 years. We trust that the state and provincial estimates of prevalent cancers will be useful to you and your local cancer control partners. The full report may be found here; [https://20tqtx36s1la18rvn82wcmpn-wpengine.netdna-ssl.com/wp-content/uploads/2020/01/CINA12-16.v5.prevalence.pdf]. Many thanks to Chris Johnson and Bozena Morawski of the Cancer Data Registry of Idaho as well as Angela Mariotto, Baozhen Qiao, Bin Huang, Donna Turner, Larry Ellison, Hannah Weir and Recinda Sherman for their work on this new volume.
As we move forward to adopt the XML transmission standard, NAACCR will no longer support the fixed-width data exchange format beginning with the Data Standards and Data Dictionary, Version 21. For example, all references to column start and end related to the fixed-width format will be removed. Visit the XML Data Exchange Standard webpage: https://www.naaccr.org/xml-data-exchange-standard/ for the NAACCR XML Data Exchange Standard Implementation Guide, the NAACCR Plan to Implement XML, software tools and other documentation.

For Version 21 there will be changes to existing data items (radiation data items and SSDIs) along with new SSDIs, new neoadjuvant therapy data items, new AJCC yc data items, and six derived versioning data items (2 each for the AJCC API, CDC Staging API and the Schema ID). Several of the new data items are currently being field tested and these results will help determine which new data items will be added in Version 21.

NAACCR is currently working on a Version 21 Implementation webpage to provide the cancer surveillance community with Version 21 implementation plans, links to reference manuals (e.g., staging manuals, standard-setter coding manuals, etc.), and other Version 21 material to keep the community abreast of the implementation process. A NAACCR ListServ announcement will be sent out as soon as the Version 21 site is completed.

**NAACCR Data Standards and Data Dictionary (Volume II) Version 21 Implementation Timeline**

<table>
<thead>
<tr>
<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 (most new and some changed data items) submitted to the Mid-Level Tactical Group (MLTG), followed by UDS for preliminary review. | July 1, 2019     | • Complete request-for-change forms for and submit to the MLTG by July 1, 2019  
• Data items approved by MLTG will be sent to UDS for preliminary review  
• Standard setters should have plans to conduct field testing within the timeframe required for final approval |
| Field testing initiated                                                  | September 3, 2019| • For items that require field testing, testing to be initiated by September 1, 2019  
• 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 not require field testing submitted to MLTG for final review. * | October 1, 2019  | • 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, 2019.  
• MLTG may elect to require field test  
• Note: MLTG to develop a request-to-change form for items that do not require field testing |
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| 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 2019) on all changes under consideration  
 |                                                                         |                        | • This will ensure HLSG can initiate dialog with standard setters, ask technical questions as deemed necessary                                    |
| MLTG transmits new proposed standards to UDS WG for final review and approval | January 1, 2020        | • UDS will not consider standards received after January 1, 2020, for NAACCR volume II version 21  
 |                                                                         |                        | • 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, 2020          | • No standards submitted for MLT 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, 2020            | • 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 2021 Implementation Guidelines Task Force                | May 1, 2020            | • 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.                                                                                                     |
| UDS submits NAACCR Standards for Cancer Registries Volume II, Version 21 to NAACCR Board for review/approval | June 1, 2020           | • UDS final review/approval at their May meeting.  
<p>|                                                                         |                        | • MLTG recommends that UDS plans two meetings for May 2020 to ensure that all changes approved by HLSG for implementation will be included in the NAACCR Standards for |</p>
<table>
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<tbody>
<tr>
<td>NAACCR Standards for Cancer Registries Volume II, Version 21 Released</td>
<td>July 1, 2020</td>
<td>Cancer Registries Volume II by June 1, 2020, deadline.</td>
</tr>
<tr>
<td>NAACCR 2021 Implementation Guidelines Released</td>
<td>August 1, 2020</td>
<td>• EDITS Work Group will have begun development of edits metafile by April 2020.</td>
</tr>
<tr>
<td>EDITS metafile release</td>
<td>August 1, 2020</td>
<td>• Develop training materials by October 1, 2020, and provide adequate training opportunities before January 1, 2021.</td>
</tr>
<tr>
<td>Education and training</td>
<td>Ongoing as material becomes available</td>
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<tr>
<td>NAACCR Standards for Cancer Registries Volume II, Version 21 effective date</td>
<td>January 1, 2021</td>
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Recinda Sherman, MPH, PhD, CTR  
NAACCR Program Manager of Data Use and Research  
rsherman@naaccr.org

Research & Data Use

Welcome to 2020! As we spend the remainder of the 365 days squinting at our computer screen, I hope we all obtain the visual clarity this year implies.

Call for Data:

It was another successful Call for Data! Thank you all for your continued herculean efforts in collection and submission. Here are the numbers: we had 68 submissions and all registries submitted in XML format. And all but one (1) registry submitted the calculated survival fields; all but one (1) US registry sent tract-level area-based social measures (ABSMs) to calculate the YOST SES Index; and 44 registries have submitted 12 Month (2018). And we anticipate all US registries will have created their VPC-CLS file by the end of January for the Camp Lejeune linkage.

Please note that we will be releasing the state-level data assessments (including DQI, CINA Submission Summary & Certification reports) through the Call for Data Submission Site. If you have not already checked it out, you will find your historic reports (for submission years 2016-2018) here: https://www.naaccr-cina.org/.
Finally, there are a few registries who have not completed the CaRRI database, and we will be reaching out to them for completion.

**NCI/NAACCR Zones and EPHT Sub-County Areas:**

You may be hearing from folks regarding your registry’s involvement in one or two projects focused on establishing small-areas for presenting cancer rates. CDC’s Environmental Public Health Tracking program has been working on establishing estimates to present cancer data as well as other health outcomes and risk factors. NAACCR is working the NCI to establish standard zones specifically for presenting cancer incidence data.

Both projects are weighing the need to unmask local variation against the need to present stable and confidential results. Both organization are reaching out to registries for feedback on how well their proposed areas would work for presenting local data. Once the areas have been designed and approved by the cancer registries, we will be incorporating these in NAACCR*Prep as another calculated ABSM. Registries can present their own small area data or consent to allow their data to be presented at the level as they so choose. We anticipate a session at NAACCR 2020 that will provide an update from NIC and CDC as well as some registries perspective on this work.

**File*Pro and SAS Files for Calculated Variables**

Historically, we have provided SAS files to help support calculated variables including the NHAPIIA, Survival variables, and ABSMs—NAACCR Poverty Code, URIC, RUCA, etc. The SAS files are used by registries to operationalize calculated variables into their registry’s database as well as by NAACCR and outside researchers to populate the data as needed.

However, providing the SAS programs in addition to calculating the fields in products like NAACCR*Prep requires duplicative work...which also means duplicative review and duplicative maintenance and (eek) duplicative chance for error. With this in mind, we are moving toward a more efficient system of relying on one source for defining these fields and will be phasing out the SAS file products.

Starting with the 2020 Call for Data, we will use a single algorithm library to calculate these fields within NAACCR*Prep and File*Pro (a generic tool provided by SEER for processing NAACCR files). If you have not already used File*Pro, I encourage you to check it out and to recommend it to outside researchers who currently rely on the SAS programs to calculate these fields.

File*Pro can:

- View & manage any dataset in a NAACCR Volume II format
- View & manage any dataset in a fixed column or CSV format (user configures the format)
- Convert NAACCR XML files, such as those created by NAACCR*Prep, into flat files
- Allow users to easily define geocoder batch results to ensure leading zeros on census data are not dropped on the boundary files
- Calculate the new NCI/NAACCR zones/IPHT sub-county areas described above (once the areas are approved by the registries)

File*Pro is fairly intuitive, but we anticipate there will be an overview of File*Pro in an XML concurrent session. Additional instructions will also be included in the Call for Data materials next fall.
As always, if you have any questions, concerns, or visually perfect ideas for 2020 in the NAACCR Research and Data Use area, please contact me rsherman@naaccr.org.

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**Survey Course: Understanding Population-Based Cancer Registries Course**


This quarter I want focus on the NAACCR Survey Course: Understanding Population Based Cancer Registries or simply the “Survey Course.” The Survey Course consists of four (4) topic areas with multiple modules under each topic. Each module was developed by NAACCR members who are recognized experts on the topic they presented. Each module consists of a short recording and slides associated with the recording. Topics are periodically updated as necessary. We recently added the seven (7) modules under Data Management modules 1-7.

The modules are free and are available to anyone with a MyNAACCR account! Just click on the link above and login. You will need to login to view the modules.

If you have any questions or comments, you can leave them in the discussion tab.

**Introduction to Cancer Registries and Cancer Surveillance**

1. Public Health Surveillance Introduction & Fundamentals
2. Establishing an Effective Population-based Cancer Registry System

**Registry Operations**

1. Casefinding
2. Follow-up
3. Data Editing
4. Record consolidation
5. Death clearance

**Registry Management**

1. Registry Development
2. Data Quality and Completeness
3. Ethics & confidentiality
4. Data Management – IT resources
Module 1 – Course Introduction  
Module 2 – Managing Central Registry’s Data  
Module 3 – Infrastructure  
Module 4 – Security  
Module 5 – Electronic Documents and Standards  
Module 6 – Interoperability  
Module 7 – Registry of the Future  
Module 8 – Course Summary  

Uses of Population-Based Registry Data

1. Calculation and Assessment of Survival Rates  
2. Calculation and Assessment of Cancer Incidence  
3. Using Central Cancer Registry Data for Cancer Control and Cancer Research  

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

Upcoming Webinar Presentations

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<th>February 2020</th>
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<tr>
<td>02/12/2020</td>
<td>NAACCR Talk: A Step-by-Step Guide to Creating a Cancer Data Visualization</td>
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<tr>
<td>02/18/2020</td>
<td>NAACCR CTR Exam Prep &amp; Review Session 6</td>
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<tr>
<td>02/25/2020</td>
<td>NAACCR CTR Exam Prep &amp; Review Session 7</td>
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<tr>
<td>03/03/2020</td>
<td>NAACCR CTR Exam Prep &amp; Review Session 8</td>
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<tr>
<td>03/05/2020</td>
<td>NAACCR Webinar Series: Abstracting and Coding Boot Camp: Cancer Case Scenarios</td>
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<th>April 2020</th>
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<tbody>
<tr>
<td>04/04/2020</td>
<td>NAACCR Webinar Series: Melanoma</td>
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For more information about NAACCR education and training opportunities or to register online, go to the Education and Training tab on the NAACCR website (naaccr.org), or contact Jim Hofferkamp (jhofferkamp@naaccr.org).

Castine Clerkin, MS, CTR
NAACCR Program Manager of Virtual Pooled Registry
cclerkin@naaccr.org

Happy 2020 everyone! Last year was a whirlwind of pilot testing activity and conversations with requestors interested in using the Virtual Pooled Cancer Registry Linkage System (VPR-CLS) to link their studies with U.S. cancer registries. I had the opportunity to present at the NCI Cohort Consortium Meeting and the World Trade Center Data Linkage Symposium. Both meetings were a good reminder about the value of the VPR-CLS and the importance of streamlining not only the linkage and application process, but also the release and allowable use of registry data. To this end, we continue to develop a Templated Data Use Agreement and are planning a webinar to begin the conversation about secondary data sharing and methods to address data confidentiality, security, and use.

On a related note, I am recruiting individuals to join the NAACCR Data Sharing Workgroup. Through this group we seek to better understand the registry context and concerns regarding data sharing, explore the intent/extent of the NIH Data Sharing Policy, and develop a plan that will support this policy while protecting the registry data. Individuals interested in participating can contact Castine Clerkin (cclerkin@naaccr.org).

For those of you who have been following the VPR-CLS development and testing, below is the latest news about our pilot testing activities.

**Phase I Pilot Testing**

Phase I pilot testing has proceeded very smoothly. The 38 pilot test registries (representing nearly 75% of the U.S. population!!) securely downloaded validated cohort files, performed linkages using standard Match*Pro configuration files, and quickly uploaded match count reports to help researchers determine where to pursue release of individual level data. While one pilot test remains, the completed Phase I pilot tests identified 268,680 high quality cancer matches across the following studies:

- Childhood Cancer Survivor Study (38K)
- Cohort Cancer Registry Follow-up Study (290K)
- Transplant Cancer Match Study (1.2M)
- Women’s Health Initiative (161K)
- Sister Study (55K)
Phase II Pilot Testing

We are excited to report that VPR-CLS Phase II pilot testing has been initiated with the Childhood Cancer Survivor Study and the Transplant Cancer Match Study. Phase II supports a streamlined process of applying for release of individual-level cancer data on matched cases identified in the Phase I linkages. The web-based Templated IRB/Registry Application (TIRA) has been submitted to the 84% of participating pilot test registries that agreed to use this form for their review process. VPR Liaisons in each registry have been entering information on the IRB/registry estimated review dates and approval status into the VPR-CLS tracking system to help researchers monitor the status of the request across registries. We look forward to receiving registry feedback on the Phase II process and sharing results of the pilot testing with the greater registry community.

Each time a New Year rolls around and I reflect on the previous year, I’m always filled with gratitude to be working in the field of cancer surveillance, surrounded by passionate and dedicated individuals. Thank you for your ongoing support of the VPR-CLS, we couldn’t do it without you!

All the best for 2020~

Castine Clerkin, NAACCR VPR Program Manager

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: Melanie Williams

Committee Highlights since last Narrative:

- The Communications Steering Committee completed a new charter describing the purpose, membership, and goals of the steering committee.

- The survey on member social media preferences was completed, and results were provided to NAACCR membership in the NAACCR Narrative. The results are also being used to help guide the NAACCR Communications Plan.
Other 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 Melanie.Williams@dshs.texas.gov.

Professional Development Steering Committee (PDSC)

Co-Chairs: Mignon Dryden and Stephanie Hill

Committee Highlights since last Narrative:

- **Survey Course and LMS Update** – Thanks to Angela Martin, what used to be called the “NAACCR Short Course” is alive and updated on the NAACCR Learning Management System (LMS) except for a couple of IT presentations that are currently being updated. The NAACCR Cancer Surveillance Webinars are also now accessed through the LMS. You can check out the new LMS at [https://education.naaccr.org](https://education.naaccr.org).

- **Telecommuting Best Practices** – Led by Lynn Giljahn, this workgroup with input from multiple state registries, drafted a best practices document outlining topics to consider for registries thinking of offering a telecommuting option to their staff. Final revisions are being made from feedback from the PDSC members.

- **Recruitment and Retention Work Group** – Led by Stephanie Hill, this workgroup developed a toolkit of best practices with input from several states. The toolkit includes sample job descriptions, recruitment strategies, training resources and other tools as well as an overview document.

- **How to Get Involved in NAACCR Work Group** – This new workgroup led by Angela Meisner is working on having a Meet and Greet at next year’s annual conference to share ideas on how new members can get more involved with NAACCR activities.

- **Hackathon at Philadelphia Annual Meeting** – A small work group led by Angela Martin is working on all aspects of hosting the Hackathon at the upcoming Philadelphia meeting.

- **Other – Salary Survey** – We have received a request to develop a central registry-specific salary survey to assist registries with recruitment. NCRA conducted a survey in 2017, but the report aggregates central registry responses with those from vendors and other registries. The PDSC is exploring options for conducting a survey specific to central registries.

If you are interested in working with Professional Development on these important projects or would like more information, please contact Stephanie Hill Stephanie.Hill@doh.nj.gov or Mignon Dryden mdryden@crgc-cancer.org

Recent Reports/Publications:

- Soon to come: Telecommuting Best Practices
- Recruitment and Retention Toolkit

Training/Education:

- New Series of NAACCR Webinars!

Other News to share with the NAACCR Community

- Please contact Stephanie or Mignon if you are interested in helping with any of these projects!
Research and Data Use Steering Committee (RDUSC)

Co-Chairs: Susan Gershman and Sarah Nash

Committee Highlights since last Narrative:

- Approved charter and revised work plan for next year.
- The CiNA Monograph Volume 5: Prevalence was approved by RDU and will be sent to Board for approval.
- Due to policy changes, Cancer Cluster Guidelines work will continue via a panel with ATSDR program staff. ATSDRI will reach out to environmental health programs and cancer registries using survey to compile information. Individual registries may comment.

Training/Education

- Next Webinar: Louisiana Data Visualization Tool Date: To be Determined

Standardization and Registry Development Steering Committee (SRDSC)

Co-Chairs: Lori Koch and Winny Roshala

Committee Highlights since last Narrative:

- Conducted the 2018 Readiness Survey, July version. The results of this second survey will be distributed to the NAACCR membership, pending board approval.
- In the process of developing the NAACCR Cancer Informatics Advisory Group, co-chaired by Eric Durbin (KY) and Gary Levin (FL)
- S&RD SC co-chairs have been serving on the Mid-Level Tactical Group, participating in the development of a new approach to requesting new data items, including field testing of proposed new data items. The first field test for new data items for 2021 will begin November 1, 2019. We encourage all registrars to participate in this field test to provide feedback for proposed data items. CEUs are available for participation in this field test process.

Recent Reports/Publications:

- The NAACCR Interstate Data Exchange Guidelines was approved by the board and posted to the website. A webinar is scheduled for December to provide an overview on the guidelines and Interstate Data Exchange agreement.

Training/Education:

- Encourage registrar participation in the inaugural field testing of proposed new data items for 2021.

Coding Changes/Updates:

- NAACCR posted an optional patch for the v18D Edits metafile on October 9, 2019, to the NAACCR Edits page: www.naaccr.org/standard-data-edits
Strategic Alliances

Co-Chairs: Nan Stroup, Randi Rycroft

Committee Highlights since last Narrative:

- Betsy Kohler attended two workshops in Lyon France sponsored by the International Association for Research on Cancer (IARC) on October 21 and 22 to improve reporting of childhood cancer worldwide. NAACCR and partners are exploring the adoption of the Toronto Childhood Cancer Stage Guidelines to comply with international standards.

Using Cancer Registry Data to Estimate Brain Tumor Survival – Ongoing Research and Emerging Collaborations

Carol Kruchko
President & Chief Mission Officer, Central Brain Tumor Registry of the United States (CBTRUS), Hinsdale, Illinois

Quinn T. Ostrom
Postdoctoral Associate, Section of Epidemiology and Population Sciences, Department of Medicine, Baylor College of Medicine, Houston, Texas

Jill S. Barnholtz-Sloan
Scientific Principal Investigator, Central Brain Tumor Registry of the United States (CBTRUS), Hinsdale, Illinois
Professor and Associate Director for Data Sciences/Translational Informatics
Sally S. Morley Designated Professor in Brain Tumor Research
Director, Research Health Analytics and Informatics, University Hospitals Health System
Director, Cleveland Center for Health Outcomes Research, CWRU
Case Western Reserve University School of Medicine & University Hospitals of Cleveland, Cleveland, Ohio

Discussions-Connections-Relationships. No matter what one calls ways of communicating it most often results in change to those individuals or groups involved. And sometimes it results in something positive—and sometimes the positive result is recognized. Recognition came to CBTRUS researcher, Quinn T. Ostrom, PhD.

Fondo Elena Moroni awarded the Enrico Anglesio Prize to Dr. Ostrom for her presentation entitled Relative survival after diagnosis with a primary brain or other CNS tumor in the National Program of Cancer Registries, 2001-2014 during the joint NAACCR / IACR Conference held in Vancouver June 2019. The Enrico Anglesio Prize recognizes a young researcher for original scientific research in cancer epidemiology. Dr. Ostrom received her doctorate in June 2018 and is now a fellow at Baylor College of Medicine in Houston, Texas.

On December 16, 2019, the study was published in Neuro-Oncology Practice (Relative survival after diagnosis with a primary brain or other central nervous system tumor in the National Program of Cancer Registries, 2004 to 2014 published in Neuro-Oncology Practice; DOI:
https://doi.org/10.1093/nop/npz059. This is the first publication on histology-specific survival patterns in primary brain tumors using the National Program of Cancer Registries (NPCR) Relative Survival Analytic Database. The NPCR survival data included 39 state cancer registries (representing 81% of the US population) for a total of 488,314 primary brain tumor cases.

The availability of these data was based on the long term relationship the Central Brain Tumor Registry of the US (CBTRUS) has with the CDC National Program of Cancer Registries (NPCR). In September 2019 CBTRUS began a second contract with the CDC. This award enables CBTRUS to provide the descriptive epidemiology on primary brain and other central nervous system found in its Statistical Reports. The award also provides CBTRUS with the opportunity to work within the cancer registry community in the United States. It is the connection that provided Dr. Ostrom with the data that resulted in the award. This connection begetted another connection which has generated additional positive results. Dr. Ostrom and another speaker in the NAACCR/IACR session, Dr. Fabio Girardi, MD (Worldwide Trends in Survival From Common Childhood Brain Tumors: A Systematic Review published in JCO Global; DOI: https://doi.org/10.1200/JGO.19.00140), are both invited speakers to the Brain Tumor Epidemiology Consortium (https://sites.usc.edu/braintumorcause) Meeting in Lyon, France, June 10-12, 2020. It remains to be seen what other connections will emerge.

Publication Information

NAACCR Narrative Publication Information
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Monica Thornton
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mthornton@naaccr.org

Spring 2020 deadline for articles to be announced.

*NAACCR members are encouraged to submit articles at any time; if you have an article for the Narrative, please submit it to the NAACCR Narrative’s Production Editor, Chandrika Rao, PhD, for review at chandrika.rao@dhhs.nc.gov.

ESTABLISHED IN 1987, NAACCR, INC. IS SPONSORED BY THE FOLLOWING ORGANIZATIONS AND AGENCIES:

American Cancer Society
American College of Surgeons Cancer Programs
Canadian Partnership Against Cancer
Centers for Disease Control and Prevention
National Cancer Institute
National Cancer Registrars Association
Public Health Agency of Canada
NAACCR Board of Directors, 2019-2020

President:
Randi K. Rycroft, MSPH, CTR
Cancer Data Registry of Idaho

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