Message From the President

Chuck Wiggins, PhD  
NAACCR President

This is an auspicious time to be involved in the field of cancer surveillance. Remarkable progress is being made in the war on cancer. Central cancer registries are contributing to these advances. Registry data support a variety of projects that address issues such as prevention, early detection, etiology, quality of care, survival and survivorship. NAACCR plays a key role in the provision of high quality cancer surveillance data that are utilized across the cancer control continuum. We also promote utilization and reasoned interpretation of these data.

As this issue of the Narrative goes to press, it is once again time to nominate individuals to serve in leadership positions for our organization. We are looking to fill three positions on the Board of Directors. We are also seeking individuals who are willing to serve a two-year term as NAACCR President beginning in June of 2017. The active participation of our members ensures that NAACCR will continue to meet the broad needs of the cancer control community.

I can attest that serving in this capacity offers a unique opportunity for growth and development – both personal and professional. You will also have the good fortune to work with some of the most knowledgeable individuals in our field.

I heartily encourage you to “throw your hat in the ring” – don’t let this opportunity pass you by!

Message From the Executive Director

Betsy A. Kohler, MPH, CTR  
NAACCR Executive Director

Fall has gotten off to a busy start! We have obtained funding through our contract with the National Cancer Institute to ramp up our Virtual Pooled Registry (VPR) project, which will allow researchers to match cohorts with data in state cancer registries behind the state’s firewall. There has been an intense level of excitement and enthusiasm on the part of both researchers and registries about this project. We have initial interest from states representing about 65% of the U.S. population. If you are interested in having your registry participate in the VPR, please be sure to contact me or Recinda Sherman (rsherman@naaccr.org).

We have also obtained funding through NCI to enhance global cancer registry-centered surveillance. Look for changes to our website, and enhancements to our learning management system to help make educational materials and tools more readily available to cancer registries beyond North America. As part of our support of the Global Initiative for Cancer Registries sponsored by IACR, I accompanied Mona Saraiya, Michelle O’Hegarty, and Hilda Razzaghi all of CDC on a site-visit to the U.S. Virgin Islands. Data collection is scheduled to begin there in January 2016.

Susan Gershman and I recently attended a forum sponsored by “The Economist” entitled the “War on Cancer” in Boston. Our complimentary tickets gave us access to an interesting program focusing on many clinical advances and innovation in technology. Some links that may be of interest to our members include:

- [www.i2b2.org](http://www.i2b2.org) i2b2 (Informatics for Integrating Biology and the Bedside) is an NIH-funded National Center for Biomedical Computing based at Partners HealthCare System.
I have just returned from the IACR meeting in Mumbai. I presented a talk on “Building Capacity for Cancer Surveillance Worldwide- Interagency Collaboration and Public/Private Partnerships.” I also moderated a session and served on the panel to choose the Enrico Anglessio Prize in Epidemiology. Chuck Wiggins (NAACCR President), Maria Schymura (IACR Board Member), Lori Swain (ED NCRA), Brenda Edwards (NCI) and Mona Saraiya (CDC) made the long journey too. Luckily, the flight to Mumbai was on a bigger plane than the one I took in the Caribbean in September!

Highlights From the Program Manager of Standards

*Lori A. Havener, CTR*

*NAACCR Program Manager of Standards*

**Standards Volume II, Version 16 - Release**

The NAACCR Standards for Cancer Registries, Volume II Data Standards and Data Dictionary, Version 16 was posted to the NAACCR website on September 30, 2015.

**2016 Implementation Guidelines:**

The 2016 Implementation Guidelines Task Force is diligently working on the guidelines. The group plans to submit the guidelines to the NAACCR Board for review in November…stay tuned!

**Standards Volume II, Version 17:**

Keep in mind the timeline below as you start thinking about 2017:

*Standards Volume II, Version 17 Timeline*

- 12/1/15 - Proposed changes submitted to CMB
- 1/1/16 - Proposed changes approved by CMB
- 1/1/16 - CMB submits request for change to UDS
- 3/1/16 - Volume II Task Force Review
- 5/1/16 - Draft submitted to UDS and the S&RD SC for review/approval
- 6/1/15 - Draft submitted to NAACCR Board for review/approval
- 7/1/15 - Post to NAACCR website
- 1/1/17 - Version 17 Implementation

**NAACCR Research and Data Use Update**

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

The NAACCR community exerts enormous effort to collect high quality, standardized data on all cancer patients in the U.S. and Canada. But a repository of information is not the purpose of cancer registration. The goal is to reduce the burden of cancer in North America, so cancer registration is merely the beginning. Cancer registry data is designed to be used at both local and national levels to improve our understanding of cancer pathology, clinical progression, etiology, and to describe populations at risk. Our cancer surveillance system is considered the “gold standard” for public health disease surveillance, and our data allow for the systematic analysis of cancer data to identify burdens, trends, and to generate hypotheses about cancer risk and etiology.

To enable such research, NAACCR currently has four datasets available that contain data on all cases of cancer in the U.S. and Canada from NAACCR-certified registries. The most comprehensive is the CINA Deluxe Analytic File (for more information click here). CINA Deluxe is available to approved researchers who are affiliated or collaborating with a population-based cancer registry. Researcher proposals are reviewed by RApR, the Research Application Review Committee for scientific merit. Approved proposals then must be approved by the NAACCR IRB and each state provides consent for their data to be included (or excluded) before the dataset is released for research.

We also have two interactive databases accessible to anyone from our website: CINA+ Online (available here) and NAACCR FastStats (available here). Both are limited datasets on the most recent five years of U.S. and Canadian data available for public use and queriable online. CINA+ Online contains a map interface and is comprised of the data presented in the most recent CINA Monographs. NAACCR FastStats contains commonly requested cancer statistics for major cancer sites. CINA+ is also available to NAACCR Members through SEER*Stat to allow more flexible analysis of the CINA data (for more information click here).

NAACCR is now developing an additional Public Use Dataset. This dataset, while still awaiting a catchy name, will be a non-confidential, limited, public-use research file from 1995 forward for U.S. and Canada. It will be available to all researchers upon request after signing a Data Use Agreement. The purpose of the new dataset will be to provide non-confidential data to both NAACCR and outside researchers, whose studies require more variables than currently provided in our public use datasets, but do not need the full CINA Deluxe file. For instance, researchers interested in stage of breast cancer by race/ethnicity do not always require all the variables included in the full CINA Deluxe dataset, but none of our public datasets include stage variables. Or a researcher would like to investigate long-term trends, but only the last five years of data are available in our current public use files. This new dataset will enable faster access for studies of this type and also ensure that a researcher receives only the variables needed for the study.

A NAACCR Taskforce is establishing the list of variables for inclusion in the new dataset. We will be reaching out to registries for input. Both NAACCR Certification and registry consent will be required to include your registry data in the new dataset.

I welcome any comments or concerns about this new approach (rsherman@naaccr.org).

NAACCR Education and Training Program Update

Jim Hofferkamp, CTR
NAACCR Program Manager of Education & Training

NAACCR is very happy to announce that Angela Martin, CTR has joined the NAACCR Team! Angela comes to us from the Missouri Cancer Registry and Research Center where she had nearly ten years’ experience working in various roles including education coordinator, electronic reporting software support, and supervisor of the non-hospital data collection unit. Angela will be spending most of her time working on NAACCR educational and training materials. However, she will also help with committee support, edits, and many, many “other duties as assigned”. Angela brings a lot of energy and drive. I think you will all enjoy working with her.

UPDATES

There are many resources and requirements for cancer data collection for central cancer registries and their data submitters, and sometimes it feels like they are changing rapidly. What follows is information on what is happening now and what is planned for the future.

Collaborative Stage Data Collection System (CS)

CS Version 02.05 is effective for cancer cases diagnosed January 1, 2014, through December 31, 2015. Collection of the CS data items is required by the American College of Surgeons (ACoS) Commission on Cancer (CoC), the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR), and the National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) Program using Version 02.05 for cases diagnosed in 2014 and 2015. Beginning January 1, 2016, standard setters will require some CS site...
specific factors. Required CS site specific factors will be documented by standard setter in NAACCR Vol II Required Status Table [http://www.naaccr.org/Applications/ContentReader/Default.aspx?c=8](http://www.naaccr.org/Applications/ContentReader/Default.aspx?c=8)

**AJCC Cancer Staging**

The ACoS CoC continues to require directly coded AJCC cancer stage.

CDC NPCR requires directly coded AJCC cancer stage as it is available from CoC providers for cases diagnosed January 1, 2014, and after. For cases diagnosed January 1, 2015, and after, CDC NPCR requires directly coded AJCC cancer stage from CoC providers and may be as available from small providers. For cases diagnosed January 1, 2016, and after, directly coded AJCC cancer stage will be required.

NCI SEER requests directly coded AJCC cancer stage for cases diagnosed January 1, 2015, and after and will require it for cases diagnosed January 1, 2016, and after.

**Summary Stage 2000**

CDC NPCR requires directly coded Summary Stage 2000 for cases diagnosed January 1, 2015, and after. NCI SEER requires directly coded Summary Stage 2000 for cases diagnosed January 1, 2016, and after. A revised Summary Stage manual is scheduled for release in 2017.

**Multiple Primary and Histology (MPH) Coding Rules**

The last revision of the MPH Coding Rules was August 24, 2012. Revised MPH Coding Rules are tentatively planned for January 1, 2017, implementation.

**Hematopoietic and Lymphoid Neoplasm Database and Coding Manual**

A revised version of the database and manual was posted January 14, 2015, and effective for cases diagnosed January 2010 and forward.

**ICD-O-3**

In September 2011, the International Agency for Research on Cancer (IARC) and the World Health Organization (WHO) released the document Updates to the International Classification of Diseases for Oncology, Third Edition (ICD-O-3). According to that document, the changes were valid for implementation with cases diagnosed January 1, 2012, and later. Many countries adopted the new terms and codes immediately; others, along with the United States, have taken a more step-wise approach to implementation. The ICD-O-3 Implementation Workgroup included representatives from the standard setters as well as central and hospital cancer registries. They created the document Guidelines for ICD-O-3 Update Implementation, which addresses implementation of the updates and can be accessed from the NAACCR website.

IARC and WHO have released an online version of ICD-O-3 that can be accessed at [http://codes.iarc.fr/usingicdo.php](http://codes.iarc.fr/usingicdo.php). The online version includes ICD-O-3 (2000) and ICD-O-3.1 (2011). ICD-O-3 (2000) and Guidelines for ICD-O-3 Update Implementation should be used to code cancer cases by hospital and central cancer registries until all of the 2011 updates are implemented in the United States and Canada. Currently standard setters are requesting that registries refrain from using the new histology codes until they begin abstracting cases diagnosed in 2017.

**NAACCR 2015-2016 Education and Training Calendar**

**OCTOBER 2015**

10/30/2015 - Cancer Surveillance Series: Proposed Updates to the Common Rule: An Overview of the NPRM

**NOVEMBER 2015**

11/05/2015 - Collecting Cancer Data: Pharynx

**DECEMBER 2015**

12/03/2015 - Directly Coded Cancer Stage…NOW (An In-depth look at AJCC and Summary Stage)

**JANUARY 2016**

01/07/2016 - Collecting Cancer Data: Bone and Soft Tissue

01/08/2016 - Session 1: CTR Exam Preparation and Review Webinar Series
01/13/2016 - Journal Club: Pre-Invasive Cervical Cancer HPV Genotyping in Kentucky: Preliminary Results and Using Cancer Registry Data to Evaluate Breast Cancer Incidence by Subtype

01/15/2016 - Session 2: CTR Exam Preparation and Review Webinar Series

01/22/2016 - Session 3: CTR Exam Preparation and Review Webinar Series

01/29/2016 - Session 4: CTR Exam Preparation and Review Webinar Series

FEBRUARY 2016

02/04/2016 - Collecting Cancer Data: Breast

02/05/2016 - Session 5: CTR Exam Preparation and Review Webinar Series

02/12/2016 - Session 6: CTR Exam Preparation and Review Webinar Series

02/19/2016 - Session 7: CTR Exam Preparation and Review Webinar Series

02/26/2016 - Session 8: CTR Exam Preparation and Review Webinar Series

MARCH 2016

03/03/2016 - Abstracting and Coding Boot Camp: Cancer Case Scenarios

APRIL 2016

04/07/2016 - Collecting Cancer Data: Ovary

MAY 2016

05/05/2016 - Collecting Cancer Data: Kidney

JUNE 2016

06/02/2016 - Collecting Cancer Data: Prostate

JULY 2016

07/07/2016 - Patient Outcomes

AUGUST 2016

08/04/2016 - Collecting Cancer Data: Bladder

NOVEMBER 2016

09/01/2016 - 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).

Twitter Digest

Dan Curran, MS, CTR
NAACCR Social Media Work Group

If you had been following @NAACCR's Twitter feed you would have seen these interesting recent tweets (visit NAACCR's Twitter page for links):

@theNCI

FDA approves expanded indication for device to treat some patients with #glioblastoma http://1.usa.gov/1RsctG7
#btsm
@theNCI
Persistence of Genetic Mutations after Chemo Linked to Poor Outcomes in Some Patients w/ AML. [http://1.usa.gov/1OW4Mtw](http://1.usa.gov/1OW4Mtw)

@AJCCancer

@NCIEpiTraining
Learn about @theNCI research on inherited #BoneMarrowFailure syndromes: [http://1.usa.gov/1YUyCBX](http://1.usa.gov/1YUyCBX)

@NCIEpiTraining
@theNCI biostatisticians develop methods & resources to strengthen cancer studies [http://1.usa.gov/1FNbsqT](http://1.usa.gov/1FNbsqT)

@genome_gov

@NCIEpi
The September edition of Cancer #Epidemiology Matters E-news is now available! [http://conta.cc/1hb2Tdy](http://conta.cc/1hb2Tdy)

@NCIEpi
Learn about @HHSgov proposed changes to #CommonRule to improve human subjects research protections. Learn more: [http://conta.cc/1P66xU2](http://conta.cc/1P66xU2)

@NCIHints
In 2014, 29% of Americans found the results of their most recent search for #cancer information hard to understand: [ow.ly/SKwDu](http://ow.ly/SKwDu)

@NCIEpi
RT @theNCI: NCI Budget Proposal for Fiscal Year 2017 Released [http://1.usa.gov/1KurJh2](http://1.usa.gov/1KurJh2) #NCIresearchfuture

@NCIEpi
Learn more about #NIH funding opportunities & research resources for biomarkers in #cancer #epidemiology research: [1.usa.gov/1P99alK](http://1.usa.gov/1P99alK)

@NCIEpi
@NIHDirector accepts Precision Medicine Initiative Report: [1.usa.gov/1P4Zfh2](http://1.usa.gov/1P4Zfh2) #PMInetwork

@CDC_Cancer
New research: Comorbidities, smoking status & life expectancy among individuals eligible for #LungCancer screening [go.usa.gov/3emBh](http://go.usa.gov/3emBh)

@NAACCR
Melanoma Risk and Survival among Organ Transplant Recipients #NAACCReview [buff.ly/1QtGjx](http://buff.ly/1QtGjx)

@NCIEpi
Can we use genomics to predict relapse & survival in acute myeloid leukemia? [1.usa.gov/1JuFyx7](http://1.usa.gov/1JuFyx7) @WUSTL

@theNCI
Cancer risk in #childhoodcancer survivors continues for decades [1.usa.gov/1JFrKM](http://1.usa.gov/1JFrKM)
@NCIEpiTraining
Looking for a #cancer #epidemiology fellowship? Check out current opportunities @theNCI.usa.gov/1L1lgf.

@NAACCReview
Ovarian Cancer Is Less Deadly Than Previously Thought #NAACCReview buff.ly/1Jviwbb

@CDC_Cancer
10% of #cancer patients getting chemotherapy are hospitalized due to infection. What you can do go.usa.gov/3FcF

@NCIHINTS
In 2014, 10% of Americans w/ a history of #cancer had their #doctor discuss clinical trials as a treatment option: ow.ly/RAmqP

@theNCI
There are different types of brain and spinal cord tumors. Here's an overview of each one: usa.gov/1NYEDqi

Contribute to NAACCReview
The NAACCReview has been live for six months now and has been averaging a post every two weeks or so. Our small Editorial Board is looking for a few more members to allow us to increase this frequency. We have two categories of postings, and the process is simple for each. For news posts, find an innovative example of registry data use – whether it be from word-of-mouth, a published study, or something you saw in the news – write a short blurb about why NAACCR members would find this of interest, include a link to the full story, and we’ll post it. For editorial posts, the process is similar, except that here we additionally solicit commentary from experts in our field.

No prior experience is necessary (but if you once wrote for your school newspaper, this would be an outstanding way to put that experience to use!) We are especially looking for people who may not have had the opportunity to get involved with a NAACCR committee previously. Cancer registries do a lot of great work and contribute to a lot of great research and it is deserving of more publicity.

If you are interested in joining the Editorial Board of the NAACCReview, please contact Rebecca Cassady at (909) 558-6174, rcassady@llu.edu.

National Data Exchange Announcement
Susan T. Gershman, PhD, MS, MPH, CTR
Massachusetts Cancer Registry

It’s Fall, so Time to Review Your Registry Bucket List and Sign on!

Thirty-seven registries have signed the modified National Data Exchange Agreement. For registries needing to re-sign and registries that are now ready to sign: Go to www.naaccr.org. Click on "Standards and Registry Operations"; click on "National Interstate Data Exchange Agreement." Then 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 a 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, Colorado, Connecticut, Delaware, Guam, Hawaii, Idaho, Indiana, Kentucky, Louisiana, Massachusetts, Michigan, Mississippi, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia,
West Virginia, Washington, Wisconsin 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 217-698-0800. Jim Hofferkamp provides a listserv announcement to the NAACCR community as soon as a new registry signs on.

I will be emailing those registries that have not signed – this needs to be a collaborative effort!

Thanks for your help.

**NAACCR Steering Committee Corner**

**Susan T. Gershman, PhD, MS, MPH, CTR**  
**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, 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)**

**Co-Chairs: Laura Ruppert and Annette Hurlbut**

*Committee Highlights since last Narrative:*

- Communications Plan submitted to the NAACCR Board. We are working on a finalized version per feedback.

NAACCReview is a publication covering various subjects within and relating to the cancer surveillance field

*Recent Reports/Publications:*

- Toolkits developed  


**Professional Development Steering Committee (PDSC)**

**Co-Chairs: Frances Ross and Mignon Dryden**

*Committee Highlights since last Narrative:*

*Training/Education:*

- Work continues on updating and revising “Understanding Population Based Cancer Registries,” formerly known as the Short Course, and turning it into an on-line offering of Voice-Over Power Point Presentations. Target availability of these presentations is early 2016.
- A Learning Management System (LMS) was purchased which will enhance all of NAACCR educational offerings.

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

**Co-Chairs: Hannah Weir and Susan Gershman**

*Committee Highlights since last Narrative:*

*Training/Education:*

- Cancer Surveillance Series  
  - *SEER*Stat: Some Highlights on New and Existing Features was presented on May 28, 2015  
- Journal Club  
  - Ovarian Cancer Incidence Trends and Changing Patterns of Menopausal Hormone Therapy Use in the United States was discussed on June 23, 2015
- Training Webinars
Producing Delay Adjustment Rates and Trends Using SEER*Stat and Joinpoint was presented on July 23, 2015


Other News to share with the NAACCR Community PAN interests:

- Cancer Control Indicators Task Force (co-chairs Recinda Sherman and Susan Gershman) met July 30, 2015, to review the data for their state/province cancer indicators report; modifications to the model are in progress.
- Survival Analysis Task Force (co-chairs Chris Johnson and Deb Hurley) will now be a work group. One major goal is to have CINA Survival Statistics published by November 2015.
- Twelve Month Data Task Force (chair Frank Boscoe) met August 20, 2015, to plan their approach to perform quality control on twelve month data. The group will also be developing plans for preliminary data release.
- If you have a suggestion for a journal club or surveillance webinar topics, 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 NAACCR.org and sign up.

**Standardization & Registry Development (S&RD)**

**Co-Chairs: Nan Stroup and Randi Rycroft**

Committee Highlights since last Narrative:

Thanks to Laurie Havener for her help with Committee updates.

The late, great NY Yankees legend and Baseball Hall of Famer Yogi Berra once said, “The future ain’t what it used to be.” This Yogi-ism has cancer registries written all over it!!

Many of us in the Standardization & Registry Development (S&RD) Priority Area Network have been working on projects that facilitate the mission-critical role of preparing central registries to adapt rapidly and successfully to changing developments in cancer surveillance...indeed, preparing for a future that is harder to predict. The following are a few of the most recent developments and activities of the S&RD priority area team

- **CAP Pathology Electronic Reporting Committee (PERT)** – The main goal of PERT is to advance the development of CAP checklists. The S&RD SC is very excited to announce Mignon Dryden as the new NAACCR representative on the PERT. Mignon is from the Cancer Registry of Greater California and will be providing a cancer registry perspective to the CAP committee. PERT has also committed to providing subject matter expertise to the NAACCR Pathology Only Record Task Force, which was very recently created to develop standards and guidelines for collecting and maintaining pathology-only data within registry database management systems

- **NAACCR XML Standard** – The XML Implementation Task Force has incorporated many of your comments and feedback since the June conference and the webinar in July. They recently submitted a draft NAACCR XML Standard Implementation Guide v.1 to the NAACCR Board for review and approval. In conjunction with its release, central registries may begin to consider implications to short- and long-term registry process and possible implementation strategies and timelines. The Task Force is now looking ahead to determine next steps and consider resources that will be needed to advance utilization of the NAACCR XML Standards over the next 1-2 years including the creation of a new Task Force that will design a pilot project to test the XML format.

- **TNM Consolidation** – The TNM Consolidation Workgroup for AJCC TNM Staging Data Items (TNMWG) has been working since July 2014 to develop and test various principles and approaches to standardize business rules and operational guidelines for consolidating AJCC TNM staging elements in a similar manner to those detailed in the Data Item Consolidation Manual published by NAACCR on October 22, 2014. The goal was to provide standardized definitions of terms, as well as an outline of basic assumptions and the overall processes involved in consolidation of AJCC TNM data items, including determination of best data values for both clinical and pathologic AJCC TNM components and best clinical and pathologic AJCC stage groups. The TNMWG has completed much of the work around defining the needs or challenges faced by central registries in relation to TNM consolidation and developing an approach and methodologies to address the needs of registries. They have compiled a progress report for the S&RD SC and will be sharing it with the broader NAACCR community in the next few weeks. Next steps may include finalization of consolidation rules and guidelines, testing different approaches with comparisons to AJCC TNM consolidation results, and incorporating standards and guidelines with the
The NAACCR office is moving!

Charlie Blackburn, MBA
NAACCR Chief Operating Officer

The NAACCR Executive is moving to a new location at the end of October. We will still remain in Springfield, Illinois but will move a few blocks away. The new location will better suit our current staffing levels, provide flexibility for the future, and reduce rental costs. Effective November 1, 2015, our new address will be:

North American Association of Central Cancer Registries, Inc.
NAACCR
2050 W. Iles Avenue
Suite A.
Springfield, IL 62704

Please notify anyone in your organization of this change. Please contact Charlie Blackburn with any questions, 217.698.0800 Ext. 4, cblackburn@naaccr.org

NAACCR Staff Addition

Jim Hofferkamp, CTR
NAACCR Program Manager of Education and Training

Please join us in welcoming Angela Martin, BS, CTR to the NAACCR Team as the NAACCR Trainer/Project Coordinator. Angela comes to us from the Missouri Cancer Registry and Research Center where she had nearly 10 years’ experience working in various roles including education coordinator, electronic reporting software support, and supervisor of the non-hospital data collection unit.

We are very excited to have her and I think she is going to continue to do a great job serving the cancer registry community!

Save the Date for 2016 Annual Conference

Jeannette Jackson-Thompson, MA, MSPH, PhD
Director, Missouri Cancer Registry and Research Center
Chair, Program Committee, 2016 NAACCR Annual Conference
Staff and friends of the Missouri Cancer Registry and Research Center (MCR-ARC) and members of the 2016 NAACCR Annual Conference Program Committee invite you to join us in St. Louis for the 2016 Conference, 11 – 17 June. Conference headquarters will be the Hyatt Regency St. Louis at the Arch, located on the riverfront (look for “Hyatt” in the photo above).

Volunteers from central registries, academic institutions and organizations around the U.S. and Canada are working on the preliminary program. The theme of the 2016 conference is: “Gateway to Cancer Discoveries.” Keynote presentations will focus on (1) visioning a blueprint for enhancing data collection and expanding research utility; and (2) strategies to accelerate translating research findings into cancer prevention actions that work and are critical to improving patient health. Plenary sessions build on the gateway theme: Gateway to Results; … to Implementation; … to Diversity; … to Information; … to Scientific Discovery; and … to Patient Centeredness and Patient Perspectives. The goal is to present multiple perspectives on cancer surveillance in North America and address potential future needs and directions.

Committed Keynote and Plenary Session speakers and their topics include:

- Grahan Colditz, DrPH, MD, MPH, Niess-Gain Professor of Surgery, School of Medicine and Associate Director of Prevention and Control, Siteman Cancer Center, Washington University, “Strategies for accelerating translation of research findings into cancer prevention that works”
- Michael LeFevre, MD, MSPH, Co-Vice Chair, U.S. Preventive Services Task Force on Lung Cancer Screening Guidelines, “Lung cancer screening guidelines and the impact on cancer surveillance”
- Diane L. Adams, MD, MPH, CHS-III, Expert Consultant, Health Resources Services Administration, Gateway to Diversity Panel Moderator; Jane A. McElroy, PhD, University of Missouri School of Medicine, “LGBTQ populations”; Ross C. Brownson, George Warren Brown School of Social Work and President, American College of Epidemiology, “Training for Diversity”
- Lynne Penberthy, MD, Associate Director, Surveillance Research Program, NCI, “Natural language processing – From information to data”
- Matthew Kreuter, PhD, MPH, Associate Dean for Public Health, Washington, University, “Transforming data into information for action”
- Mario Schootman, PhD, Associate Dean for Research, St. Louis University, “Using local data for optimal outcomes”
- Eduardo J. Simoes, MD, MSc, DLSIHTM, MPH, Chair, Department of Health Management and Informatics, University of Missouri School of Medicine, “Integrating population science into cancer center research activities”
Additional plenary session speakers will be added in the coming months. A preliminary program will be available online early next year. Other important aspects of the conference are pre-conference workshops and breakout sessions.

Breakout sessions are organized around the Gateway themes listed above. The NAACCR 2016 Annual Call for Abstracts is now open at http://www.naaccr.org/educationandtraining/annualconference.aspx. Click on the blue “Call for Abstracts Letter” button for a list of five oral presentation and poster tracks; a number of topics are suggested for each track. NAACCR welcomes submissions from colleagues, other health professionals and students interested in cancer surveillance, research and registry operations. Click on “Abstract Submission Instructions/Student Abstract Submission Instructions” (underlined text under the blue button) for details.

One of the Program Committee’s innovations for the 2016 Conference is to have different deadlines for general abstract submission and for submission of student abstracts. The deadline for submitting general abstracts is Monday, 14 December 2015 aby 11:59 PM Eastern Time (8:59 PM Pacific Time). Potential presenters (including students) who meet this deadline and whose abstracts are selected for oral presentation will present in one of the breakout sessions under Tracks 1 – 5; those whose abstracts are selected for poster presentation will be considered for a NAACCR Poster Award if they submit a PDF of their poster(s) by 11:59 PM EST (8:59 PM PST), on Monday, 28 March 2016.

The deadline for students to submit abstracts for oral or poster presentation is 11:59 PM EST (8:59 PM PST) on Monday, 28 March 2016. The later deadline gives students additional time to work with faculty advisors and registry contacts, identify an appropriate topic, initiate work on the project, etc. NAACCR and the Program Committee hope that this later deadline will lead to a larger number of student submissions. Students whose abstracts are accepted for oral submission will be considered for a Student Oral Presentation Award; these students will present in a student-only session. Students giving poster presentations will be considered for a Student Poster Presentation Award (but not for a NAACCR Poster Award) and will be evaluated on their poster and their responses to judges’ questions. Up to three awards will be given in each category; each recipient will receive a certificate and a small monetary award.

Pre-conference workshops will also be offered. Pre-conference workshops include Basic SEER*Stat, Advanced SEER*Stat and other topics to be determined. A new workshop tentatively titled “Introduction to Cancer Surveillance” is under development. This workshop is intended for students and young researchers. It will provide attendees with a basic introduction to cancer surveillance methods. Suggested topics include types of cancer registries; history of, and legislation regarding cancer surveillance; data collection methods, using cancer registry data for cancer prevention and control research, planning, and policy; and a hands-on experience with accessing and analyzing publically-available cancer surveillance data.

In the next NAACCR Narrative, we will have more details about the 2016 conference. The 2015 Annual Conference – “First in Flight: Launching a New Era in Cancer Surveillance” – held in Charlotte, NC, in June was a big success with more than 400 NAACCR members in attendance and positive evaluations on speakers and sessions and quality of the food at the opening reception. The 2016 Program Committee will honor requests for vegetarian appetizers, more tables and an area where attendees who want to network can gather while those who want to dance can hear the beat. We can’t promise good weather but the average high is c. 85° and the average low, c. 62°. We can promise good food (downtown, “the Hill”, Central West End), attractions (ride the tram to the top of the Arch, tour Anheuser-Busch Brewery, visit the Missouri Botanical Garden (known locally as “Shaw’s Garden for its founder) Forest Park – St. Louis Art Museum, Missouri History Museum, St. Louis Zoo – and take in a St. Louis Cardinals game.

For those of you who enjoy trivia:

- Forest Park is approximately 500 acres larger than Central Park in New York City
- The Missouri Botanical Garden is the nation’s oldest botanical garden in continuous operation and a National Historic Landmark
- The Gateway Arch was built as a monument to the vision of Thomas Jefferson and St. Louis’ role in the westward expansion of the United States
- The University of Missouri, founded in 1839, is the first public university west of the Missouri River and the first in Thomas Jefferson’s Louisiana Purchase Territory
- The main campus in Columbia, MO – known as MU or Mizzou and location of the Missouri Cancer Registry and Research Center – is a community of more than 35,000 students and 12,000 full-time faculty and staff members; the staff
- The Missouri Cancer Registry, established in 1972, is the 6th oldest state cancer registry in the US, after state registries in Connecticut (1935), Wyoming (1962), South Carolina (1966), Kentucky (1968) and Idaho
(1971) established a state cancer registry

We hope to see you in St. Louis!

### NAACCR Annual Conference Call for Abstracts

**St. Louis**

**June 11-17, 2016**

**Deadline December 14, 2015**

This year's conference theme is "Gateway to Cancer Discoveries." Attendees will explore how data collected on virtually all cancer cases in North America form the basis for improving our understanding of cancer on every level. [Abstract Letter-Instructions and Guidelines](http://www.naaccr.org/LinkClick.aspx?fileticket=gaXuRq5kqyo%3d&tabid=161&mid=523)

**Abstract Submission**

Abstracts for general consideration are due by 11:59 pm Eastern Time (8:59 pm Pacific Time) on Monday, December 14, 2015. Abstracts for consideration for Student Poster Awards or Student Oral Awards ONLY are due by 11:59 pm ET (8:59 pm PT) on Monday, March 28, 2016. Accepted abstracts and posters will be posted on the NAACCR website after the conference.

**Venue**

HYATT REGENCY ST. LOUIS AT THE ARCH

**Visit Hotel**

Student Submissions Are Encouraged

[View Announcement Letter for Student Submission Information](http://www.naaccr.org/LinkClick.aspx?fileticket=S7Upn8RO0CI%3d&tabid=161&mid=523)

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**SUBMIT ABSTRACT**

**Nominating Committee**

Bobbi Jo Matt, Chair
State Health Registry of Iowa

Hello everyone!

The NAACCR Nominating Committee is pleased to announce five leadership positions within the organization for election in 2016: **President-Elect, a Sponsoring Member Organizations Representative, and three (3) openings for Representative-At-Large.**

The success of any organization depends on the efforts of individuals who facilitate and promote its operations. Within NAACCR, that success relies in part on individuals participating as Representatives-at-Large and in other leadership positions on the Board of Directors. Through guiding existing programs and identifying future opportunities, Board members play a pivotal role in managing NAACCR affairs and moving the organization forward.

NAACCR is fortunate that knowledgeable, dedicated, and progressive members have volunteered 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 these five vacancies. Or, nominate yourself! For additional information on duties and eligibility, please visit [http://www.naaccr.org/LinkClick.aspx?fileticket=gaXuRq5kqyo%3d&tabid=161&mid=523](http://www.naaccr.org/LinkClick.aspx?fileticket=gaXuRq5kqyo%3d&tabid=161&mid=523)

The Nomination Form is at [http://www.naaccr.org/LinkClick.aspx?fileticket=S7Upn8RO0CI%3d&tabid=161&mid=523](http://www.naaccr.org/LinkClick.aspx?fileticket=S7Upn8RO0CI%3d&tabid=161&mid=523)

**COMING SOON! NAACCR President Dr. Chuck Wiggins’ special address!**

Deadline for receipt of nomination forms in the NAACCR Office is 5:00 PM, Monday, December 7, 2015.

Submitted by:

Nominating Committee Members:

Mignon Dryden, CTR
E-Reporting Director, Cancer Registry of Greater California
NAACCR Liaison, CAP’s Pathology Electronic Reporting Committee (PERT)

The College of American Pathologists (CAP) Cancer Protocols have been a resource and reference for complete reporting of malignant tumors since they were developed in 1986. The number of protocols continues to increase over the years and in 2007 they were integrated into the pathologist AP-LIS workflow with the release of the CAP electronic Cancer Checklists (eCC).

A document of Cancer Protocol Frequently Asked Questions (FAQ) is now available. This document will be useful for facilities with questions about the CAP Cancer Protocols. These include such topics such as:

- What is a Cancer Protocol?
- Are Cancer Protocols required for accreditation purposes?
- When should a Cancer Protocol be used?
- Is use of the Cancer Biomarker Reporting Templates required for CoC accreditation?

Click here to access the document: http://www.cap.org/web/home/resources/cancer-reporting-tools/cancer-protocol-frequently-asked-questions?_afrLoop=286399032734598

Audits of Cancer Registry Data – Not Necessarily a Bad Thing

Allen D. Austin, III, BA, CTR
North Carolina Central Cancer Registry

The word “audit” has gotten a negative connotation over the years. Who wants to get a call from the IRS saying they’re going to audit your tax returns for the last five years?!

Audit is defined as a systematic review or assessment of something. So, when you conduct an internal audit of your database, it’s not necessarily a negative process but a positive result. You are improving the quality of your data, thus enhancing the accuracy of your reporting information.

Audits are often thought of as massive, labor-intensive reviews of data. In particular, we often think of a re-abstracting audit in which the medical record, for a given period of time, is reviewed against the abstract. However, audits can take on a much more manageable form. Audits that focus on a common coding error, a conflict of logic...
between two or more data items, or reviewing a specific type of cancer or situation for possible errors can also be a very effective way of auditing your cancer data. Below are a few examples of these types of focused audits:

Site & Histology

There are easy audits, like a female with prostate cancer; or more complex audits like cholangiocarcinoma (81603) coded to the liver (C22.0). Cholangiocarcinoma can only occur in the intrahepatic (C22.1) and extrahepatic bile ducts (C24.0), (for instance, 90% of cholangiocarcinomas occur in the extrahepatic bile duct). Another example is mesothelioma (90503) coded to the lung (C34.9) when these occur in the pleura lining of the lung (C38.4). Hepatocellular carcinoma (81703) coded to anything but the liver (C22.0) or leukemia coded to blood. These would occur in the bone marrow (C42.1), whereas Waldenstrom macroglobulinemia (97613) should be coded to blood (C42.0).

Site-Specific Factors

Let’s talk about some common site-specific factor errors. Conversion and placement of the decimal point are a chronic problem for all of us as each prognostic factor has a different method for converting the value and recording that value in the SSF. For example, Breslow’s depth for melanoma (SSF 1) of 0.5 mm should be coded 050; whereas a PSA for a prostate cancer (also SSF 1) of 4.8 should be coded 048.

The North Carolina Central Cancer Registry (NC CCR) reviewed the Breslow’s depth for 2014 melanoma cases and 536 out of 6,176 cases were determined to be coded erroneously based on the validating text. Also the PSA value for prostate cases for 2004 – 2014 was reviewed. Due to the high number of prostate cases, only those cases with extremely low (< 010) or extremely high (> 100) PSA values were isolated for manual review of the text. Of the 4,154 cases reviewed, the PSA value was coded incorrectly 1,464 times.

To highlight the seriousness of this chronic conversion problem, SEER has determined that the PSA value in its database is unreliable to the point that they have decided to exclude the PSA value from the data it releases! Imagine the research that won’t be able to be done because of this.

Remembering conversion rules for the various sites can be difficult. A conversion quick reference is provided that you may want to cut out and place beside your computer. (See figure 1).

When you make corrections, don’t forget to send them to us at the CCR. This is easily done by uploading the correction file that is created by most software systems along with your new case file to the Eureka portal.

So, in conclusion, an audit is not something to be afraid of, but instead something that should be embraced. Focusing on a specific item can readily identify training needs to prevent errors from continuing to occur. As with any audit, be sure to re-evaluate the data later after the training has occurred to document the improvement in your data.
Massachusetts Cancer Registry’s Fifth Annual Fall Workshop

Susan T. Gershman, PhD, MS, MPH, CTR
Massachusetts Cancer Registry

The Massachusetts Cancer Registry’s Fifth Annual Fall Workshop hosted by Dana-Farber / Brigham and Women’s Cancer Center will be held at the Dana-Farber Cancer Institute in Boston, MA on Tuesday, December 8, 2015. This will be an all day workshop with the following topics: pediatric cancer staging, head and neck cancers including staging, ovarian cancer including staging and target therapy, interpretation of genetic markers as they relate to targeted treatment and prognosis, environmental public health tracking, and NAACCR Version 16.0.

A draft agenda and registration form (for those attending in person) will be emailed the end of October. The workshop will also be a live webcast so URLs will be provided approximately a week prior to the webcast. The request for continuing education credits will be submitted to the National Cancer Registrars Association.

As this is a wonderful opportunity to hear some of Dana-Farber’s leading experts on these topics, we look forward to either seeing you in-person or having you log on via the live webcast! It’s free so grab a cup of Joe, log onto your pc and prepare for an excellent educational experience!

In Memorium - Xiaoling NIU, MS
It is with great sadness that we report the death of our dear colleague and friend Xiaoling Niu, who passed away on September 20, 2015, following a long battle with gallbladder cancer. Xiaoling worked as a research scientist at the New Jersey Department of Health for 12 years. She made many contributions to the New Jersey State Cancer Registry and the cancer epidemiology field, including peer-reviewed articles on cancer disparities and countless surveillance reports on cancer incidence, mortality, and survival in New Jersey. Xiaoling also conducted data linkages for research studies, including a study of cancer in World Trade Center rescue and recovery workers and a national study of cancer incidence in organ transplant recipients, and provided statistical expertise to other researchers. Xiaoling was an excellent statistician, knowledgeable colleague, team player, and a caring person.

Many in the NAACCR community have collaborated with Xiaoling on research projects over the years or met her at NAACCR annual conferences. Xiaoling also volunteered for many years on NAACCR’s committees, including the Data Use and Research Committee Survival Analysis workgroup and the NAACCR CINA editorial work group.

Prior to her time at the New Jersey Department of Health, Xiaoling worked as an assistant professor at the Wuhan Institute of Textile Technology in China, earned her Master’s degree in statistics at Rutgers University, and worked at the Commission on Higher Education of New Jersey. She is survived by her husband, Shanfu Zheng, her son, Luyu Zheng, her father, Qianmao Niu, her mother, Ruixia Zhao, her brothers Jianlei Niu and Jianzhong Niu, and her sister Yanling Niu. The New Jersey State Cancer Registry extends our deepest sympathies to Xiaoling’s family.

**NJSCR Summer Highlights**

Click [here](#) to view all the activities from this Summer at the NJSCR.

**Summer 2015 Narrative Poll Results: NAACCReview**

*Dustin Dennison, MMIS*
*NAACCR Information Technology Administrator*

In our Summer 2015 edition of the *NAACCR Narrative* we asked the community what topics they would like to see covered on the NAACCR blog, NAACCReview.

Here are the Summer 2015 *NAACCR Narrative* poll results:

1. **What topic(s) would you like to see covered on NAACCR's Blog, NAACCReview?**
   - Data Standards: 47.07%
   - External forces in health care affecting cancer research & patient care: 23.53%
   - Meaningful Use and impact on cancer surveillance: 64.71%
   - Personalized medicine: 17.65%
   - Registry Operations: 47.06%
   - Research: 23.53%
   - Other: 11.76%

I don't plan on following NAACCReview: 5.88%
We want to thank you for your input as we strive to improve our communications with the NAACCR community. If you have not had a chance please check out NAACCRReview and let us know what you think!

http://www.naaccr.org

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