



Message From the President

Jill A. MacKinnon, PhD, CTR

NAACCR President



Happy New Year! I hope everyone had a wonderful holiday season.

'Tis the Season'...or more accurately, 'Twas the Season'...

If you think about it...from October through December, our lives at a central registry are synonymous with the holiday season. Regardless of our best intentions from previous years, in the last few months, we are busy, running around like crazy, preparing our data for our respective calls for data. Once data are perfectly cooked, wrapped, and given as a present to our grateful sponsors, we sit back and relax for the first time in months. After we have rested and reflect back on the previous year, we make plans (and resolutions) for the New Year...which may or may not be kept.

Sound familiar?

For me at least, during the reflective part of my healing, I am humbled and honored to be doing the work we do. This is serious business and we are serious professionals. It is easy to sometimes get caught up in the trappings of our work...the edits, operationalizing new data items, finding all the cases, training abstracting personnel, funding issues, producing reports, etc... But at the end of the day it helps me to remember that every drop of sweat that trickles down from our brow is in some way helping a cancer patient. That is why we do what we do.

The future is always uncertain as to what we will be collecting and how we will be operationalizing the data as the management of cancer changes. But one thing that is certain, as the management of cancer changes, the cancer surveillance professionals in the NAACCR community are certainly the folks to handle it. We are making our systems (and our thought processes) more agile to handle the ever-changing requirements. We are developing more and more ways to use the data to be relevant to the surveillance and research communities. We are expanding our methodology in order to make the integration of data from other sources into ours more seamless. We are embracing the state-of-the-art technology to develop relationships with other data sources in order to integrate our data with theirs. We are embracing technology to collaborate with our colleagues and expand our communication. We are expanding our educational endeavors through a robust distance learning system.

In a nut shell, our members, individually and collectively, are doing what seemed impossible (or at least improbable) several years ago. Buckle up...the ride will always have a few bumps, but collectively, the NAACCR community has always been up for a good road trip.

Best Wishes to you and yours for a wonderful New Year!

Message From the Executive Director

Betsy A. Kohler, MPH, CTR

NAACCR Executive Director



Union for International Cancer Control

I attended the UICC meeting during the first week of December. This is the second time I have attended the World Cancer Congress (the first time was Montreal in 2012). The UICC monitors cancer trends, focuses on lives, and strives to be a catalyst in cancer control. UICC wants to inspire movement, create new strategic partnerships, and develop new young leaders in the field. The UICC currently has 833 members; over 60 countries attended the

Congress. UICC initiatives include the following: Global Access to Pain Relief; Childhood Cancer; Cervical Cancer Initiative; Global Education and Training; **Global Initiative for Cancer Registries (GICR)**; **International Cancer Control Partnership (ICCP)**; McCabe Center for Law and Cancer; and UICC TNM.

While NAACCR has an interest in many of these topics, the two initiatives in bold above are of particular interest to us. NAACCR has been invited to participate in the ICCP, and we signed a letter of support for the GICR. The GICR is establishing six hubs to support cancer registry development in different areas of the world. NAACCR's expertise is being sought in relation to building infrastructure in the Caribbean. We will be talking in more detail to the agencies involved in this initiative to determine how NAACCR members can best assist in this effort.

"The Cancer Atlas," a joint project between UICC, ACS, and IARC was launched at the Congress. Please visit the following website:

<http://www.cancer.org/aboutus/globalhealth/cancer-atlas-second-edition>. This will be a great resource to cancer registries, researchers, and the surveillance community.

World Cancer Day is February 4, 2015. Please keep an eye on the NAACCR website and our social media outlets for more information about NAACCR's support of this global event. For information about World Cancer Day or to learn what your organization can do, see <http://www.worldcancerday.org/>.

Virtual Pooled Registry Network - Update and Invitation

We continue to develop our Virtual Pooled Registry concept, and will be presenting information to a group of stakeholders in Washington, DC, on February 6, 2015. We have been working on a pilot project to facilitate cohort matching in states (ID, NC, KY) and are ready to build upon our experience by expanding to other states. We are seeking modest funding that would go to individual registries to offset the costs of conducting this type of work.

Essentially, an investigator would submit a protocol to NAACCR which would be reviewed by a Scientific Review Committee. If approved, NAACCR (via IMS) would work with the researcher to make sure their file was in our standard format and passed edits. Once the file is good to go, IMS would send it to participating states to match using a standard protocol BEHIND THE STATE'S FIREWALL. The state would report only the number of matches identified back to the researcher (and possibly the number of possible matches). The researcher would then work with individual states once they knew how many potential matches existed - going through state protocols and IRBs at that time. Only after these details were worked out with each state would the state release any confidential information to participate in the study. If you are interested in learning more about this project, or would like to participate in the next phase, please contact me as soon as possible at bkohler@naaccr.org.

Strategic Management Plan

The Board of Directors met on January 13-14, 2015, with Steering Committee Chairs and staff to assess progress on the Strategic Management Plan and discuss priorities for the upcoming year. Look for updates from this meeting in February.

Steering Committee Corner

Susan T. Gershman, PhD, MS, MPH, CTR
NAACCR Treasurer

Welcome to the Steering Committee Corner!

This column provides 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: Annette Hurlbut

Committee Highlights since the last *Narrative*:

- Best wishes to those who have left the CSC due to career changes. We thank Roberta Koscielny (Cancer Care Manitoba) and Janna Harrell (Utah Cancer Registry) for years of service and wish them well in their new endeavors!
- The CSC is thrilled to welcome the following new members: David Sampson, ACS; Joe Schramm, CAP; NAACCR Intern Benjamin Manthei; and new NAACCR *Narrative* Work Group member Laura Ruppert, Indiana Cancer Registry.

- The CSC is actively reviewing its portion of the Strategic Management Plan (SMP) as well as currently drafting a NAACCR Communications Plan. The results of these activities will be shared with the NAACCR Board during this quarter.

NAACCR Explainer Video:

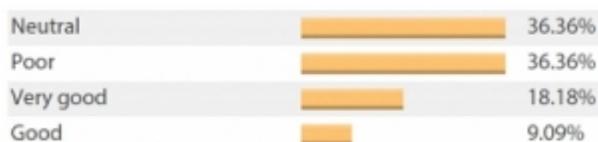
- If you have not already taken a look, please do so – a short explainer video, developed in cooperation with the CSC and NAACCR staff, can be accessed via the [NAACCR website](#) (click on “Who We Are” on the home page) or [NAACCR’s YouTube channel](#). Take a moment to watch it and share it with your friends, family, and colleagues.

Other news to share with the NAACCR Community PAN interests:

- Members of the CSC are currently performing a review of the NAACCR website (www.naacccr.org). Please take a look, the CSC would love to hear what changes would make your NAACCR website visit more beneficial to you and your registry.
- A future *NAACCR Narrative* issue will include an opportunity for your registry to spotlight “registry data usage.” Laura Ruppert will be in touch during the year to encourage registry participation in sharing “data usage” success stories and idea exchange.

NetLink to Causeway:

- The poll that appeared in the last issue of the *NAACCR Narrative* asked readers to **rate their overall satisfaction with the NetLink workspace platform that NAACCR uses for committee collaboration**. Here are the results:



- The NAACCR Community has a voice! As of December 2014, NAACCR has implemented Causeway for all Committees and Work Groups. Causeway is a workspace collaboration platform application to replace the NetLink system. We have tested it extensively with the NAACCR Board and other groups and have received very positive feedback. While no one system will be perfect, we have received feedback that Causeway is easier to navigate and more intuitive for the user. We now have all the Steering Committees and subcommittees populated on the system. Quick access to the site can be found on the upper right of the NAACCR Homepage or on the committee web pages.
- Note: Be sure to participate in this issue's poll, which appears towards the bottom on the left-hand side of this page. The *Narrative* is the prime vehicle for reaching out to the cancer surveillance community. Pitch your poll interest, story idea, column, or feature. Write it yourself, or *Narrative* staff will assist. Contact Annette Hurlbut at annette.hurlbut@elekta.com.

Research and Data Use Steering Committee (RDUSC)

Co-Chairs: Hannah Weir and Frank Boscoe

Committee Highlights since the last *Narrative*:

Training/Education:

- Surveillance Webinar: Please join us on Thursday, January 28, 2015, at 2:00 p.m. EST for a presentation by the Utah Cancer Registry on their Annual Report production.
- Journal Club: Two future discussions include *Using the National Death Index to Identify Duplicates and the NPCR-NDI Agreement* and *Ovarian Cancer Incidence Trends in Relation to Changing Patterns of Menopausal Hormone Therapy Use in the United States*. Be on the lookout for a NAACCR listserv announcement.

Other News to share with the NAACCR Community PAN interests:

- If you have a suggestion for a journal club or surveillance webinar topic, please contact Hannah Weir (hweir@cdc.gov).
- If you would like to join the Research and Data Use Priority Area Network (RDU PAN) and receive notices about these and other upcoming events, please go to MyNAACCR at www.naacccr.org and sign up under your member profile. PAN sign-up areas are located at the bottom of your MyNAACCR profile.

Professional Development Steering Committee (PDSC)

Chair: Deirdre Rogers

Committee Highlights since the last *Narrative*:

Training/Education:

- The PDSC has established the Short Course Task Force. The Short Review Course for Central Cancer Registries has been presented as an in-person workshop prior to the NAACCR Annual Conference for many years, and it provided an overall review of the functions and processes of the central cancer registry. The Short Course Task Force has been tasked with turning the course into an online offering. When completed, it will be accessible to NAACCR members through a learning management system that is being developed.

Additional SCs include:

Standardization and Registry Development Steering Committee (S&RDSC)

Co-Chairs: Nan Stroup and Randi Rycroft

Strategic Alliances Steering Committee (SASC)

Chair: Thomas Tucker

Twitter Digest

Dan Curran, MS, CTR

Chair, NAACCR Social Media Workgroup



If you had been following [@NAACCR's](#) Twitter feed, you would have seen these interesting recent tweets:

@NCIEpi

Applications due Jan 28 for #BreastCancer and the Environment Research Program funding opportunities 1.usa.gov/1tKpFz9 #BCERP #bcm

@NCIEpi

What effect does obesity have on the cancer burden? 1.usa.gov/13WjmMc @NatureNews

@NCIEpi

How does [@NCIEpi](#) provide opportunities for scientists to increase understanding of cancer etiology? 2014 in review: conta.cc/14jqQOB

@JNCI Now

Human Papillomavirus Testing in the Prevention of Cervical Cancer ow.ly/GxtZr #HPV #CervicalCancer

@AJCCancer

RT [@NCIEpiTraining](#) [@theNCI](#) researchers identify genetic marker for aggressive #BladderCancer 1.usa.gov/1xCUMe3

@NCICancerStats

Welcome to Week 9 of #StateCancerStats. This week we will focus on #Minnesota. Stay tuned! statecancerprofiles.cancer.gov/quick-profiles..

@NCIEpiTraining

#NewYear #resolution: take the next step in your #career. Find a #cancerresearch #epidemiology #genetics fellowship: 1.usa.gov/1HI72UC

@NAACCR

NAACCR in the news: [@AmericanCancer](#) reports a 22% decline in the US cancer death rate over the past two decades ow.ly/GEmh1

@NCIEpi

Little evidence that tobacco & alcohol are associated w/ risk of male #breastcancer: 1.usa.gov/1D5uAKI @michaelbcook #MensHealth

@NCIEpiTraining

#TopTen2014 1/13 @theNCI scientists identify new gene mutation related to familial #melanoma
1.usa.gov/1tv9zG

@NCIEpi

Are you familiar with #SEER biospecimens? Learn more about SEER's valuable resource in this CEBP article
1.usa.gov/1ztOwTV @NCI Stats

@theNCI

One subtype of stomach cancer is positive for Epstein-Barr virus, #TCGA researchers recently reported. Learn more
1.usa.gov/1D4lduW

@NCIEpi

What research did @NCIEpi fund in Fiscal Year 2014? Learn more about our funded projects at
1.usa.gov/1xc5xVD

@theNCI

Cancer survivors will account for about 5% of the US population in 2022. go.usa.gov/6aAQ #NCIresearchfuture

@AJCCancer

How big data in healthcare is not only improving, but saving, lives - goo.gl/alerts/zzdr

@NCIEpi

Blog post from @NIOSH: Is there a link between firefighting and cancer? 1.usa.gov/1xgTc4B #epidemiology

@NAACCR

A new version of GenEDITS Plus software with several important enhancements has been released by @CDCgov
ow.ly/Gp0zN

@NCIEpi

Reminder to scientific community: implementation of #NIH #genomic #datasharing policy begins January 25, 2015
1.usa.gov/13ri77n

@AJCCancer

RT @AmCollSurgeons 2014 Executive Director's Annual Report | The Bulletin ow.ly/FyPOT

New LinkedIn Page and Annual Conference Sites

Dan Curran, MS, CTR

Chair, NAACCR Social Media Workgroup



Check out the new LinkedIn pages:

- [NAACCR company page](#)
- [Annual Conference page](#)

And our existing page:

- [NAACCR private membership page](#)

NAACCR's new Information Technology Administrator, Dustin Dennison, has been busy updating our LinkedIn accounts. The new pages are in addition to the NAACCR private membership page. According to LinkedIn, these will "help others learn more about your business, brand, products and services, and job opportunities." Dustin believes that the original page will be focused on collaboration and networking between members, while the new "company" page will allow us to share organizational updates with the public.

The new Annual Conference page will generate interest in the 2015 Annual Conference in Charlotte, NC. Please join the new pages and help spread the word about NAACCR on LinkedIn!

Central Registry Job Opportunities

Jim Hofferkamp, CTR

NAACCR Trainer



Several registries have recently posted open positions to the NAACCR Job Opportunities page.

For more information or to post an open position at your registry, see <http://www.naacr.org/Applications/Employment/Default.aspx>.



The National Cancer Institute's Surveillance Research Program is seeking Branch Chief candidates for its Surveillance Research Branch (<http://surveillance.cancer.gov/branches/ssb/>).

Excellent candidates will have:

- A PhD, MD, and/or equivalent level of training or experience in areas such as quality improvement/quality assurance, epidemiology or cancer statistics;
- Substantial career experience in cancer registration or cancer surveillance; and/or
- Experience in methods for assessing data quality from nontraditional data sources, such as secondary data linkages and/or innovative methods that will enhance the efficiency, depth, and scope of the surveillance data collected by the SEER registries.

Interested candidates may submit a letter of interest and vitae to Emilee Pressman (pressmane@mail.nih.gov).

2015 NAACCR Annual Conference

Narrative Staff

NAACCR will hold its 2015 Annual Conference in Charlotte, NC, June 13 through June 19. The North Carolina Cancer Registry has this year graciously offered to host the conference. Volunteers from central registries around the U.S. and Canada are working on the preliminary program that will make the 2015 conference exciting and innovative!

The theme this year is: "First in Flight: Launching a New Era in Cancer Surveillance." The 2015 conference will provide attendees with the opportunity to learn from national experts in cancer surveillance, cancer registry operations, and cancer research. Sessions will explore the new era in cancer surveillance from multiple perspectives in North America. All abstracts have been reviewed. A special thanks to the Abstract Review Subcommittee and Chair, Jim Martin, PhD.

The range of topics in each content area is wide; all who attend will experience interesting and useful sessions. Topics will be organized into five major categories: Data Collection and Operations, Data Analysis, Cancer Epidemiology, Update on Cancer Staging, and Registry of the Future. Pre-conference workshops will also be offered. The scheduled workshops are Basic SEER*Stat, Advanced SEER*Stat, SEER*Prep Software Training, and the Geocoding Operations Course.

Plenary session topics will include "Launching a New Era in Research," "Big Data!," and a late-breaking topic session still in the works. We will end the conference with our closing plenary, "Launching a New Era in Cancer Control" and an invitation to the 2016 Annual Conference.

The 2015 conference will also host the June in-person meeting of the NAACCR Board of Directors. Everyone should make arrangements to attend the traditional "Committee Day" on Monday, June 15. The Exhibitor Preview will give you a sneak peak of our conference sponsors and exhibitors. Tuesday will offer the Registry of the Future Open Forum again. This was a new event in 2014, and was quite popular. The Tuesday Opening Welcome Reception is a great way for you to make new friends and connect with colleagues. On Wednesday, we will hold the ever-popular Birds of a Feather "Using Our Registry Data – What Works and What's Next?" and the Annual Awards Luncheon. Thursday activities will include the NAACCR Fun Run and Walk and the invitation to the 2016 conference. The Program Committee is still working on other exciting events that are sure to make the 2015 conference a can't-miss event.

Registration and information updates can be found on the [NAACCR Annual Conference web site](#).



National Data Exchange Announcement

Susan T. Gershman, PhD, MS, MPH, CTR
NAACCR Treasurer

Make a belated New Year's resolution and sign on! Twenty-nine registries have signed the modified national data exchange agreement.

For registries that need to re-sign and registries that are now ready to sign, visit the [National Interstate Data Exchange Agreement page](#) on the NAACCR website and follow the instructions below:

1. Central registry downloads agreement.
2. Central registry has proper authority review agreement and adds state-specific restrictions if needed.
3. Appropriate registry representative signs agreement.
4. Agreement is sent to NAACCR; central registry retains copy.
5. NAACCR posts states that have signed agreement on NAACCR website, including specific restrictions.
6. Registry contacts other participating states to determine the logistics of how data will be exchanged.



The registries that have signed the National Interstate Data Exchange Agreement include: Alabama, Alaska, Arkansas, Connecticut, Guam, Hawaii, Idaho, Indiana, Kentucky, Louisiana, Massachusetts, Michigan, Mississippi, Montana, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, South Carolina, Texas, Utah, Virginia, and Wyoming. Join our team so you can add another important step towards efficient registry operations!

Please fax your signed National Interstate Data Exchange Agreement to the NAACCR office at 217-698-0188.

Highlights From the Program Manager of Standards

Lori A. Havener, CTR
NAACCR Program Manager of Standards

2015 Implementation Guidelines Revisions

The NAACCR 2015 *Implementation Guidelines and Recommendations* (January 2015) has been revised and includes changes to section 3.5 Country Codes and the hematopoietic rules and/or conversion sections (1.1, 7.2, 8.6, 9.5 and appendix B).

The *Implementation Guidelines* include material for central cancer registries, hospital cancer registries, and registry software vendors. There is information on the seven new survival data items; updates/new codes/descriptions for Sex [220], RX Date Other Flag [1251], Over-ride Site/TNM-StgGrp [1989], SEER Coding Sys--Current [2120] and SEER Coding Sys--Original [2130], and the Country codes [102, 254, 1832, 1847, and 1944]; a summary of the hematopoietic conversion/edits; an excerpt from the ICD-O-3 updates document; a piece on EDITS; and a section of the standard setter requirements.

CS Transition Update

NAACCR has compiled a table of new and revised data items proposed by CDC NPCR and NCI SEER as part of the CS transition process. Information from that table has been included below. The description and rationale fields include the information provided in each proposal. Most of these data items have been reviewed/approved by the CS Transition Group and the Change Management Board, and have been forwarded to the Uniform Data Standards Work Group.

Just a reminder that on June 17, the CS Transition Group agreed to continue collecting site-specific factors (SSFs) using the current NAACCR data layout and definitions at least through 2016. This approach will continue to use the programming and logic structure established in Collaborative Stage to collect those variables. The CS Transition Group felt that this would be the least disruptive way to proceed for 2016. The intention is to maintain the SSFs as they are until there is an opportunity to carefully evaluate the SSFs and to make decisions on how to structure the collection of these variables within the NAACCR record layout. In addition, any changes that will be needed to accommodate prognostic indicators in the AJCC 8th Edition will be better known in 2016.

Proposed Changes for CS Transition as of December 11, 2014

Item Name: **TNM Clin Staged By** (revised)

Item #: 990

Length: 2

Description: Expanded length to 2 digits to accommodate new codes.

Rationale: The use of this data item could be broadened to look at the quality and completeness of staging from

many sources and help in targeting training.
Source of Proposed Change: CDC NPCR

Item Name: **TNM Path Staged By** (revised)

Item #: 930

Length: 2

Description: Expanded length to 2 digits to accommodate new codes.

Rationale: The use of this data item could be broadened to look at the quality and completeness of staging from many sources and help in targeting training.

Source of Proposed Change: CDC NPCR

Item Name: **Tumor Size** (new)

Length: 3

Description: New data item to collect tumor size information.

Rationale: To collect tumor size that is independent of stage. Size collected in millimeters with a few special codes. This variable would reflect the "best" available information on the actual tumor size before therapy with priority given to the pathological resection. However, it may be based on imaging or other clinical information as necessary.

Source of Proposed Change: CDC NPCR

Item Name: **Mets at Diagnosis - Distant Lymph Nodes** (new)

Length: 1

Description: New data item to collect specific information on mets at the time of diagnosis.

Rationale: This is a replacement for the current CS fields and replacements for information on mets to distant lymph nodes and other sites currently captured in the CS mets variable under individual schemas.

Source of Proposed Change: NCI SEER

Item Name: **Mets at Diagnosis - Bone** (new)

Length: 1

Description: New data item to collect specific information on mets at the time of diagnosis.

Rationale: This is a replacement for the current CS fields and replacements for information on mets to distant lymph nodes and other sites currently captured in the CS mets variable under individual schemas.

Source of Proposed Change: NCI SEER

Item Name: **Mets at Diagnosis - Brain** (new)

Length: 1

Description: New data item to collect specific information on mets at the time of diagnosis.

Rationale: This is a replacement for the current CS fields and replacements for information on mets to distant lymph nodes and other sites currently captured in the CS mets variable under individual schemas.

Source of Proposed Change: NCI SEER

Item Name: **Mets at Diagnosis - Liver** (new)

Length: 1

Description: New data item to collect specific information on mets at the time of diagnosis.

Rationale: This is a replacement for the current CS fields and replacements for information on mets to distant lymph nodes and other sites currently captured in the CS mets variable under individual schemas.

Source of Proposed Change: NCI SEER

Item Name: **Mets at Diagnosis - Lung** (new)

Length: 1

Description: New data item to collect specific information on mets at the time of diagnosis.

Rationale: This is a replacement for the current CS fields and replacements for information on mets to distant lymph nodes and other sites currently captured in the CS mets variable under individual schemas.

Source of Proposed Change: NCI SEER

Item Name: **Mets at Diagnosis - Other** (new)

Length: 1

Description: New data item to collect specific information on mets at the time of diagnosis.

Rationale: This is a replacement for the current CS fields and replacements for information on mets to distant lymph nodes and other sites currently captured in the CS mets variable under individual schemas.

Source of Proposed Change: NCI SEER

Item Name: **Derived Path Stage Group** (new)

Length: 4

Description: New data item to store the results of the derived algorithmic calculation of Pathologic Stage Group.

Rationale: This will ensure that directly assigned stage group (TNM Path Stage Group #910) can be distinguished from pathologic stage group that has been algorithmically derived from T, N, and M.

Source of Proposed Change: NCI SEER

Item Name: **Derived Clin Stage Group** (new)

Length: 4

Description: New data item to store the results of the derived algorithmic calculation of Clinical Stage Group.

Rationale: This will ensure that directly assigned stage group (TNM Clin Stage Group #970) can be distinguished from clinical stage group that has been algorithmically derived from T, N, and M.

Source of Proposed Change: NCI SEER

Item Name: **Derived Combined Stage Group** (new)

Length: 4

Description: New data item to store the results of the derived algorithmic calculation of Combined Stage Group.

Source of Proposed Change: NCI SEER

Item Name: **Derived Combined T** (new)

Length: 4

Description: New data item to store the results of the derived algorithmic calculation of combined T.

Rationale: This will ensure that directly assigned Clinical T (TNM Clin T #940) or Pathologic T (TNM Path T #880) can be distinguished from the T derived through a Combined calculation.

Source of Proposed Change: NCI SEER

Item Name: **Derived Combined N** (new)

Length: 4

Description: New data item to store the results of the derived algorithmic calculation of combined N.

Rationale: This will ensure that directly assigned Clinical N (TNM Clin N #950) or Pathologic N (TNM Path N #890) can be distinguished from the N derived through a Combined calculation.

Source of Proposed Change: NCI SEER

Item Name: **Derived Combined M** (new)

Length: 4

Description: New data item to store the results of the derived algorithmic calculation of combined M.

Rationale: This will ensure that directly assigned Clinical M (TNM Clin M #960) or Pathologic M (TNM Path M #900) can be distinguished from the M derived through a Combined calculation.

Source of Proposed Change: NCI SEER

Item Name: **Derived Combined T Source/Timing** (new)

Length: 1

Description: New data item to store the results of the source information selected for the derived algorithmic calculation of Combined T.

Source of Proposed Change: NCI SEER

Item Name: **Derived Combined N Source/Timing** (new)

Length: 1

Description: New data item to store the results of the source information selected for the derived algorithmic calculation of Combined N.

Source of Proposed Change: NCI SEER

Item Name: **Derived Combined M Source/Timing** (new)

Length: 1

Description: New data item to store the results of the source information selected for the derived algorithmic calculation of Combined M.

Source of Proposed Change: NCI SEER

Item Name: **Primary Tumor** (new)

Length: 3

Description: New data item to collect information on the primary tumor so that a summary stage can be easily derived for cases not staged under TNM.

Rationale: There are a number of schemas or portions of schemas which are not staged under TNM. Under CS, these have been Summary Staged algorithmically using CS Extension, CS Lymph Nodes, and CS Mets. Beginning with cases diagnosed in 2016, this will no longer be the case.

Source of Proposed Change: NCI SEER

Item Name: **Regional Nodes** (new)

Length: 3

Description: New data item to collect information on the regional nodes so that a summary stage can be easily derived for cases not staged under TNM.

Rationale: There are a number of schemas or portions of schemas which are not staged under TNM. Under CS, these have been Summary Staged algorithmically using CS Extension, CS Lymph Nodes, and CS Mets. Beginning with cases diagnosed in 2016, this will no longer be the case.

Source of Proposed Change: NCI SEER

Item Name: **Mets** (new)

Length: 2

Description: New data item to collect information on the mets so that a summary stage can be easily derived for cases not staged under TNM.

Rationale: There are a number of schemas or portions of schemas which are not staged under TNM. Under CS, these have been Summary Staged algorithmically using CS Extension, CS Lymph Nodes, and CS Mets. Beginning with cases diagnosed in 2016, this will no longer be the case.

Source of Proposed Change: NCI SEER

Item Name: **Derived SS2016** (new)

Length: 1

Description: New data item to store the results for derived Summary Stage 2016 and to allow for the direct assignment of this variable.

Source of Proposed Change: NCI SEER

Item Name: **Directly Assigned SS2016** (new)

Length: 1

Description: New data item to store the results for derived Summary Stage 2016 and to allow for the direct assignment of this variable.

Source of Proposed Change: NCI SEER

NAACCR Education and Training Program Update

Shannon Vann, CTR

NAACCR Program Manager of Education & Training

A very important part of the NAACCR Cancer Registry and Surveillance Webinar Series is the questions from the participants we receive during each webinar. My update this quarter features some of the questions and answers from the first three webinars of the 2014-2015 NAACCR Cancer Registry and Surveillance Webinar Series.

Directly Coded Stage Data: Using the AJCC Cancer Staging Manual 7th Ed. and Summary Stage 2000

Q: Bladder cancer patient has a TURB. Pathology indicates an *in situ* tumor. There is no clinical indication of lymph node or distant metastasis. You stated the following for AJCC stage:

- pTis cN0 cM0 clinical stage group 0is.
- pTis cN0 cM0 pathologic stage group 99.

Why is the pathologic stage group 99? Per AJCC manual page 12 at the bottom of table 1.8, carcinoma *in situ*, stage PTis cN0, M0 are both clinical and pathologic stage 0.

A: For bladder, pathologic staging is based on the histologic review of the radical or partial cystectomy specimen. This patient did not have a cystectomy so the pathologic stage group is unknown.

Collecting Cancer Data: Hematopoietic and Lymphoid Neoplasms

Q: If a patient is diagnosed with acute leukemia, most likely acute myeloid leukemia (AML), and the clinic notes always refer to the patient being treated as AML, is this case coded as acute leukemia, NOS or acute myeloid leukemia?

A: This case would be coded as AML. Per the primary site and histology coding instructions and rules, if you have ambiguous terminology used with a specific histology and then the physician states that they are treating for the specific disease, then you can assign the specific histology. (See #5 Example 2 in *Primary Site and Histology Coding Instructions and Rules* page 26). For this question, the physician is treating this as AML, so the specific histology (9861/3 for AML) may be used.

Q: I often see the abstractor code the lymph node regions where the biopsy was taken but the CT reveals lymphadenopathy above and below the diaphragm. Please stress that this should be coded to C77.8.

A: Per Module 6 and 7: Do not simply code the site of a biopsy; use the information available from scans to determine the correct primary site. Use the PH rules in Module 6 and Module 7 to help you to determine the primary site.

Using the Multiple Primary and Histology Coding Rules

Q: Would you use rule H4 in the colon rules for carcinoid tumor arising in a polyp and assign code 8210?

A: I sent the question to SEER and their response follows: "H4 does not apply as carcinoid in a polyp is not a final diagnosis listed in the histology column. Rule H11 applies, and the histology should be coded to carcinoid."

Q: Should the ICD-O-3 code for ductal carcinoma mixed with apocrine adenocarcinoma in the breast be 84103 (apocrine) based on rule H12? SEER SINQ 20081031 states that apocrine is a type of ductal carcinoma. It further states this will be added to Table 2.

A: The question was sent to SEER for clarification. Their response follows: "Per WHO, apocrine is a carcinoma showing cytologic features of apocrine cells in >90% of cells. Any type of breast cancer can display apocrine differentiation including invasive ductal, tubular, medullary, papillary, neuroendocrine, micropapillary, and even lobular. Our breast SMEs (subject matter experts) instructed that when apocrine appears with infiltrating duct, the mixed code was the correct option. If the pathologist states the histology is only apocrine, then 8401 is correct. (The 4th Edition *WHO Tumors of the Breast* states that carcinomas with apocrine differentiation should be coded to the primary invasive type. This instruction will be updated in the coming revisions but is not to be applied now.)"

NAACCR 2015 Education and Training Calendar



FEBRUARY 2015

2/3/15 - Session 5; CTR Exam Preparation & Review Webinar Series
2/5/15 - Collecting Cancer Data: Uterus
2/10/15 - Session 6; CTR Exam Preparation & Review Webinar Series
2/17/15 - Session 7; CTR Exam Preparation & Review Webinar Series
2/24/15 - Session 8; CTR Exam Preparation & Review Webinar Series

MARCH 2015

3/5/15 - Abstracting and Coding Boot Camp: Cancer Case Scenarios
3/24/15 - Feedback session; CTR Exam Preparation & Review Webinar Series

APRIL 2015

4/21/15 - Session 1; CTR Exam Preparation & Review Webinar Series
4/28/15 - Session 2; CTR Exam Preparation & Review Webinar Series

MAY 2015

5/5/15 - Session 3; CTR Exam Preparation & Review Webinar Series
5/7/15 - Collecting Cancer Data: Larynx and Thyroid
5/12/15 - Session 4; CTR Exam Preparation & Review Webinar Series
5/19/15 - Session 5; CTR Exam Preparation & Review Webinar Series
5/26/15 - Session 6; CTR Exam Preparation & Review Webinar Series

JUNE 2015

6/2/15 - Session 7; CTR Exam Preparation & Review Webinar Series
6/4/15 - Collecting Cancer Data: Pancreas
6/9/15 - Session 8; CTR Exam Preparation & Review Webinar Series

JULY 2015

7/9/15 - Survivorship Care Plans
7/14/15 - Feedback session; CTR Exam Preparation & Review Webinar Series

AUGUST 2015

8/6/15 - Collecting Cancer Data: Central Nervous System
8/25/15 - Session 1; CTR Exam Preparation & Review Webinar Series

SEPTEMBER 2015

9/1/15 - Session 2; CTR Exam Preparation & Review Webinar Series
9/3/15 - Coding Pitfalls
9/8/15 - Session 3; CTR Exam Preparation & Review Webinar Series
9/15/15 - Session 4; CTR Exam Preparation & Review Webinar Series
9/22/15 - Session 5; CTR Exam Preparation & Review Webinar Series
9/29/15 - Session 6; CTR Exam Preparation & Review Webinar Series

NAACCR Narrative
OCTOBER 2015

10/6/15 - Session 7; CTR Exam Preparation & Review Webinar Series
10/13/15 - Session 8; CTR Exam Preparation & Review Webinar Series

NOVEMBER 2015

11/10/15 - Feedback session; CTR Exam Preparation & Review Webinar Series

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.naacccr.org); or contact Shannon Vann (svann@naaccr.org) or Jim Hofferkamp (jhofferkamp@naaccr.org).

NAACCR News

Jim Hofferkamp, CTR
NAACCR Trainer

2015 Implementation Guidelines and Recommendations

The 2015 Implementation Guidelines and Recommendations, revised January 2015, is posted to the NAACCR website. It includes changes to the country codes and hematopoietic conversion sections (including Appendix B). The revisions are marked by using "track changes;" however, Appendix B was completely replaced so there are no tracked changes. The heme computer conversion specs are posted on the website as a sub-bullet under the 2015 guidelines.

The 2015 Implementation Guidelines and Recommendations document is available online on the [NAACCR Implementation Guidelines page](#).

In addition, the country codes crosswalk was updated to include the code change of Brunei to BRN. Click [here](#) to be directed to NAACCR's Data Standards & Data Dictionary (Volume II) web page.

Tips for Creating Central Registry Statistical Cancer Reports Efficiently

Tips for Creating Central Registry Statistical Cancer Reports Efficiently is the next NAACCR Cancer Surveillance Webinar. It will be presented Thursday, January 29, 2015, from 1:00 - 2:00 p.m. ET by Kim Herget of the Utah Cancer Registry. Registration is free and audio will be through your computer.

Those interested in attending should register [here](#).

Monitoring regional cancer rates is critical for strategic local and state planning and can provide a "report card" on the health of a community and insight into how well cancer prevention programs are working. However, with increasingly scarce monetary resources, producing local cancer reports on a regular basis can be challenging. We tried to develop best practices for creating effective and easily updateable cancer reports in a timely manner using limited resources. NAACCR and NCI both have an abundant array of freely available software tools for analyzing cancer statistics. Utilizing these tools in conjunction with integrated Microsoft Office products resulted in quicker updates for our Cancer in Utah reports. Ultimately, the key to refining and streamlining the process was planning. Once specific table and figure formats were developed, updating them from year to year became much quicker and less resource intensive.

A recording of the session will be posted to the [NAACCR Town Hall webpage](#).

Delay Adjustment for NAACCR Registries Webinar

A recording of the December 3, 2014, *Delay Adjustment for NAACCR Registries* webinar is now available online at <http://www.naacccr.org/EducationandTraining/TownHallWebinars.aspx>.

AJCC Curriculum for Registrars Module I

AJCC has posted Module I of their *AJCC Curriculum for Registrars*. The modules are free for everyone and can be accessed online at <https://cancerstaging.org/CSE/Registrar/Pages/AJCC-Curriculum.aspx>. An outline of the module is below:

Module I Introduction

- Overview of staging

- High level explanation of why and how
- For staff that does not assign stage (many central registry staff, statisticians, researchers): (1) basic principles of stage, (2) understand terminology used, (3) only lesson they will need
- For staff assigning stage: (1) foundation of why AJCC staging is different from CS and summary stage, (2) how it is used

NAACCR Fees



Many of you are in the process of writing registry budgets for the upcoming fiscal year. As you prepare budgets, NAACCR fee schedules will not change for the upcoming year.

NAACCR will once again present the Cancer Registry and Surveillance Webinar Series during fiscal year 2015-2016. It will be a series of 12 webinars.

- 12 webinars \$1,440
- 9 webinars \$1,215
- 6 webinars \$900
- Single webinar \$185

NAACCR will also present the CTR Exam Preparation and Review Webinar Series over a series of 8 weeks prior to the June/July 2015 CTR exam, October/November 2015 CTR exam, and the March 2016 CTR exam. The subscription price for each series will be \$400.

NAACCR dues for 2015-2016 will remain the same as last year; Full Member at \$500, Sustaining For-Profit at \$2,000 / Non-Profit at \$650, Sponsoring Member at \$3,000, and Individual Member at \$150. The full conference early-bird registration fee for the 2015 NAACCR Annual Conference will be \$495.

If you have any questions about this, please forward them to Charlie Blackburn (cblackburn@naaccr.org).

NAACCR Survival Analysis Task Force Update

The Survival Analysis Task Force (SATF) provides resources and guidance to NAACCR members on survival analysis-related activities. SATF members have made numerous contributions to the registry community in the form of scientific papers and educational trainings and webinars.

Chris Johnson, MPH

*Epidemiologist, Cancer Data Registry of Idaho
Representative-at-Large, 2014-2016, NAACCR Board of Directors*

Deborah Hurley, MSPH

Assistant Director, South Carolina Central Cancer Registry

The purpose of the Survival Analysis Task Force (SATF) is to provide resources and guidance to NAACCR members on survival analysis-related activities. Formed in 2008 as the NAACCR Survival Analysis Work Group, chiefly to evaluate how survival estimates are impacted by active follow-up versus ascertainment of deaths only, SATF members have made numerous contributions to the registry community in the form of scientific papers and educational trainings and webinars. SATF members and their organizations have participated in many survival-analysis related collaborative efforts, some of which recently culminated in noteworthy publications and reports:

- The CONCORD-2 study, published in *The Lancet*, reports 5-year survival estimates for 25.7 million cancer patients diagnosed with one of 10 common cancers and 75,000 children diagnosed with acute lymphoblastic leukemia between 1995 and 2009, using individual patient data from 279 cancer registries in 67 countries. The most comprehensive international comparison of cancer survival to date, covering countries that are home to two-thirds of the world’s population, it shows extremely wide differences in survival between countries. The full article is available online [here](#).
- The National Cancer Institute announced the publication of *Cancer Survival From a Policy and Clinical Perspective: US Surveillance, Epidemiology, and End Results (SEER) Program, 1975-2010* in *Journal of the National Cancer Institute Monographs* (No. 49: November 2014), available online [here](#). The monograph’s

focus is on methods implemented in SEER*Stat that could be readily used with cancer registry data, and on illustrating which survival measures should be used for specific purposes: research and policy versus prognosis and individual decision making. The overview paper in the monograph presents up-to-date survival estimates for selected cancers sorted by these purposes. One paper evaluates CINA data for fitness for use for survival analysis and presents U.S. and Canadian survival estimates: "Evaluation of North American Association of Central Cancer Registries' (NAACCR) Data for Use in Population-Based Cancer Survival Studies." A single printed copy of the monograph may be ordered online from the NCI Publications Locator, while supplies last (<https://pubs.cancer.gov/ncipl/detail.aspx?prodid=T315>).

- CDC's National Program of Cancer Registries (NPCR), for the first time ever, published relative survival statistics in the United States Cancer Statistics (USCS) web-based report. Data from 30 NPCR central cancer registries that met the USCS publication criteria and conducted linkage with the National Death Index for all years 2003-2010 were included in the analysis. 5-year relative survival was calculated for cases diagnosed during 2003-2010 and followed through 2010. The current release includes 5-year relative survival by selected primary site, race, sex, and age group for all sites combined, lung and bronchus, colon and rectum, female breast, cervix uteri and prostate cancer and is available online [here](#).

The SATF Life Tables Subgroup, led by Angela Mariotto (NCI) and Bin Huang (Kentucky Cancer Registry), is focused on generating state-specific life tables for use in relative survival analysis. When the life tables are finalized, SATF will work towards routinely generating state and province-specific 5-year relative survival estimates by race, gender, and cancer site for inclusion in the *CINA Annual Report*.

Data Use and Research: Data in Action

This year's *Annual Report to the Nation on the Status of Cancer* contains a focus on breast cancer incidence by subtype based on estrogen, progesterone, and human epidermal growth factor-neu (HER2) receptor status. The *Annual Report to the Nation* is complete, and the database used for analysis is now available for NAACCR-approved research.

Recinda Sherman, PhD, MPH, CTR

NAACCR Program Manager of Data Use and Research

As we all know, the only constant in the field of cancer registration is change. As we increase our knowledge of pathogenesis, we must accommodate this information in our data collection standards. This often means collecting additional, clinically relevant data like HER2 status for breast cancer. As described in previous *NAACCR Narratives*, this year's *Annual Report to the Nation on the Status of Cancer* contains a focus on breast cancer incidence by subtype based on estrogen, progesterone, and human epidermal growth factor-neu (HER2) receptor status. The *Annual Report to the Nation* is complete, and the database used for analysis is now available for NAACCR-approved research.

Using Site-Specific Factors 1, 2, and 15, the database classifies breast cancer cases diagnosed in 2011 into a joint hormone receptor status (HR), a combination of estrogen and progesterone receptor statuses, and HER2 status. To align with commonly used molecular categories, four HR/HER2 categories were used (HR+/HER2-, HR+/HER2+, HR-/HER2+, and HR-/HER2- or "triple negative"). A case was considered incomplete if ER, PR, or HER2 status was unknown or if HER2 was borderline (borderline HR cases were considered positive). Cases with incomplete HR/HER2 status were imputed based on a set of relevant demographic variables.

To access this dataset for research, a request should go through the standard CINA Data Request process. The research proposal must be approved first by the Research and Application Review (RApR) Workgroup, then the NAACCR IRB, and finally each individual registry be asked for consent. All needed forms are available on-line at www.naacccr.org/Research/CINADeluxe.aspx. For additional information about this dataset, including case selection criteria and assistance analyzing imputed data, please contact me (rsherman@naaccr.org).

Another well-known state of the cancer surveillance environment is that our data must be relevant for research without additional funding for data collection. One approach to this challenge is to include area-based social measures in cancer surveillance data by linking our cases to external datasets like census data through geocoding. Geocoding allows for the combination of otherwise disparate databases, such as registry data and census data, linked by spatial location. As mentioned in the Fall 2014 *NAACCR Narrative*, NAACCR has added two tract-level urban-rural codes to the CINA Deluxe Database: Rural-Urban Commuting Areas (RUCA) and Urban-Rural Indicator Codes (URIC). This allows for health disparity research using measurements that are more precise than county-level data and can address multiple barriers to care (e.g., rural residence, distance from urban health care systems, and poverty status).

In addition, NAACCR has worked with Dr. Dan Goldberg of Texas A&M University and NCI to launch an update to the NAACCR geocoder. The NAACCR geocoder is now housed on a new server, contains updated address data, and has restructured webpages. Plans for additional improvements over the next year are focused on improving the speed and reliability of the NAACCR Geocoder as well as widening the scope of the geocoding service to include Puerto Rico. We appreciate any comments or questions users might have with the new geocoder. Users

will notice that old databases were not moved over during this transition. If a registry requires access to a database stored on the old server, please contact me (rsherman@naaccr.org).

NCDB News

Ryan M. McCabe, PhD

Senior Manager, National Cancer Data Base, American College of Surgeons

The National Cancer Data Base (NCDB) is charged with serving the needs of cancer patients, clinicians, and hospitals across the country. The great work of developing the database over the past 25+ years has put us in a leading position of collecting data and providing data-driven resources that serve approximately 1,500 Commission on Cancer-accredited hospitals and 70% of newly diagnosed patients nationwide.

The NCDB is also in a time of transition as we prepare for the next wave of challenges we must face in order to continue to successfully fulfill our mission.

- Jerri Linn Phillips, who has served the NCDB in multiple ways for over 19 years, retired on December 19, 2014. Jerri Linn has been instrumental in developing and growing the NCDB as our Manager of Information and Data Standards. She is a nationally recognized figure in data standards and will be greatly missed by all who have had the pleasure of working with and knowing her over the years.
- After conducting a comprehensive, nationwide search for candidates for NCDB Manager of Information and Data Standards, we are pleased to announce that Kathleen Thoburn has accepted the position and started work on November 24, 2014. Kathleen comes from Northrup Grumman contracting with the CDC, working on central registry software for NPCR and Registry Plus and brings experience from the New York State Department of Health and 12 years of experience with various NAACCR working groups. Kathleen has already hit the ground running with the NCDB as an enthusiastic, passionate, and diligent contributor. Feel free to reach out to her directly at ktthoburn@facs.org.

Please join me in wishing Jerri Linn all the best in her retirement and in welcoming Kathleen aboard.



American College of Surgeons CTRs: Debbie Etheridge, Jerri Linn Phillips, Vicki Chiappetta, (front) Anna Delve, Donna Gress, Asa Carter, and Kathleen Thoburn

FORDS: Revised for 2015 Posted

The new *FORDS: Revised for 2015* has been posted online and is available [here](#). *FORDS* (Facility Oncology Registry Data Standards) is the coding manual used by Commission on Cancer-accredited programs. Although there are no new data items introduced for 2015, there are some important changes in instructions and code options.

Please read the Preface for an overview of the changes, and review Appendix C for a complete summary of modifications made since the previous edition of *FORDS*. The following highlights the major changes:

- **Required Staging.** Both clinical and pathologic AJCC T, N, M and Stage Group as well as Collaborative Staging are required for Class of Case 10-22.
- **Rules for Coding Grade/Differentiation.** New rules for coding Grade/Differentiation were implemented by all U.S. cancer registry standard setters beginning with cases diagnosed in 2014, and were widely published at that time. However, no *FORDS* update was produced for 2014. The new rules are included in *FORDS: Revised for 2015*.

- **Clarification for Coding Biopsies Followed by Surgery.** If a needle biopsy preceded an excisional biopsy or more extensive surgery, even if no tumor remained at the time of surgery, both the needle biopsy (Surgical Diagnostic and Staging Procedure) and the Surgical Procedure of the Primary Site are to be reported. That is because surgical margins must be examined to determine whether a biopsy intended as incisional is excisional instead, and margins cannot be evaluated for a needle biopsy.
- **Clarification for Reporting Dose for Photon Treatment.** For photon treatment, dosage is reported in cGe units (Cobalt Gray Equivalent) rather than cGy. Record 100x cGe for Regional Dose: cGy (note that it is necessary to multiply cGe by 100 to code this).
- **New Sex Codes.** New codes 5 (Transsexual, natal male) and 6 (Transsexual, natal female) are introduced for use in 2015, and may be used for historic cases if desired. Code 4 (formerly “Transsexual”) is now “Transsexual, NOS”. The new codes will be accepted by registry software using NAACCR layout version 15.0, which should be implemented in hospital registries early in 2015.
- **New Code for RX Date-Other Flag.** Code 15 was added to be used when treatment coded as Other Therapy was planned, but had not been administered yet at the time of last follow-up. Code 15 may be assigned for cases diagnosed prior to 2015, if applicable. The new code will be accepted by registry software using NAACCR layout 15.0, which should be implemented in hospital registries early in 2015.
- **Discontinued Items.** Grade Path System and Grade Path Value are required for cases diagnosed from 2010 through 2013, but are discontinued beginning in 2014 under the Grade/Differentiation coding rules. The ICD Revision Secondary Diagnosis is no longer required for any diagnosis year because the separate fields for ICD-9-CM and ICD-10-CM eliminate the need for the item.

FORDS: Revised for 2015 is provided as a downloadable .pdf file. Sticky notes and highlighting are enabled. Note that it is necessary to save the file to your computer (or network) to use the commenting features, which are not functional when you open the manual through your browser.

Coding questions should be submitted to the CAnswer Forum (<http://cancerbulletin.facs.org/forums/>). Address questions or comments about the *FORDS: Revised for 2015* document to Kathleen Thoburn at kthoburn@facs.org. Kathleen is assuming the NCDB position being vacated by Jerri Linn Phillips.

CONCORD-2 Update

Provisional results from the CONCORD-2 study were presented at the NAACCR meeting in Ottawa in June 2014. International comparison of survival trends reveals very wide differences that are likely to be attributable to differences in access to early diagnosis and optimal treatment. Continuous worldwide surveillance of cancer survival should become an indispensable source of information for cancer patients and researchers and a stimulus for politicians to improve health policy and health-care systems.

Global Surveillance of Cancer Survival 1995-2009: Analysis of Individual Data for 25,676,887 Patients From 279 Population-Based Registries in 67 Countries (CONCORD-2)

Provisional results from the CONCORD-2 study were presented at the NAACCR meeting in Ottawa in June 2014. The full article was submitted to *The Lancet* for fast-track review in October 2014, less than 2 years after the call for data in November 2012. It was published online (available [here](#)) on 25 November 2014, 6 weeks after submission. It has aroused world-wide media attention. The paper is fully open-access, meaning it can be downloaded without charge. Results were presented at the World Cancer Congress in Melbourne, Australia, on December 6, 2014.

The article runs to 34 pages, 2 of which are required simply to list all 496 contributing authors with their institutional affiliations! The article is linked to an online web-appendix. This contains 175 pages with extensive tables with the quality-control figures and the survival estimates for each cancer, for each calendar period (1995-99, 2000-04, 2005-09) and for each of the 279 participating registries. The appendix also includes a set of 3 graphics for each cancer summarizing world-wide survival patterns and trends, as well as 28 high-resolution maps of the countries and territories from which data were provided.

Worldwide data for cancer survival have been scarce until now. The CONCORD-2 study aimed to initiate worldwide surveillance of cancer survival by central analysis of population-based registry data, as a metric of the effectiveness of health systems, and to inform global policy on cancer control.

Briefly, individual tumor records were submitted by 279 population-based cancer registries in 67 countries for 25.7 million adults (age 15-99 years) and 75,000 children (age 0-14 years). This included data from all 13 Canadian provincial and territorial cancer registries and 44 NPCR and SEER cancer registries, covering 100% and 84% of the Canadian and U.S. populations, respectively. Eligible patients included those diagnosed with cancer during 1995-2009 and followed up to Dec 31, 2009, or later. Data were included for cancers of the stomach,

colon, rectum, liver, lung, breast (women), cervix, ovary, and prostate in adults, and adult and childhood leukemia. Standardized quality control procedures were applied; errors were corrected by the registry concerned. Five-year net survival was estimated adjusted for background mortality in every country or region by age (single year), sex, and calendar year, and by race or ethnic origin in some countries. Estimates were age-standardized with the International Cancer Survival Standard weights.

Five-year survival from colon, rectal, and breast cancers has increased steadily in most developed countries. For patients diagnosed during 2005-09, survival for colon and rectal cancer reached 60% or more in 22 countries around the world; for breast cancer, 5-year survival rose to 85% or higher in 17 countries worldwide. Liver and lung cancer remain lethal in all nations: for both cancers, 5-year survival is below 20% everywhere in Europe, in the range 15-19% in North America, and as low as 7-9% in Mongolia and Thailand. Striking rises in 5-year survival from prostate cancer have occurred in many countries: survival rose by 10-20% between 1995-99 and 2005-09 in 22 countries in South America, Asia, and Europe, but survival still varies widely around the world, from less than 60% in Bulgaria and Thailand to 95% or more in Brazil, Puerto Rico, and the USA. For cervical cancer, national estimates of 5-year survival range from less than 50% to more than 70%; regional variations are much wider, and improvements between 1995-99 and 2005-09 have generally been slight. For women diagnosed with ovarian cancer in 2005-09, 5-year survival was 40% or higher only in Ecuador, the USA, and 17 countries in Asia and Europe. Five-year survival for stomach cancer in 2005-09 was high (54-58%) in Japan and South Korea, compared with less than 40% in other countries. By contrast, 5-year survival from adult leukemia in Japan and South Korea (18-23%) is lower than in most other countries. Five-year survival from childhood acute lymphoblastic leukemia is less than 60% in several countries, but as high as 90% in Canada and four European countries, which suggests major deficiencies in the management of a largely curable disease.

International comparison of survival trends reveals very wide differences that are likely to be attributable to differences in access to early diagnosis and optimal treatment. Continuous worldwide surveillance of cancer survival should become an indispensable source of information for cancer patients and researchers and a stimulus for politicians to improve health policy and health-care systems.

On behalf of the CONCORD Steering Committee, we want to thank NAACCR member registries that participated in the CONCORD-2 study.

Claudia Allemani (LSHTM)

Michel P Coleman (LSHTM)

Brenda K Edwards (NCI)

Diane Nishri (Cancer Care Ontario)

Thomas Tucker (University of Kentucky)

Donna Turner (CancerCare Manitoba)

Hannah K Weir (CDC)

Global Initiative for Cancer Registry Development

The Global Initiative for Cancer Registry Development (GICR), a collaboration between international partners to share knowledge and facilitate research to inform cancer control, recently launched a new website. The revised website describes the unified strategy developed to address global disparities in cancer information and outlines significant progress made to date, including examples of the GICR's key activities and related resources to cancer registration and descriptive epidemiology.



The Global Initiative for Cancer Registry Development (GICR) recently launched a new website. Led by the International Agency for Research on Cancer (IARC), the GICR is a collaboration between international partners to share knowledge and facilitate research to inform cancer control. The revised website describes the unified strategy developed to address global disparities in cancer information.

The next phase of the initiative is also described, as it targets a growing number of low- and middle-income countries to identify their needs and provide the necessary support.

The website outlines the significant progress made to date, including examples of the GICR's key activities and related resources to cancer registration and descriptive epidemiology. To visit the website, see <http://gicr.iarc.fr/>.

EHR and Meaningful Use Webinar Series

The Kentucky Cancer Registry has been sponsoring a series of electronic health record (EHR) and meaningful use webinars for NPCR states. The final webinar in this series, "Integration of EHR Data Into Registry Workflows Through Linkages," will be held on February 11, 2015, at 3:00 p.m. Eastern.

This training will focus on the development of workflow to incorporate EHR data into the central registry in order to improve central registry data for comparative effectiveness research. The session will describe methods to assess, edit and validate cancer abstracts derived from EHR data submissions. The session will cover the

complete cycle EHR data processing beginning with the receipt of an EHR message, export of an EHR derived cancer abstract, linkage with existing cancer abstracts, and conclude with the addition of more complete treatment, disease progression, and recurrence information to the patient record.

For additional information, including registration and technical assistance, click [here](#).

CAP Awarded California Department of Public Health and California Cancer Registry Grant

The College of American Pathologists has been awarded a \$300,000 grant from the California Department of Public Health and the California Cancer Registry (CCR). The funding lays the foundation for California hospitals to securely transmit live data to CCR using the CAP's electronic Cancer Checklists (eCC).

The CCR is actively seeking more funding, in collaboration with the CAP, to continue this work to include more laboratories and in hopes to eventually provide real-time analytics for improved cancer surveillance and patient care.

Electronic transmission of patient data to cancer registries helps hospitals to streamline reporting and improve patient outcomes. The eCC enables pathologists to use the CAP Cancer Protocols directly within their laboratory information system and to ensure that each report is completed with the necessary elements required for accreditation by the American College of Surgeons – Commission on Cancer and the CAP Laboratory Accreditation Program.

The CAP and CCR are leading the way in the development of electronic submission of cancer data to:

- Provide ease of access to information and analytics for the public, laboratories, and health systems;
- Significantly decrease delay for access to this information; and
- Ensure information accuracy using structured data.

For more information, click [here](#).

Collaborative Staging and Its Impact on Cancer Registry Data: Information for Data Users on Analysis and Interpretation of Registry Data

Collaborative Stage (CS) is a data collection system that uses a single set of data elements based on extent of disease and clinically relevant factors. It is designed to meet the needs of multiple staging systems and eliminate duplicate data collection by cancer registrars reporting to facility-based and central population-based registries. The CS system was updated in 2010 (CSv2) in conjunction with the release of the 7th Edition of the *AJCC Cancer Staging Manual*, which presents the Tumor (T), Node (N), Metastasis (M), and stage descriptions along with a section on prognostic factors for which collection is recommended. Those recommendations are the basis for the development and collection of the site-specific factors (SSFs) for CS.

The National Cancer Institute is pleased to announce the publication of *Collaborative Staging and Its Impact on Cancer Registry Data: Information for Data Users on Analysis and Interpretation of Registry Data* in *Cancer* (Volume 120, Issue Supplement S23: December 1, 2014). The special issue describes the information collected under CSv1 and CSv2 within the SEER Program for eight common cancer sites. Each report discusses how changes between the AJCC 6th and 7th Editions affect stage distributions and trends, and then quantifies the potential impacts on outcomes and incidence trends stratified by stage. SSFs are described in detail, with particular emphasis on the factors newly collected in 2010. Analyses are performed to evaluate the completeness and quality of each SSF. The special issue was made possible by NCI's Surveillance Research Program, experts from SEER registries, and other leaders from the surveillance community.

2015 Hematopoietic Manual and Database

Jennifer Ruhl, CTR

National Cancer Institute

Here we are again with a new year. I hope that your new year has been going well.

The 2015 Hematopoietic *Manual* and Database have been completed and posted on the SEER website. There is also a list of changes that you can review (<http://seer.cancer.gov/tools/heme/update.html>). The important thing is: **no rule changes** (additions/deletions).

There are several other hematopoietic-related changes which are important:

1. Hematopoietic Glossary: Removed from the manual (see notice below)
2. Non-reportable Hematopoietic Terms:
 - a. These have also been removed from the *Hematopoietic Manual*. They are now included in the

Hematopoietic Database and are indicated as non-reportable.

3. Hematopoietic Conversions for cases diagnosed 2010 and forward:

a. Based on the changes in 2014 (combination of 2010 and 2012 *Manuals* and databases) and the decision to no longer use OBS codes for 2010 and forward, it was decided for cases diagnosed 2010 and forward to convert all the obsolete codes to their current code. In addition, we are correcting grade and primary site when needed. These changes are based on the Heme *Manual* and Database.

b. The Hematopoietic Conversion document is on the SEER website and describes in detail the reasons behind this decision and the process.

c. There will be some required manual reviews. Based on data from SEER and NPCR for cases diagnosed 2010-2012, the cases requiring manual review are few. Guidelines are also provided in this document on how to make the changes. Information is provided on what to do when no additional information is available.

d. In addition to the hematopoietic conversion documentation, an excel spreadsheet is also posted which shows how the computer conversion will work. The conversion program will be provided by your software vendor.

Documentation for the hematopoietic conversions, can be found at:

<http://seer.cancer.gov/tools/heme/conversion.html>.

I would like to take this opportunity to publicly thank the NAACCR Edits Workgroup and the NAACCR Edits Impact Workgroup for their help. A special thanks to Susan Capron, Lynn Ries, and Jennifer Seiffert for their extensive time and expertise. They were critical to this project being completed. The conversions are currently being tested and will be released soon as part of the NAACCR v15 metafile.

If you have any questions regarding the changes above, please submit your questions to Ask a SEER Registrar (Hematopoietic Rules) at <http://seer.cancer.gov/tools/heme/conversion.html>.

Have a great 2015!

NCI Announces CI*Rank Tool!

The Surveillance Research Program within the NCI is pleased to announce the launch of the web-based CI*Rank tool, which provides confidence intervals for ranks of age-adjusted cancer incidence and mortality rates by geographic region in the U.S. Confidence intervals for ranks of mortality rates for other causes of death are also provided. Users can compare counties, states, and specific geographical regions such as Appalachia and Gulf Coast counties.

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Ranking health indices is useful for seeing where a geographic area stands in comparison to other areas. However, ranks are inherently random and are dependent on the variability of the rates. Providing ranks and their level of uncertainty (i.e., the confidence intervals) together demonstrates not only the variability of that area's rates but also the variability of closely ranked areas' rates. Dr. Li Zhu, Mathematical Statistician in the Surveillance Research Program, is the NCI scientific lead for this valuable new resource.

CI*Rank is available at <http://surveillance.cancer.gov/cirank/>.

<http://www.naacccr.org>



North American Association of Central Cancer Registries
Working together to make every cancer count.

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