Greetings to all of my NAACCR colleagues! I am writing this from my remote, undisclosed location and I hope that all of you are still safe and well, and remain as sane as possible. I know that many of you have been pulled from your regular jobs to work on that other ‘C’ and I have heard numerous stories of how our various skillsets have improved the data collection, data quality, and tracking for COVID-19. Bravo, NAACCR Community!

As you all know, NAACCR had to come to the incredibly difficult decision to cancel our in-person conference. But in true form, NAACCR staff rallied to solve the problem and quickly developed a virtual program for us. Registration for the online sessions is now open – click here to register. Special thanks to Nan Stroup and Wendy Aldinger, our Program Committee Co-Chairs, as well as the entire Program Committee for their work in planning our conference and securing the plenary speakers. We also really appreciate how flexible our plenary speakers were in agreeing to deliver their talks virtually.

Please also plan to attend the virtual NAACCR Business Meeting on June 24. Among other things, we will have several bylaws changes for the membership to approve and we must have a quorum present to carry out the vote. If you are the voting member for your organization and you cannot attend, you must arrange for a proxy to attend the meeting — be sure to work with the NAACCR office to designate your proxy officially. Because the proposed bylaws changes are numerous, NAACCR has also scheduled a separate webinar to go through all the proposed bylaws changes in detail and to allow the membership to ask questions and voice any concerns.

I do have some exciting news to share. Later this year, NAACCR will be providing all the content for the fall edition of the Journal of Registry Management, the official journal of the National Cancer Registrars Association. This is a wonderful opportunity for us to highlight original research and operations information from the central cancer registry world. The plan going forward is that NAACCR will do this each fall, with the Research and Data Use Committee taking the lead on soliciting and peer-reviewing submitted articles.

I know we will all miss seeing one another at the annual conference – the networking opportunities are a significant part of why our conference is so successful each year. I hope to “see” all of you at our virtual conference in June. Until then, please take care and stay well!
**NAACCR Welcomes Stephanie Hill**

We are pleased to welcome Stephanie Hill, MPH, CTR as the newest member of the NAACCR team. In her role as Associate Director, Stephanie will be coordinating the National Childhood Cancer Registry (NCCR), working with registries to establish and implement procedures and managing several working groups focused on various aspects of the NCCR that involve utilization of data, confidentiality and other important components. Stephanie will also be coordinating the NAACCR Covid-19 data collection task force and several other initiatives.

Stephanie brings to the position nearly two decades of central and hospital registry experience. Prior to joining NAACCR, Stephanie was Program Manager of Operations for the New Jersey State Cancer Registry, where she led the registry in fulfilling the requirements of both SEER and NPCR. Earlier in her career, she played a role in establishing New Jersey’s comprehensive cancer control program and managing the network of workgroups and committee’s involved in implementing the state’s cancer control plan. More recently, Stephanie has served as a member of the NAACCR Nominating Committee and member and co-chair of the Professional Development Steering Committee. Stephanie earned her Masters of Public Health degree from Johns Hopkins University in 2008 and is a certified Lean Six Sigma Green Belt. She lives in New Jersey where she spends her free time gardening and caring for her menagerie.

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**Collecting COVID-19 And its Impact on Cancer Treatment**

*Stephanie M. Hill, MPH, CTR, Associate Director*

*shill@naaccr.org*

The cancer surveillance community expects the current COVID-19 global pandemic to have far-reaching implications for cancer patients, both directly, for those infected with the disease, and indirectly, for patients who may experience delays or changes in their cancer treatment plan due to the availability of health services, the widespread postponement of elective surgeries, and other changes to health care delivery. Organizations such as the American Society of Clinical Oncology (ASCO), the American College of Surgeons (ACS), and the National Comprehensive Cancer Network (NCCN) have published guidelines and resources for making cancer treatment-related decisions during the COVID-19 outbreak. We recognize that it will be important for registries to monitor, assess and analyze these impacts and their effect on patient outcomes.
In May, NAACCR convened two task forces comprised of representatives from NCI, CDC, NCRA, NAACCR, CoC and central and hospital cancer registries to strategize methods for collecting and documenting COVID-19 infection status and treatment impacts. The groups assessed the feasibility of implementing new data items or modifying existing data items in the registry abstract to capture COVID-19 related data. Ultimately, it was determined that it is not feasible to introduce new data items in the existing NAACCR record layout. Instead, the groups developed guidelines for documenting COVID-19 in existing text fields. The guidelines are available at https://seer.cancer.gov/tools/covid-19/.

In addition, the Mid-Level Tactical Group and High-Level Strategic Group are considering a proposal from the Commission on Cancer to introduce four new COVID-related data items in NAACCR v21, scheduled for implementation in January 2021. Although the deadline for introducing new data items has passed, the groups felt the unprecedented nature of the global pandemic warranted consideration of an exception. If approved, NAACCR will make every attempt to minimize the resulting delay in v21 implementation.

For many central registries, population-based COVID-19 infection status for incident and prevalent cancer patients can be obtained via linkage with the state’s infectious disease surveillance system or electronic laboratory reporting system. NAACCR will be working with our partners over the coming weeks and months to assess the potential for linkages, as well as for targeted special studies. More information on NAACCR’s COVID-19 activities will be available at www.naaccr.org.

**Highlights from the Program Manager of Standards**

![Lori Havener](https://www.naaccr.org/images/lori_havener.jpg)

*Lori Havener, CTR, NAACCR Program Manager of Standards*

lhavener@naaccr.org

**Data Standards and Data Dictionary, Volume II, Version 21:**

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. All references to column numbers (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/](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), the length for Medical Record Number and data item name changes to the AJCC TNM Post Therapy (yp) data items. The new data items include five new SSDIs, three new neoadjuvant therapy data items, new AJCC TNM Post Therapy yc data items, six derived versioning data items (2 each for the AJCC API, CDC Staging API and the Schema ID), and Name Birth--Surname.
The NAACCR v21 Reference Page provides information for 2021 implementation. It includes 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 2021 implementation process.

2021 Implementation Guidelines:

The 2021 Implementation Guidelines Task Force held their first meeting the end of March 2020 to start working on the 2021 Implementation Guidelines. This task force will routinely meet as they develop the guidelines. These implementation guidelines are scheduled for release by August 1, 2020.

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.

<table>
<thead>
<tr>
<th>Activity</th>
<th>NAACCR Deadlines</th>
<th>Considerations/suggestions to meet NAACCR deadlines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proposed requests-for-change for new data items requiring field testing</td>
<td>July 1, 2020</td>
<td>• Complete request-for-change forms for and submit to the MLTG by July 1, 2020</td>
</tr>
<tr>
<td>(most new and some changed data items) submitted to the Mid-Level Tactical Group (MLTG), followed by UDS for preliminary review.</td>
<td></td>
<td>• Data items approved by MLTG will be sent to UDS for preliminary review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Standard setters should have plans to conduct field testing within the timeframe required for final approval</td>
</tr>
<tr>
<td>Field testing initiated</td>
<td>September 3, 2020</td>
<td>• For items that require field testing, testing to be initiated by September 1, 2020</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Testing of newly proposed SSDI data items and “yc” data items and concept</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• NCI with support from IMS and NCRA will facilitate testing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• All Standard Setters invited to participate</td>
</tr>
<tr>
<td>Proposed requests-for-change for changes to existing data items that do not require field testing submitted to MLTG for final review.</td>
<td>October 1, 2020</td>
<td>• 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.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• MLTG may elect to require field test</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Note: MLTG to develop a request-to-change form for items that do not require field testing</td>
</tr>
<tr>
<td>Activity</td>
<td>NAACCR Deadlines</td>
<td>Considerations/suggestions to meet NAACCR deadlines</td>
</tr>
<tr>
<td>----------</td>
<td>------------------</td>
<td>---------------------------------------------------</td>
</tr>
</tbody>
</table>
| 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  
• 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, 2021 | • 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 |
<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Convene NAACCR 2022 Implementation Guidelines Task Force</td>
<td>May 1, 2021</td>
<td>• Materials for the Data Standards and Data Dictionary must be in final format for the Task Force to develop the implementation guidelines.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Final versions of mapping and/or conversions.</td>
</tr>
<tr>
<td>UDS submits NAACCR Standards for Cancer Registries Volume II, Version 22 to NAACCR Board for review/approval</td>
<td>June 1, 2021</td>
<td>• UDS final review/approval at their May meeting.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 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.</td>
</tr>
<tr>
<td>NAACCR Standards for Cancer Registries Volume II, Version 212 Released</td>
<td>July 1, 2021</td>
<td></td>
</tr>
<tr>
<td>NAACCR 2022 Implementation Guidelines Released</td>
<td>August 1, 2021</td>
<td></td>
</tr>
<tr>
<td>EDITS metafile release</td>
<td>August 1, 2021</td>
<td>• EDITS Work Group will have begun development of edits metafile by April 2021.</td>
</tr>
<tr>
<td>Education and training</td>
<td>Ongoing as material becomes available</td>
<td>• Develop training materials by October 1, 2021, and provide adequate training opportunities before January 1, 2022.</td>
</tr>
<tr>
<td>NAACCR Standards for Cancer Registries Volume II, Version 22 effective date</td>
<td>January 1, 2022</td>
<td></td>
</tr>
</tbody>
</table>

**Pathology Laboratory Electronic Reporting, Volume V, Version 5.0**

The NAACCR Volume V Revision Task Force has been working to update the Pathology Laboratory Electronic Reporting document to capture the evolving electronic pathology data. For example, capturing information from multiple types of reports, originating from the same specimen, in order to gather and group anatomical and additional reports. The previous Pathology Laboratory Electronic Reporting, Version 4.0 considered the SPM segment as option. In the updated document, Version 5.0, the SPM segment is required to correctly track identifiers in modern laboratory analyses.

Inclusion of the SPM segment into registry interface required the taskforce to:

- Expand on descriptions of pathology report formatting.
- Add clarification to specimen definitions and expand specimen types and workflow between multiple facilities.
- Introduce the ‘Registry Use Case.’
Have you had a chance to look at the NAACCR Education and Training Calendar?

https://education.naaccr.org/upcomingevents

There is a lot happening in the spring, summer, and fall of 2020! Let me point a few of the highlights:

**NAACCR 2020 Virtual Conference**

Since you can’t join us for the NAACCR Annual Conference in Philadelphia this year, we are bringing the conference to you! Well, maybe not the whole conference, but we are bringing you the plenary speakers: https://www.naaccr2020.org/plenary-speakers.

Registration is free and everyone is invited to join: https://www.naaccr2020.org/

All sessions will be recorded and posted to the NAACCR Education page: https://education.naaccr.org/

**NAACCR Talks**

Keep an eye on the NAACCR Education and Training Calendar. We have two NAACCR talks scheduled in the next couple of months and several more still in the planning phase. NAACCR talks are free webinars developed in conjunction with the NAACCR Research and Data Use Steering Committee. All presentations are recorded and made available to everyone at https://education.naaccr.org/freewebinars

**V21 webinars**

2021 will not see as many changes to the registry world as we saw in 2018, but the changes are not insignificant. NAACCR is doing everything we can to make sure registries have the time and resources to absorb these changes! NAACCR is planning on hosting webinars on the following topics.

- Grade 2021: While there are only relatively minor updates to the grade data for 2021, the NAACCR SSDI WG felt it was time to have another free training on the Grade data items. This webinar will be similar to the free grade webinar given in 2018, but will include updates that have occurred since the previous presentation and will include instructions for the new grade data item Grade Post Therapy Clin (YC). We expect this webinar to be presented in late August.
- SSDI 2021-During this webinar we will review all of the updates to the current SSDIs and review the coding instructions for the new SSDIs. This webinar will be free and we expect it to be presented in late November or early December.
- ICDO-3.2 and updates to the Solid Tumor Rules-During this webinar we will review changes in histology coding as we move to ICD-O 3.2. We will also review changes to the Solid Tumor rules and how registrars should use ICD O 3.2 along with the Solid Tumor Rules to assign histology.
- Customizing a Central Registry Edits Metafile-NAACCR will be hosting an online training for central registry edit metafile administrators. During this training we will review the basics of customizing a central registry edits metafile and how update a central registry metafile to accommodate an .xml record.

**NAACCR 2019-2020 Webinar Series (this season)**

With so many people unexpectedly working from home these past few months, NAACCR has given all of our subscribers (at no additional charge) the option to have their staff the option to login from home rather than viewing the webinars in a group setting. We will continue this option at least through July. Once things start to get back to normal, we will no longer be able to offer this option. However, we do offer a very reasonable priced option for staff working remotely. If you purchase a full webinar series, you can have up to 5 staff members login remotely for just an extra $300. That means up to 5 staff have full remote access to all 12 webinars for the one-time fee!

- +1 Remote Staff Member $100
- +3 Remote Staff Members $200
- +5 Remote Staff Members $300

**NAACCR 2020-2021 Webinar Series (next season)**

Registration is now open. We have a great line-up this year with all-star trainers! [https://20tqtx36s1la18rvn82wcmpn-wpengine.netdna-ssl.com/wp-content/uploads/2020/05/Webinar-Sched-Descrip-2020-2021.docx](https://20tqtx36s1la18rvn82wcmpn-wpengine.netdna-ssl.com/wp-content/uploads/2020/05/Webinar-Sched-Descrip-2020-2021.docx)

- For more information see NAACCR 2020-2021 web page: [https://education.naaccr.org/2020-2021-webinar-series](https://education.naaccr.org/2020-2021-webinar-series)

**NAACCR CTR Prep and Review Series**

At the time of this article we are preparing for week 7 of our 8-week series. We have a great group this session! They have been very active on the discussion boards and have had lots of questions during our live sessions! Our next series will start 8 weeks prior to the October testing window. NCRA has scheduled an additional testing window in September. We will not have a series prior to that session.

Questions, comments, or suggestions?

Send me an email at [jhofferkamp@naaccr.org](mailto:jhofferkamp@naaccr.org)

Angela Martin amartin@naaccr.org  Jim Hofferkamp jhofferkamp@naaccr.org
### Upcoming Webinar Presentations

<table>
<thead>
<tr>
<th>Date</th>
<th>Upcoming Webinar Presentations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>June 2020</strong></td>
<td></td>
</tr>
<tr>
<td>6/16/2020</td>
<td>NAACCR CTR Exam Prep &amp; Review Session 7</td>
</tr>
<tr>
<td>6/23/2020</td>
<td>NAACCR CTR Exam Prep &amp; Review Session 8</td>
</tr>
<tr>
<td>6/23/2020</td>
<td>NAACCR 2020 Virtual Conference</td>
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<tr>
<td>6/24/2020</td>
<td>NAACCR 2020 Virtual Conference</td>
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<tr>
<td>6/25/2020</td>
<td>NAACCR 2020 Virtual Conference</td>
</tr>
<tr>
<td><strong>July 2020</strong></td>
<td></td>
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<tr>
<td>7/8/2020</td>
<td>NAACCR Virtual Student Oral Presentation</td>
</tr>
<tr>
<td>7/9/2020</td>
<td>NAACCR Webinar Series: Navigating the 2020 Survey Application Record (SAR)</td>
</tr>
<tr>
<td>7/22/2020</td>
<td>NAACCR Talk: Informatics Tools and Processes for the XML Data Exchange Standard</td>
</tr>
<tr>
<td><strong>August 2020</strong></td>
<td></td>
</tr>
<tr>
<td>8/8/2020</td>
<td>NAACCR Webinar Series: Corpus Uteri</td>
</tr>
</tbody>
</table>

For more information about NAACCR education and training opportunities or to register online, go to the Education and Training tab on the NAACCR website [naaccr.org](http://naaccr.org), or contact Jim Hofferkamp [jhoferkamp@naaccr.org](mailto:jhoferkamp@naaccr.org).
Research & Data Use

As we navigate these challenging times, it is important to remember that the work we do is important. Cancer surveillance remains a vital piece in the effort to reduce the burden of cancer in our communities. For decades in the U.S., we have been committed to providing high quality demographic data to quantify the impact of race and social issues on cancer outcomes. In the past few years, we have greatly increased the availability of area-based SES measures in the CiNA dataset to support such research. Currently, NAACCR members are coordinating with SEER to begin to collect Covid-19 data in our registry data to assess the direct and indirect impact of the disease on the cancer population (see more in Stephanie’s section: Collecting Covid-19 and its Impact on Cancer Treatment). These activities are a testament to the unwavering commitment of NAACCR members to high quality data collection that is responsive to increasing, and relevant, demands on data use.

Certification

Certification has been released along with 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 2016-2019) here: https://www.naaccr-cina.org/ along with a new Data Visualization Tool for the data assessment reports. An introductory tutorial is available on our Call for Data Site: https://www.naaccr.org/call-for-data/#Submit. The Data Visualization Tool is presented in Tableau, so registries without a Tableau license can download the free reader here: https://www.tableau.com/products/reader.

Along with Certification, NAACCR has also released the inaugural Fitness for Use for Survival/Prevalence Recognition. Qualifying registries may download the updated logos here: https://www.naaccr.org/certification-criteria/. Official certifications will be sent out after our Virtual 2020 Conference.

CiNA

Our CiNA 2013-2017 Monograph has been released. This year’s CiNA Report marks the 30th year of publication and represents the most complete assessment of cancer burden in North America. We are grateful for the efforts of NAACCR member registries to collect high quality and timely cancer surveillance data to support such publications.
Now that the *CiNA Monograph* is released, we are able to release the CiNA Research Datasets for 1995-2017, including the CiNA Public Use File. To access the Public Use File or submit a proposal for a CiNA Research File go here: [https://www.naaccr.org/cina-data-products-overview/](https://www.naaccr.org/cina-data-products-overview/).

The *CiNA Monograph* encompasses five separate volumes:

1. **Volume One: Combined Incidence for the United States, Canada, and North America.** Includes aggregated cancer incidence data by site, sex, race, ethnicity, and stage, including pediatric cancer and cancer by stage at diagnosis from the high quality registries in the U.S. and Canada.

2. **Volume Two: Registry-Specific Cancer Incidence in the United States and Canada.** Includes registry-specific cancer incidence rates by cancer site, sex, race, ethnicity and stage for all NAACCR member registries submitting data for inclusion in the monograph. To help interpret the statistics, data tables for each registry include demographic and data quality information and registry descriptions are presented.

3. **Volume Three: Registry-Specific Cancer Mortality in the United States and Canada.** Includes registry-specific cancer death rates by cancer site, sex, race, and ethnicity.

4. **Volume Four: Cancer Survival in the United States and Canada.** Includes cancer survival data for the U.S. and Canada from 61 registries on more than 13 million cases diagnosed among North Americans between 2010 and 2016.


There are two important methodological changes to the *CiNA Monograph*.

1. **Registry inclusion/exclusion.** We used to apply the registry inclusion/exclusion criteria for each year and a registry needed to “pass” all five years to be included in the monograph. However, since we do not present the data by year, we applied the inclusion/exclusion criteria based on the 5-year aggregated data. This results in more consistent data and the most complete coverage for both US and Canada.

2. **Case Counts.** We used to include Total Case Counts in the Incidence and Mortality Tables, but this year we switched to Average Annual Count. This provides a more intuitive metric and is in-line with the practice of many registries. It is important to note that this is a change in how we are presenting the data but not in what data are presented. We are still suppressing at <6 cases, but instead of the 5-year count, we are presenting the average over the 5 years. Previously, users would divide the count by 5 to get this number.

**Call for Data**

Our 2018 diagnosis year Call for Data planning has begun. This will be a year with a number of challenges that may impact our submissions. We will be establishing a Call for Data listerv site to help facilitate communication on the Call for Data timelines, process, and tools.

Note: there are still a few registries that need to complete or review the CaRRI database. This process is requested at time of Call for Data but can be completed throughout the year.

As always, if you have any questions or concerns, please contact me at rsherman@naaccr.org.

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**Virtual Pooled Registry Update**

_Castine Clerkin, MS, CTR, NAACCR Program Manager of Virtual Pooled Registry_

cclerkin@naaccr.org

Boy, the world has gone a little topsy-turvy since the last _NAACCR Narrative_! I hope that you are all adjusting and staying well. Despite the upheaval, progress on the VPR Cancer Linkage System (VPR-CLS) testing and associated resources continues. Here are some recent highlights:

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

**NEW! National Death Index Fact Sheet**

Over the past year or so, it has come to our attention that there are different interpretations about how information from the National Death Index (NDI) linkage, including cause of death, can be shared with external parties. A fact sheet summarizing the allowable release was created based on review of the NPCR-NDI application used by all NPCR and SEER registries. The NDI Fact Sheet can be found here: [https://www.naaccr.org/registry-operations-guidelines/](https://www.naaccr.org/registry-operations-guidelines/)

**Phase I Pilot Testing**

Our final Phase I pilot test study, _The Effects of Education on Cancer in High School and Beyond_, was released for linkage in the midst of registry staff transitioning to work from home and being recruited to support COVID-19 activities in their health departments. Even so, 75% of the pilot test registries completed the Phase I
linkage and uploaded match count reports within the intended 2 ½ week timeframe, and a number of registries submitted shortly after the May 1st due date. Thank you! This is a testament to both the commitment of the registries and the ease of the process.

**Phase II Pilot Testing**

Phase II supports the streamlined process of applying for release of individual-level cancer data on matched cases identified in the Phase I linkages. Two studies from the Phase I testing are now involved in Phase II testing. The web-based Templated IRB/Registry Application (TIRA) has been adopted by 84% of the 38 participating pilot test registries, significantly reducing the number of individual applications completed by the researcher. For reviewing bodies unable to use the TIRA, the VPR-CLS provides a list and URL for any state-specific applications. Once submitted, VPR Liaisons in each registry are populating the VPR-CLS tracking system with information on the estimated IRB/registry review dates and approval status to help researchers monitor the request across registries. To date, the Childhood Cancer Survivor Study has been approved by 11 registries, the Transplant Cancer Match Study has been approved by 14 registries, and the researchers are excited to be receiving cancer data!

**Templated Data Use Agreement**

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 Project 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. Once completed, the Templated DUA will be shared with registries and their legal teams for feedback and input on the ability to adopt a standard form. Vetting of the Templated DUA is anticipated this summer.

**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. Please save the date! 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
- P3RLS – Privacy Preserving Patient Record Linkage Software Evaluation
- Towards a new paradigm in data sharing: A pilot study of remote access to cancer registry data

Wishing you all the best as we navigate through these uncharted waters together!

Castine Clerkin, NAACCR VPR Program Manager
2020 NAACCR Election Results

Chandrika Rao, PhD
Chair, NAACCR Nominating Committee

2020 NAACCR Election Results

The NAACCR Nominating Committee was charged to identify volunteers to serve on the NAACCR Board. For the 2020-2021, there were five key leadership roles: President Elect; three (3) openings for Representatives-at-Large; and a Sponsoring Member Organization Representative.

Sixty-eight of 86 voting members voted (80%). The Nominating Committee would like to thank everyone who agreed to be included in the election as well as Charlie Blackburn and Tyler Scott from the NAACCR office for their assistance.

Elected candidates are:

President Elect:
Winny Roshala, BA, CTR; Director
Cancer Registry of Greater California

Representatives-at-Large:
Monique Hernandez, Ph.D; Manager and
Meaningful Use Coordinator
Florida Cancer Data System

Mary Jane King, MPH, CTR; Manager
Ontario Cancer Registry

Angela Meisner, MPH;
Epidemiologist/Epidemiology Section Manager
New Mexico Tumor Registry

Sponsoring Organization Representative:
Lori Swain, MS; Executive Director
National Cancer Registrar’s Association

NAACCR Nominating Committee members:

Chair – Chandrika Rao, PhD; Director
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Cancer Registry of Greater California
Results of the NAACCR Assessment of Telework & COVID-19

Thank you to the 55 registries who participated in the NAACCR Assessment of Telework & COVID-19! We know you are facing a lot of demands on your time – now more than ever – and we appreciate your taking the time to send us your responses.

The assessment revealed a marked increase in the percent of registries allowing telework before the COVID-19 pandemic (56%) and since the outbreak began (96%). Registry operations and epidemiology/research staff are most commonly using telework (91% and 92%, respectively), while contracted (44%), part-time/per diem (52%), and trainees/probationary staff (61%) were least likely to be permitted to telecommute, although those numbers are increased from prior to the pandemic. See Figure 1.

![Figure 1. Percent of Registries with Staff Working Remotely Before COVID-19 and Since the Pandemic Began](image)

Some registries have reported staff being reassigned to work on COVID-related activities. This was most common among management and epidemiology/research staff, with more than 30% of registries reporting staff in being reassigned in part or in full. Some registries reported operations, IT and administrative staff also being reassigned. See Figure 2.
The greatest barriers to telework were technical, with 50% of registries reporting either a lack of equipment (i.e., laptops) or lack of a technical solution (i.e., VPN) as a barrier (see Figure 3). However, of those staff working remotely, 83% are able to perform the same tasks they were performing on-site (see Figure 4).
NAACCR is dedicated to helping registries through the challenges posed by the COVID-19 pandemic. In April, we held a NAACCR Talk to demonstrate the new NAACCR Telecommuting Toolkit and address questions from registries. A recording of the webinar is available on the NAACCR web site. Also be sure to check out the NAACCR Central Registry Telecommuting Forum for ongoing discussions at https://share.naaccr.org/public-forum/.

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

*Mignon Dryden, CTR*
NAACCR Liaison to PERT

**Update from College of American Pathologists (CAP) Pathology Electronic Reporting Taskforce (PERT)**

NAACCR and CAP are working toward a more enhanced collaboration and details will be shared as they develop. In addition, a collaboration has started with NCI-SEER, CDC, AJCC and WHO to standardize ICD-O-3 mapping codes for registrars and more information will be shared as it becomes available.

PERT is working on new modeling for Margins sections and Lymph Node sections of CAP Cancer Protocols which should begin rolling out in 2021.
The latest release of the CAP Cancer Protocols and eCC Templates, which occurred the end of February, included many updates such as:

- 87 eCC templates in SCD-XML format
- 34 templates have changes that do affect accreditation date; new accreditation date is 11/1/2020
- For Colon and Rectum Resection template, added requirement for Macroscopic Evaluation of Mesorectum for rectal cancers and included revisions to Margin section
- Anus Local Excision template was revised to include changes to the Mucosal margin section
- For the Prostate Radical Prostatectomy template, added Tertiary Pattern 5 (less than 5%) in Overall Gleason Score 7 (if applicable), changed Gleason Pattern at Positive Margin(s) to select all that apply, and added Laterality to Lymph Nodes
- For the Prostate TURP template, removed Urothelial tumor, including variants from list of tumor types that should NOT be reported and added Histologic Grade reporting for urothelial carcinoma and squamous cell carcinoma, if applicable
- Breast DCIS Biopsy template has an added section for Architectural Pattern
- Breast Invasive Biopsy template has an added section for Tumor Size
- Uterine Cervix Excision and Resection templates have revised Extent of Invasion sections

Many thanks to Keren Hulkower of CAP for generously sharing his slides regarding the recent release.

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**CAP eCC Users are Reporting Cancer Cases Across the U.S.**

_Samantha Spencer_
College of Pathologists

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**CAP electronic Cancer Checklist (eCC) users are reporting cancer cases across the US.**

Over 6500 pathologists across the US and Canada use the College of Pathologists electronic Cancer Checklists (eCC) to report on their diagnostic cancer cases [www.cap.org/capecc](http://www.cap.org/capecc). The eCC is the electronically implementable and usable version of the CAP Cancer Protocols [www.cap.org/cancerprotocols](http://www.cap.org/cancerprotocols) that pathologists can use to create a complete standardized, structured diagnostic cancer report within their LIS workflow. These reports provide critical information about the diagnosis, prognosis, and inform the treatment pathways for patients. The data from these reports is sent to local, state, and national cancer registries, with joint projects currently underway with to better harmonize and automate sending this data to registries.

Hospitals and health systems across the US use the eCC for cancer reporting in 49 out of 50 states, with the number of users growing each year. If you have questions about how the CAP and cancer registries are coordinating to improve cancer reporting, please reach out to [capecc@cap.org](mailto:capecc@cap.org).
The Challenges and Successes of Transitioning to CRS Plus

David O’Brien
Alaska Cancer Registry

The Challenges and Successes of Transitioning to CRS Plus after 18 Years with a Private Vendor

Background: For the previous 18 years, the Alaska Cancer Registry (ACR) had been using Precis-Central, a central registry database system developed by Elekta. With the announcement of the extensive NAACCR v18 standard changes, the vendor made the business decision to no longer support the software, prompting ACR to search for another central database system.

Purpose: ACR chose CRS Plus and Prep Plus from NPCR’s Registry Plus software suite to replace its current database system. The move from the old system to the new system would have to include both NAACCR and state-specific data items, and preserve consolidated data items that may not necessary be consolidated by default in the new system.

Methods: During the transition to the new software, pre-planning and close collaboration occurred between ACR and the NPCR SMEs and software engineers. The ACR data analyst was able to produce files of consolidated patient-level, consolidated tumor-level, and attached facility-level cases, as well as of unattached facility-level cases in Pending that still needed dispositioning. The software engineer created “special import” SQL scripts that uploaded each data file into the CRS Plus database. ACR used
this initial database on an interim basis for about a month for testing and training purposes before repeating the process for a final special import. The SMEs for CRS Plus and Prep Plus provided ACR with comprehensive training manuals for the new software. In-person training was also available at the 2019 NCRA and NAACCR conferences.

Results: The transition of the ACR database from the old system to CRS Plus was successful. The old and new software systems are actually based on the same core program from about 20 years ago and have similar database structures and data flows. This greatly helped with the data analyst’s transition tasks and the registrar staff’s training.

Conclusions: Once the transition was completed in August 2019, the data analyst worked closely with the CRS Plus SME and software engineer to upgrade the CRS Plus database from NAACCR v16 to v18. ACR is now fully operational in its use of CRS Plus and Prep Plus.

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**NAACCR Narrative Publication Information**

Summer 2020 Submission 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.*

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