Message From the President

Chuck Wiggins, PhD
NAACCR President

I am honored to once again represent NAACCR at the Annual Meeting of the International Association of Cancer Registries (IARC). As I write this short piece, I am in Marrakech, Morocco, with our Executive Director, Betsy Kohler and fellow Board member Lori Swain. Many of you know that Lori is also Executive Director of the National Cancer Registrars Association. The first IACR conference that I attended was held in conjunction with NAACCR’s Annual Meeting in Ottawa, Canada in 2013. I’ve been hooked ever since. It is fascinating to see how cancer surveillance and associated research is conducted around the globe. The burden of cancer varies dramatically by geographic region and it is highly instructive to see how registries contribute to control activities within their various catchment areas. The IACR meetings also provide a venue to promote various NAACCR priorities and activities.

Speaking of conferences, the Call for Abstracts for the 2017 NAACCR Annual Meeting will be released this month. Historically, the deadline for submitting abstracts has been mid-December. We are shaking things up a bit by extending the “due date” until January 30, 2017. We hope to increase the number of submitted abstracts and decrease our members’ stress level by extending the due date through the first month of the New Year.

My colleagues and I at the New Mexico Tumor Registry are pleased to be hosting the 2017 NAACCR Annual Meeting in Albuquerque. The conference title will be “Breaking Barriers in Cancer Surveillance.” The NAACCR Program Committee is working hard to identify plenary sessions and speakers that will engage our members. I can tell you that we’ve already reserved places on the agenda to address cancer disparities and cancer in special populations, including a focus on cancer in Native Americans. We look forward to welcoming you to Albuquerque next June!

Message From the Executive Director

Betsy A. Kohler, MPH, CTR
NAACCR Executive Director
bkohler@naaccr.org

Greetings from Marrakech!

NAACCR is well represented at the 38th International Association of Cancer Registries (IACR) Conference in Marrakech, Morocco this week. With at least 13 individuals representing North American central registries and partner organizations, we are sharing our knowledge with Keynote addresses, posters, oral presentations, and by moderating sessions. We are learning a great deal as well, gathering ideas for the next NAACCR meeting, future surveillance webinars, and much, much more.

I am delighted to report that our own Dr. Vivien Chen, former NAACCR President and Calum Muir Lifetime Achievement Award winner, is being honored this year by the IACR with an Honorary Membership for her dedication, contributions, and leadership in the field of international cancer surveillance. Vivien’s accomplishments and enthusiasm are well known to us, and it is rewarding to see her acknowledged by IACR with this prestigious award. Congratulations Vivien!
From here, some of us are travelling to the UICC meeting in Paris at the end of October, where NAACCR will once again be well represented. This time the focus of our participation will be on the role of cancer registries in cancer control.

NAACCR members at the 38th International Association of Cancer Registries (IACR) Conference in Marrakech, Morocco

**Highlights From the Program Manager of Standards**

*Lori A. Havener, CTR*

*NAACCR Program Manager of Standards*

**Standards Volume II, Version 17**

The NAACCR Uniform Data Standards (UDS) Work Group has diligently worked on the new and changed data items for Standards Volume II, Version 17. The standard setters have agreed to implement the AJCC 8th Edition data items that are required for staging in 2017, these will use the existing SSF structure with the addition of 2 new SSF data items (SSF 26 and 27). NAACCR Standards Volume II, Version 17 is scheduled for release on December 1, 2016.

**2017 Implementation Guidelines**

The NAACCR 2017 Implementation Guidelines Task Force is being convened to work on the 2017 Implementation Guidelines and Recommendations. Please contact Lori Havener ([lhavener@naaccr.org](mailto:lhavener@naaccr.org)) if you are interested in participating on this group.

**Standards Volume II, Version 18**

If you have any requests for new or changed data items for Standards Volume II, Version 18, they must be submitted to the CMB in October 2016!

<table>
<thead>
<tr>
<th>Standards Volume II, Version 18</th>
<th>Timeline</th>
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<tbody>
<tr>
<td>Proposed changes submitted to CMB</td>
<td>October 1, 2016</td>
</tr>
<tr>
<td>Proposed changes approved by CMB</td>
<td>December 1, 2016</td>
</tr>
<tr>
<td>CMB submits request for change to UDS</td>
<td>January 1, 2017</td>
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<tr>
<td>Volume II Task Force review</td>
<td>March 1, 2017</td>
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<tr>
<td>Draft submitted to UDS and the S&amp;RD SC for review/approval</td>
<td>May 1, 2017</td>
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<tr>
<td>Draft submitted to NAACCR Board for review/approval</td>
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<tr>
<td>Post to NAACCR website</td>
<td>July 1, 2017</td>
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<tr>
<td>Version 17 Implementation</td>
<td>January 1, 2018</td>
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**Current Activities:**
NAACCR has a great group of dedicated volunteers who work on the many activities that are under the Standardization and Registry Development (S&RD) priority area. See the [NAACCR Strategic Management Plan for 2016 – 2021](#) for more information on the S&RD priority area. The S&RD Steering Committee is assessing the new objectives and planning for 2016 – 2021. Here is a list of the some of the current activities:

- **EHR Reporting and Volume II Harmonization Task Force**: Evaluate the need for addition/revision of data elements in NAACCR Standards for Cancer Registries, Volume II Data Standards and Data Dictionary (Volume II) as a result of the electronic health record (EHR) reporting from the Meaningful Use (MU) activities. The goal is to harmonize Volume II to better accommodate EHR reporting.
- **SSN Removal Initiative Task Force**: Create a new data item for 2018 to collect the Medicare Beneficiary Identifier; and, evaluate the issue of the unavailability of the SSN.
- **Volume V Revision Task Force**: Develop additional guidance in the NAACCR Standard Volume V, Pathology Laboratory Electronic Reporting to address reporting of original pathology report information with biomarker and molecular laboratory test data.
- **XML Data Exchange Work Group**: Provide the documentation, tools, and training that enables the NAACCR community to transition from the fixed-width data exchange standard to the NAACCR XML data exchange standard.

### NAACCR Research and Data Use Update

**Recinda Sherman, MPH, PhD, CTR**  
*NAACCR Program Manager of Data Use and Research*

This is a busy time of year with Call for Data preparations. It is amazing that we get anything done as our flow tends to fall into a bimodal pattern of postponing everything until “after the Call for Data” and then postponing everything again until “after the Annual Meeting.” So, I hope you take a moment, grab a hot cider, and enjoy the Fall weather as I take you through the weeds on the county at diagnosis variables...

#### County at DX

Historically, we had a single County at DX, NAACCR Item #90. This was a problem because: (1) counties change over time (which impacts our derived variables such as poverty code indicator which don’t directly align with year of diagnosis); and (2) the county reported by the facility does not always match the geocoded county. In the vast majority of cases where geocoded county and reported county differ, the geocoded county is correct.

NAACCR layout v16 has three sparkling, new data items for county at diagnosis (#94 Geocoded County at DX 1990, #95 Geocoded County at DX 2000, #96 Geocoded County at DX 2010). Although the inclusion of these variables ensures more accurate assignment of County at DX, registries need to be aware of a couple of issues.

Many states do not override the reported county data with the geocoded county data. Note: only high-quality geocoded data should override a reported county (Census Tract Certainty 1, 6, or, after manual review, 2-4). With the new v16 geocoded county variables, this is no longer an issue. But for registries that have not yet converted, relying solely on reported county in Item #90 can result in erroneous county designations and incorrect derived data when the reported county is paired with the geocoded census tract.

The tract number is only unique when combined with state and county. Tract number 001100 is a common tract number that is valid for many U.S. counties. So if the reported county is wrong, the poverty codes and other area-based SES measures are also wrong. The use of these area-based SES measures has become a critical component to our understanding of the health of communities. We have an edit that looks for incorrect year-state-county-tract combinations. But because tract numbers are often the same in multiple counties, the edit can only identify an unknown proportion of the errors if the reported county is paired with the geocoded census tract.

Using the new geocoded county codes addresses the accuracy of the county, census tract, and the derived tract area-based SES measures. However, it also creates a new issue. In order to report county-level rates, we need to use a derived county code for analysis. If the reported county and the geocoded county associated with the year of diagnosis are the same, the derived county can be pulled from either for field. Otherwise, for ungeocoded cases, PO Box only cases, and ungeocodable cases (Census Tract Certainty blank, 5 or 9, respectively), the derived county equals the reported county. For cases geocoded to a street address or based on a city or zip with only one census tract (Census Tract Certainty 1 or 6, respectively), the derived county should equal the geocoded county associated with the decade of diagnosis. For example, pull Geocoded County 2010 for cases diagnosed 2010-2019. In the less
common instance that a geocode is based on a residence address but still geocoded to the centroid of a zipcode (Census Tract Certainty 2-4), manual review is required to improve the geocoded data quality. If the quality cannot be improved, the derived county will pull data from the reported county. Note: We plan to include this derived variable in new NAACCR layout versions. In the meantime, all our CiNA data products will include this derived data item.

Using the derived county for analysis will improve the accuracy of our county-level rates. However, this will result in spurious changes in our county rates, particularly for smaller counties. In general, large counties with high-volume cancer centers will “lose” cases but not enough to significantly impact county rates. But smaller, rural counties without medical facilities may “gain” enough cases to impact their rates (I have seen increases as high as 30%). There are also counties with large medical facilities that serve retirement communities outside of major metro areas, and these counties may also “lose” enough cases to significantly decrease their rates (I have seen decreases as high as 20%). Although these difference do not represent a change in county-level risk, the extent of the county changes will need to be reviewed and described before releasing county-level rates.

**Update on the Public Use Dataset**

Over the summer, 46 U.S. states plus DC and PR and 12 Canadian provinces covering 93% of the U.S. and 64% of the Canada population provided consent to include their data in the 1995-2013 CiNA-Public Dataset. The dataset is still being tested, and we anticipate the data being available by December 1, 2016. Subsequent consents for the 1995-2014 CiNA-Public Dataset will be conducted through the Call for Data process and annual release will be in July, after the CiNA Monographs have been published.

**Call for Volunteers!**

Recinda Sherman, MPH, PhD, CTR  
NAACCR Program Manager of Data Use and Research

We are looking for a few good NAACCR members for three areas in Research and Data Use.

1. Are you interested in NAACCR Research? We have three openings on the NAACCR IRB. We are looking for at least one Canadian representative as well as at least one member who would fill the role of community member (i.e. not a current NAACCR member and possibly a cancer survivor). The NAACCR IRB meets twice a year on a Friday, in April and October. Throughout the year, IRB members are asked to review papers for compliance with IRB, amend IRB proposals, and, occasionally, review exempt IRB protocols if the Chair and Vice-Chair are unavailable. All IRB members must be certified in Protecting Human Subjects Research by CITI, NIH, or their host institution. The certification process takes between 1 – 2 hours, and the NIH Training Materials are on our [NAACCR IRB page](mailto:NAACCR IRB page).

2. Are you concerned about confidentiality or have addressed confidentiality issues in your registry? We are starting a new task force (limited duration committee) to update the NAACCR resources on confidentiality. The task force will need to include issues related to geospatial data and may also develop products like online tutorials.

3. We are also looking for volunteers for another task force (limited duration committee) with the mission of developing training materials for central registry analysts. Products will include an on-line Research Analyst Handbook as well as developing other training resources for central registries.

   If you would like to volunteer or would like to suggest a volunteer for any of these projects (or if the discussion about county at dx made your head swim), please contact Recinda Sherman at rsherman@naaccr.org.

**NAACCR Education and Training Program Update**

Jim Hofferkamp, CTR  
NAACCR Program Manager of Education & Training

The first session of the 2016-2017 [webinar series](http://example.com) was held on October 6, 2016, and was on melanoma. We spent quite a bit of time discussing AJCC TNM Staging for melanoma of the skin. The rules for melanoma are quite a bit different from most sites, which led to quite a bit of discussion. Coding surgery for melanoma is also different from most other sites which, also led to quite a bit of discussion. Our Q&A document was 7 pages long!

The November webinar will be on Hematopoietics. This is a huge topic! We are going to focus on two topics; the hematopoietic database and manual and staging of lymphoma. We are very fortunate to have Jennifer Ruhl from SEER as a guest speaker to discuss the hematopoietic database and manual!

Speaking of the CTR Prep and Review Webinar Series...registration will soon be open for the February/ March Series. The test is early this year, so we will start the series early. Our first session will be on December 20, 2016,
and we’ll meet every Tuesday for 8 weeks. We record all of the sessions. If you can’t participate in the live session you can still view the recordings. One of the things I really like about the series is the interaction between the participants. Sometimes I think the support and encouragement between participants is just as important as the review of the material! There is still time to register if you are interested!

Check out the NAACCR Education and Training Calendar for a list of all of the upcoming training activities. Don’t overlook the Cancer Surveillance Webinar Series. These are free webinars presented by experts in their fields. If you miss the live session, we post the recordings on the Webinar Recordings page.

If you have questions about any of the NAACCR educational products or are interested in having the NAACCR Education and Training team develop a training workshop for your registry, send Angela or me an e-mail at jhofferkamp@naaccr.org or amartin@naaccr.org.

**NAACCR 2016-2017 Education and Training Calendar**

**October 2016**
- 10/04/2016  Session 7: CTR Exam Preparation and Review Webinar Series
- 10/06/2016  Collecting Cancer Data: Melanoma
- 10/11/2016  Session 8: CTR Exam Preparation and Review Webinar Series

**November 2016**
- 11/03/2016  Collecting Cancer Data: Hematopoietic and Lymphoid Neoplasm

**December 2016**
- 12/01/2016  Collecting Cancer Data: Lung

**January 2017**
- 01/12/2017  AJCC Staging

**February 2017**
- 02/02/2017  Collecting Cancer Data: Colon

**March 2017**
- 03/02/2017  Abstracting and Coding Boot Camp

**April 2017**
- 04/13/2017  Collecting Cancer Data: Lip and Oral Cavity

**May 2017**
- 05/04/2017  Multiple Primary and Histology Coding Rules

**June 2017**
- 06/01/2017  Collecting Cancer Data: Liver and Bile Ducts

**July 2017**
- 07/13/2017  Hospital Cancer Registry Operations – Topic TBD

**August 2017**
- 08/3/2017  Collecting Cancer Data: Central Nervous System

**September 2017**
- 09/7/2017  Coding Pitfalls

For more information about NAACCR education and training opportunities or to register online, go to the Education and Training tab on the NAACCR website (www.naaccr.org); or contact Jim Hofferkamp (jhofferkamp@naaccr.org).

**Virtual Pooled Registry Update**
Castine Clerkin, MS, CTR  
Program Manager of Virtual Pooled Registry

It’s been a busy few months for the Virtual Pooled Registry Cancer Linkage System (VPR-CLS). We would like to extend a huge thank-you to the 43 registries that volunteered for the second VPR-CLS pilot linkage with the NCI Radiologic Technologist cohort. More than 22,000 high-quality matches resulted from the linkage. In the coming months, the NCI and its contractor at the University of Minnesota will begin contacting registries to begin the request process for release of patient identifiers on matched cases. Investigators from the ATSDR Camp Lejeune pilot test have already begun directly contacting registries to pursue IRB approval.

You may have noticed that the NAACCR Call for Data instructions now include guidance for creating a VPR-CLS file. Our goal is for registries to create a single, standardized file once a year and have that file available for linkages that may occur during the year. Generating the VPR-CLS file is voluntary; however, we are optimistic that all registries will create this file as we identify ways to provide resources that will support registry participation in these linkages.

Activities to help streamline the IRB application process have also been pursued. State IRB applications were reviewed to identify common data elements for a templated IRB form. In addition, Vivien Chen, as a NAACCR consultant, talked with registries about acceptance and use of a centralized IRB and templated IRB form. Given the new NIH policy regarding central IRB review for multi-site research that Dennis Deapen discussed in the summer issue of the *NAACCR Narrative* (available here), we will continue to engage with registries to advance progress in this area.

Colorado and Idaho performed a linkage on hashed registry data. Hashed data allows registries to perform linkages on confidential data while that data is encrypted. The goal of this linkage was to perform inter-registry deduplication without sharing identifiable data. The registries then met in person to link their identifiable data, adjudicate the matches, and compare the results to the hashed linkage. This pilot linkage demonstrated proof-of-concept and identified areas for improvement in the process and the software. A second test of the system is being planned with multiple large registries.

On a personal note, Castine and her family welcomed Seamus Cavan Clerkin to the world on August 4th, weighing in at 7 lbs., 13 oz. and measuring 21 1/2” long. Seamus is happy, healthy, and sweet. Welcome to the NAACCR community little one!

Questions related to the VPR-CLS can be addressed to Castine Clerkin at cclerkin@naaccr.org.

**NAACCR Steering Committee Corner**

**Susan Gershman**  
*Massachusetts Cancer Registry*

Welcome to the Steering Committee Corner! This column will provide brief Steering Committee updates such as new reports or projects, coding changes, new data standards, 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)**

Co-Chairs: Laura Ruppert and Annette Hurlbut

Committee Highlights since the last *Narrative:*
A Best Practice document, a supplement to the Communications Plan, has been approved by the NAACCR Board. Available to download [here](http://news.naaccr.org/).

Recent Reports/Publications:


Other News to share with the NAACCR Community:

- Redesign of NAACCR website is in review with NAACCR staff; outside vendors and recommendations will be shared with the Committee soon.

**Professional Development Steering Committee (PDSC)**

Co-Chairs: Frances Ross and Mignon Dryden

Committee Highlights since the last Narrative:

- Work continues with updating the Survey Course “Understanding Population Based Cancer Registries” to web-based learning modules. Most of the modules have been completed by the authors with a voice-over PowerPoint presentation. A gradual release is planned.
- A web-based Learning Management System (LMS) has been developed and is successfully in use with the CTR Prep Course.

Other News to share with the NAACCR Community:

- Discussion on developing and implementing strategies for Recruitment and Retention in central registries continues. Efforts will be focused on two major careers (registrars and epidemiologists).
- Developing a specific action plan to increase awareness and employment in these fields.

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

Co-Chairs: Hannah Weir and Susan Gershman

Training/Education:

- NAACCR Webinars
  - Registry of the Future Open Forum: Real-Time Reporting Update and Discussion held on September 29, 2016, 2:00 pm Eastern Time.
  - Data Imputation held on October 12, 2016, 2:00 pm Eastern Time.

Other News to share with the NAACCR Community:

- Cancer Control Indicators Task Force Co-Chairs Recinda Sherman and Susan Gershman submitted an abstract to the National Cancer Registrars Association’s 2017 Annual Educational Conference.
- Two new task forces were organized: Confidentiality and NAACCR Certification Enhancement. The NAACCRR Certification Task Force met in August, but will need further meetings before any decision regarding modification to the present certification process is determined.

If you have a suggestion for a journal club or surveillance webinar topics, please contact Hannah Weir (hweir@cdc.gov) or Susan Gershman (susan.gershman@state.ma.us).

**Encore of Real Time Reporting Presentation From the 2016 NAACCR Conference**

*Mary Jane King  
Ontario Cancer Registry*

The Assessment of Central Cancer Registry Timeliness and Reporting Standards Task Force (ACCR-TRS TF) is a NAACCR group that evolved from the interest and special sessions on “The Registry of the Future” over the last few years. The Task Force is under the governance of the Standards and Registry Development Steering Committee. On September 29th, this group gave a webinar presentation that was an encore of the 2016 NAACCR Conference presentation from the results of the registry timeliness and completeness survey administered to American and Canadian jurisdictional cancer registries earlier in the year. This talk, and subsequent discussion, was entitled “Registry of the Future Open Forum - Real-Time Reporting Update and Discussion.”

The in-person conference event had 81 participants; and, the encore webinar showed at least 117 active lines into the presentation, probably representing multiple listeners at a site in many cases. A bonus feature of the encore
webinar was a presentation by Frank Boscoe (NY), who shared preliminary findings from an analysis conducted on the 12-month data submitted to NAACCR. Based on feedback, the audience included a great mix of central registries, vendors, and surprisingly (but very welcome!), several hospital cancer registrars. The webinar generated some very good discussion that will assist the Task Force going forward.

The webinar was facilitated and recorded – thanks to Angela Martin. The website for the NAACCR page where you can get more info about the webinar and access the slides and link to the recording is here.

Next Steps

The Task Force is still soliciting for central registry volunteers to participate in a special study that will be a detailed analysis of early reporting (2015 or 2016 data). Topics for consideration include data quality at varying points in time and characteristics of cases reported at specific times, including their timeliness and completeness. The study might also include a comparison between Canadian provincial 14-month data and U.S. 12-month data – so the Task Force certainly needs Canadian volunteers. Additionally, focus groups will be conducted to further illuminate the characteristics and challenges of volunteer registries.

To participate in the special study and for more information please contact Lori Havener at lhavener@naaccr.org.

We hope that you will join us!

ACCR-TRS TF Members:
Nan Stroup (NJ), Randi Rycroft (CO), Mary Jane King (ON, CA), Winny Roshala (CA), Lori Havener (NAACCR), Maria Celeya (NH), and our newest member Donna Morrell (CA)

12-Month Data TF Members:
Frank Boscoe (NY), Susan Gershman (MA), Reda Wilson (CDC), Mary Beth Culp (CDC), Alana Hudson (WV), and Recinda Sherman (NAACCR)

NAACCER Call for Nominations

Greetings to All NAACCR Members!

Have you been looking for a new challenge? Are you seeking a new way to contribute to the cancer surveillance community? Would you like to contribute to NAACCR decisions in a new way? If you answered “yes,” or even “maybe” to any of these questions – keep reading – we can help.

October is a very important time of the year for our organization as we start the process of identifying volunteers to serve on the NAACCR Board. The NAACCR Nominating Committee is seeking nominees to run for election in four key leadership roles in 2017: Treasurer and three (3) openings for Representative-At-Large.

NAACCR has been a unique and innovative partner in the cancer registration world for close to 30 years and volunteers have been a mainstay of our organization’s success. One of the many important ways that volunteers contribute to NAACCR is by serving on the Board of Directors. Through guiding existing programs and identifying future opportunities, Board members play a pivotal role in governing NAACCR affairs and moving the organization forward.

NAACCR recognizes that it is fortunate to have knowledgeable, dedicated, and progressive members who volunteer each year to serve on the Board. These members of the NAACCR community generously contribute their time and expertise, allowing NAACCR to make significant, valuable contributions to cancer surveillance.

Please consider recommending a qualified colleague for one of the four 2017 vacancies. Or, nominate yourself! For additional information on duties and eligibility, please click here.

The Nomination Form is available here.

The deadline for receipt of nomination forms in the NAACCR Office is 5:00 PM, Friday, December 9, 2016.

Submitted by:
Nominating Committee Members:
AJCC Releases Cancer Staging Manual, Eighth Edition

Kathleen K. Thoburn, CTR
Manager, Information & Data Standards
National Cancer Data Bank

The American Joint Committee on Cancer (AJCC) has released the eighth edition of its Cancer Staging Manual, which reflects current understanding of cancer biology concepts and emphasizes a more individualized approach to cancer classification and treatment. This edition presents evidence-based revisions for staging cancer for a number of organ sites and includes the rationale and rules for staging; the definitions of tumor, lymph node involvement, and metastasis (TNM); stage groupings; and histologic grade.

Cancer staging provides patients and physicians with the standards for determining the best treatment approach for their disease and their prognosis. Mahul B. Amin, MD, FCAP, Editor-in-Chief of the eighth edition, noted that 430 experts from 184 institutions in 22 countries on six continents collaborated to produce this resource. Dr. Amin is Professor and Chairman Emeritus, Department of Pathology and Laboratory Medicine, Cedars-Sinai Medical Center, Los Angeles, CA, and incoming chairman and endowed professor of the department of pathology and laboratory medicine at the University of Tennessee Health Sciences Center, Memphis.

Since the seventh edition was published in 2009, researchers and medical practitioners have learned that genomic alterations drive cancer and may vary considerably among tumors that, in the past, were thought to be in the same category, Dr. Amin said.

The American College of Surgeons Commission on Cancer will require accredited hospitals to use the eighth edition for all cancer cases diagnosed on or after January 1, 2017. The manual, developed in cooperation with the TNM Committee of the Union for International Cancer Control (UICC), is available for purchase online.

Find additional information on licensing the content for electronic products at cancerstaging.org.

Electronic Cancer Checklists (eCC) Project Update

Mignon Dryden, CTR
NAACCR Liaison to CAP PERT

The College of American Pathologists (CAP) and the California Cancer Registry (CCR) efforts on transmitting live data using CAP’s electronic Cancer Checklist (eCC) continues to move forward. As reported previously in the Narrative (see Winter 2015 issue), work on Phase I and Phase II of this project began in January 2014 and the first complete data set was transmitted by St Joseph’s Health System to the CCR in March 2015. Currently, 28 facilities with 17 associated labs (some facilities share labs) are transmitting eCC data to the California Cancer Registry.

The eCC allows pathologists to use the CAP Cancer Protocols directly within their laboratory information system and to ensure that each report is complete as required by both the American College of Surgeons – Commission on Cancer and the CAP Laboratory Accreditation Program.

Phase III of this project continues the standardization of ongoing transmissions with the full set of eCC templates from facilities to the CCR as well as implementation of eCC at other facilities. It also includes the creation of additional biopsy templates to extend and improve diagnostic and structured data capture within California. Twenty-seven CAP biopsy templates ranging from brain to soft tissue already exist. The goal is to implement at least 5 additional cancer biopsy templates for sites that do not currently have an existing template (e.g. breast, lung). The templates to be created will be prioritized by the frequency of occurrence. In addition, a generic cancer biopsy template and a generic cancer resection template for use in reporting on cancers that are not covered by the current CAP Cancer Protocols will be created.
With the addition of the biopsy templates, upwards of 97% of cases diagnosed via a specimen resulting from a resection or biopsy can be documented using a CAP eCC checklist.

Registries interested in reviewing these additional biopsy templates, once they have been drafted, are welcome to contact Jeffery Karp at the College of American Pathologists at JKarp@cap.org.

California Passes E-Path Reporting Law

Dennis Deapen, DrPH
Director, Los Angeles Cancer Surveillance Program

In August, California’s governor Jerry Brown signed AB 2325, which establishes the requirement for submission of electronic pathology reports as an enhancement of the state’s cancer reporting program. Furthermore, the bill directs the California Department of Public Health to determine a standard format for the reports which will be required starting in 2019.

Electronic pathology reporting creates significant benefits for population-based cancer reporting. When based on a “smart” computer algorithm to determine which reports represent reportable cancers, this method can result in more complete casefinding than is often achieved by manual means. Perhaps even more importantly, electronic pathology reporting can create a much faster mechanism for early reporting for the vast majority of cases, also called “two-tiered” reporting. The key to achieving this goal is to assure that the electronic pathology report is structured (i.e., pre-coded) and contains sufficient patient and residential identifiers to classify the case.

California’s experience may also be of interest to other states contemplating legislative change to benefit the cancer registry. The process was rapid, requiring just 7 months in the 2016 legislative session, and required no expense to the registry other than telephone conversations. Finally, it is gratifying to observe the support expressed by the legislature: both the Senate and Assembly passed this bill with unanimous votes.

For the full language of the bill, visit: http://www.leginfo.ca.gov/

County Related Edits and Confidence in Geolocation

Christian Klaus, Spatial Analyst
North Carolina Central Cancer Registry

County at Diagnosis can be a problematic field for passing edits, primarily in eastern U.S. states that were not subdivided with the U.S. Public Land Survey System (PLSS), and whose county boundaries are therefore not coincident with PLSS survey lines. Even now, county boundaries resurveyed with modern methods may be a distinct minority in these states, and this uncertainty is reflected in USPS, Census, and Emergency Dispatch data (E911) discordance with respect to county for a given address. Thus, the Postal Code-City-County state-specific edit used in these states requires more ongoing attention to changes and uncertainty than in other states. To mitigate the uncertainty, many Central Cancer Registries (CCRs) receive just the cases that have a known Postal Code-City-County combination according to the USPS ZIP+4 database, along with corrections to those fields that enabled passing the edit.

By enabling hospital-based CTRs to identify Postal Code-City-County combinations for a given diagnosis address, the USPS ZIP+4 database plays a starring role in identifying the associated county and pass the edit for a given case. However, when this database contains county error it may propagate to the CCR for a large number of cases.

Because of this potential county uncertainty, the change of County-tract edit from advanced to core precipitates comparison with Postal Code-City-County. When these edits disagree on county for a case, confidence in the geolocation of that case is greatly diminished. For CCRs in the U.S., identifying the correct county (if possible) is often not an option. U.S. Census data is not always right, nor USPS ZIP+4 always wrong, when they don’t agree on the county in which an address is located. Due to the time required to investigate address locations when the two edits disagree, it would be beneficial to CCRs to minimize the number of these cases.

In North Carolina, there are more than 74,000 E911 address points whose USPS assigned county disagrees with those assigned by either Census or E911 data stewards. Almost all of these fall close to a county boundary. Not surprisingly there are cancer cases among them. Given these circumstances, North Carolina CCR staff feel compelled to append non-USPS combinations to their Postal Code-City-County edit list to prevent error from being introduced by hospitals, and to manage discordance between these edits by maximizing cases for which these edits concur, and keeping track of particular Postal Code-City-County combinations for which discordance exists.

Focusing on Site, Histology, Grade, and Surgery in SEER*Educate

Mary Potts, RHIA, CPA, CTR
Director, Information Services
Fred Hutchinson Cancer Research Center, Cancer Surveillance System
Learn by Doing: Improve Coding a Data Item at a Time

The full case coding exercises in SEER*Educate's Practical Application section help new hires and experienced registrars identify sites and data items that proved challenging to code accurately and consistently among all registry staff members. But, then where does one go to find additional training exercises designed to focus on improving the quality of those data items? That was the need presented to us.

We ran a de-identified search across all the completed Practical Application tests to identify the most problematic data items. Site, histology, grade, and surgery topped the list.

Our e-trainer at the Seattle-Puget Sound SEER Registry created new case scenarios, preferred answers, and rationales for coding drills that supports focused practice in these areas:

- Grade/Differentiation: 11 tests, 10 scenarios per test, 110 total scenarios.
- Histology (Solid Tumors): 100 scenarios (each one its own test).
- Histology (Heme and Lymphoid): 20 scenarios (each one its own test).
- Site: 6 tests, 10 histologic diagnoses per test. Focuses on identifying a primary site for a given specific histology when a site is not provided by either the clinician or the pathologist.
- Surgery fields: 135 scenarios (each one its own test).

This new content is being released in October in the CTR Prep section of SEER*Educate. Although no CEs are available for content in the CTR Prep section, these drills are challenging for both new and experienced staff.

At the Seattle-Puget Sound SEER Registry, we have all staff including new hires to our most experienced members (20+ years) code all the new material before it is made public. Table 1 shows the staff averages on the first 15 scenarios and the second 15 scenarios in the solid tumor Histology drills.

<table>
<thead>
<tr>
<th>Histology Scenarios</th>
<th>Histology Average</th>
<th>H Rule Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cases 001-015</td>
<td>73%</td>
<td>43%</td>
</tr>
<tr>
<td>Cases 016-030</td>
<td>82%</td>
<td>62%</td>
</tr>
</tbody>
</table>

At first, we were a bit startled at the results but then we remembered that we had selected the most problematic histologic types from which to create the targeted data item level training modules. None of the scenarios were intentionally created to be tricky. They are intended to teach people how to improve their accuracy in applying the 2007 Multiple Primary and Histology Coding Rules.

Even though these drills are in the CTR Prep section of SEER*Educate, the material may be useful for full staff training at both hospital and central registries. We encourage both hospital and central registries to use the Management Report functionality of SEER*Educate to enable you to compare staff coding accuracy and consistency over groups of cases and to help identify cases or topics that might best be addressed in a staff meeting.

We chose not to apply for CEs for the coding drills because we wanted the option of adding more scenarios to each of those sections, particularly as new ICD-O-3 codes and terminology are approved for data collection. In addition, as we release more full case coding exercises, we will continue to monitor them to identify other topics for inclusion in the data item specific drills.

This fall, treat your staff to focused training opportunities in SEER*Educate and Learn by Doing!

SEER*Educate is a web-based training platform for students and cancer registry professionals to learn and assess technical skills related to coding guidelines and concepts. It is a jointly funded project sponsored by the NCI and Fred Hutchinson Cancer Research Center. (NCI Contract Number HHSN26120100029C).

Benign Brain

Barbara Hempel, BA, CTR
Quality Assurance Specialist
North Carolina Central Cancer Registry

One of my favorite duties at the North Carolina Central Cancer Registry is conducting quality control audits that identify issues in the database. Although we manually review a percentage of cases on a continuous basis,
conducting what we call a “Recoding Audit” helps identify specific issues that need to be corrected or re-coded. As important as the recoding function may be, communicating coding mistakes or problems to the reporting facilities by way of friendly reminders for training may be more important. Failure to communicate your findings of an audit is a missed opportunity to address pertinent training topics. If coding mistakes are not communicated to the reporting facilities, they will continue to occur which causes the CCR staff to continue to make these same corrections.

My original idea for a recoding audit was to identify all the sequence 60, 61, 62 etc. (benign) cases for 2015 cases to see if the directly coded Summary Stage fields were coded correctly. Previously, Summary Stage information was included in the Collaborative Stage algorithm, but beginning in 2015, it became a requirement that the Summary Stage data field/item must be coded directly. Our database yielded a list of 1,700 cases with a sequence number of 60, 61, 62 etc. in which I found 236 cases with a directly coded Summary Stage with a value other than 8. My query data also included site and histology codes, so I was able to identify 31 of 366 cases with a site code C75.1, (Pituitary Gland), that were reported as histology 8140, (Adenoma) that I recoded to 8271, (Prolactinoma), or 8272, (Pituitary adenoma). Additionally, I identified 19 of 29 Acoustic Neuroma cases were incorrectly coded to C72.5, (Cranial Nerve, NOS), instead of C72.4, (Acoustic Nerve). A total of 46 cases had site/histology combinations that the NCCCR does not collect which were predominantly cervical in situ cases and a behavior code of “1” for ovarian cancer.

In conclusion, this quality control query provided enough information to identify several different re-coding items that could be corrected and shared with reporting facilities. Hopefully, with feedback to facilities and articles in our newsletter, these types of mistakes can be reduced in the future.

**Melanoma Audit**

*Allen D. Austin, III, BA, CTR*

*Supervisor, Quality Assurance Specialists/Audit Coordinator*

*North Carolina Central Cancer Registry*

The majority of cancer registrars realize that melanoma occurs most often in the skin, but it can also occur as an ocular (C69.9) melanoma. Although this is rare, (about 2,500 people are diagnosed with ocular melanoma in the U.S. per year), that’s an average of 5–7 people per 1,000,000. According to the Skin Cancer Foundation, it’s estimated that 76,380 people in the U.S. will be diagnosed with melanoma in 2016. Although melanoma accounts for less than 1% of all skin cancers, it is the cause of the vast majority of skin cancer deaths. Someone dies from melanoma every 52 minutes, and it’s estimated that 10,130 people will die from melanoma in 2016!

The purpose of this audit was to recode any melanomas that had been coded to unknown primary (C80.9) instead of skin, NOS (C44.9).

As a resource, I used a tool from the SEER website listing each site and what type of cancer can occur there. This tool is located [here](#).

The results of my audit surprised me!

Although there were 71 cases coded erroneously to unknown primary, there were also cases coded to stomach, lymph nodes, colon, small intestine, bladder, kidney, gall bladder, cervix, soft tissue and lung. Although you can have metastasis occur in these sites, these can’t be the primary site.

I discovered during this process that melanoma can occur in the esophagus, the pharynx, and the oropharynx. Although this is rare, it can, and does occur.

Out of 144 cases identified for review, 132 were coded incorrectly.

So, if you’re looking for an audit to clean up your database, try identifying the range of melanoma codes not coded to (C44.0 – C44.9, or C69.0 – C69.9). What you find may surprise you. And people, let’s use sunscreen and stay out of tanning beds!

**The Nose Knows**

*Allen D. Austin, III, BA, CTR*

*Supervisor, Quality Assurance Specialists/Audit Coordinator*

*North Carolina Central Cancer Registry*

Dogs have 25 times more smell receptors than humans, which boosts their smelling ability by 100,000 times. Whereas the brain of a human is dominated by the visual cortex, the brain of a dog is controlled by the olfactory cortex, which is 40 times larger than that of a human. A dog’s olfactory cortex has between 125 and 200 million
smell-sensitive receptors, which makes it 1,000,000 times more reactive than humans. Dogs can smell in parts per trillion. For example, if you put 1 cc of blood into a body of water as big as 20 Olympic-sized swimming pools, a dog would be able to detect the presence of blood.

So, can dogs detect cancer? The answer is yes. Cancerous cells release different metabolic waste products than healthy cells. The difference is so significant that dogs are able to detect it even in the early stages (including in situ). Studies have confirmed that dogs can detect melanoma just by sniffing the skin lesion and prostate cancer simply by smelling the patient’s urine. Dogs may also be able to detect the presence of cancerous cells through a human’s breath.

But, before you have your miniature collie sniff that funny-looking mole on your leg, and bark like “Timmy’s in trouble” as a Lassie wannabe, let me make this disclaimer: Just like dogs are trained to sniff out drugs or explosives, they also have to be trained to sniff out cancer.

Some researchers believe trained dogs will become integrated directly into patient care, while other researchers recommend the skills of cancer-detecting dogs be confined to laboratories. By using gas chromatographs to identify the specific compounds that are being identified by these trained animals, we might develop a simple breathalyzer that will change color reacting to those compounds in our breath indicating the presence of cancer.

Here are some studies validating this premise:

- A study in Amersham, England published by the British Medical Journal used trained dogs to identify bladder cancer based on urine odor. The dogs were able to correctly identify bladder cancer 41% of the time.
- In a research study conducted by Pine Street Foundation, using breath samples of 31 breast cancer patients, 55 lung cancer patients, and 83 healthy patients, they were able to detect or rule out breast and lung cancer with 90% accuracy.
- In a study in Tallahassee, TN, conducted by Dr. Armand Cognetta, a dog trained to sniff out melanomas was able to detect this cancer 99% of the time.
- According to US News and World Report, a black lab was able to detect colon cancer in 200 patients 97% of the time. The dog was even more accurate than fecal occult blood tests by 25%.
- In Milan, Italy, Dr. Gianluigi Taverna, a urologist at the Humina Research Center, used 677 urine samples, 320 from men with prostate cancer and 357 without. The dogs they used, which had been trained to detect prostate cancer, had a 98% accuracy rate.

This is a prime example of cutting-edge research that is being conducted to assist doctors in making an early diagnosis in order to aid in the treatment of cancer.

Central Cancer Registries and NAACCR well represented at national geospatial conference

Antoinette Stroup, PhD
NJ, NAACCR President-Elect

Several central cancer registry researchers and representatives from NAACCR attended the NCI’s Conference on Geospatial Approaches to Cancer Control and Population Sciences, held on the NIH Campus in Bethesda, MD from September 12-14, 2016. The conference successfully facilitated discussions around how geographic information scientists and cancer researchers have and can continue to work together to “accelerate the integration of state of the art tools and theories from spatial research into cancer control and population sciences.” ([http://epi.grants.cancer.gov/events/geospatial/](http://epi.grants.cancer.gov/events/geospatial/)).

The value and relevance of population-based cancer registries was reinforced throughout the conference by both speakers and attendees as both geographic information scientists and cancer researchers recommended leveraging the infrastructure of registries to collect additional geospatial data to advance epidemiological research and cancer control efforts. Guest speakers were a “who’s who” of the GIS and cancer community including:

- Nancy Krieger, Professor of Social Epidemiology, and Timothy Rebbeck, Professor of Cancer Epidemiology, from the Harvard T.H. Chan School of Public Health;
- Mai-Po Kwan, Professor of Geography and Geographic Information Science at the University of Illinois School of Earth, Society, and Environment;
- Geoffrey Jacquez, Professor of Geography from the State University of New York at Buffalo and Biomedware, Inc.; and,
- Alan MacEachren, Professor of Geography at PennState College of Earth and Mineral Science.

There were also invited speakers from our NAACCR community including Dave Stinchcomb (Westat), Kevin Henry (Temple University), Scarlett Gomez (CPLIC/Greater Bay Area), Angela Meisner (NM), Myles Cockburn (University of CO), Frank Boscoe (NY), Dan Goldberg (Texas A&M), and Zaria Tatalovich (NCI). Special congratulations to Scarlett, Kevin, and Zaria who also served on the Steering Committee! Recinda Sherman
(NAACCR, Manager of Data Use and Research), Nan Stroup (NJ, NAACCR President-Elect), and Chuck Wiggins (NM, NAACCR President) also attended.

Now is your opportunity to contribute to the discussion! Recognizing the significance of geographic context and the environment in cancer etiology and outcomes and the emerging technological capacity in mapping and spatial analysis, Cancer, Epidemiology, Biomarkers and Prevention (CEBP) has issued a call for papers for a special Geospatial Approaches Focus Issue, which will “showcase recent, cutting-edge research in the development and application of novel geospatial approaches in cancer control and population sciences.” Click HERE for more information. All manuscripts are due November 15, 2016.

Jennifer Tsui (Rutgers Cancer Institute of New Jersey), Nan Stroup (NJ), and Scarlett Gomez (CPIC/Greater Bay Area)

Frank Boscoe (NY), Chuck Wiggins (NM), Myles Cockburn (University of Colorado) – reviewing an interesting poster
Kevin Henry (Temple)

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