Message From the President

Chuck Wiggins, PhD
NAACCR President

Once more, I'd like to offer thanks and a hearty "well done" to everyone who contributed to the success of this year's NAACCR Annual Conference. Special kudos to those who planned and implemented the conference, including Dr. Jeannette Jackson-Thompson, her colleagues at the

Missouri Cancer Registry and Research Center, members of the NAACCR Program Committee, NAACCR professional staff, and our colleagues at Venue West.

I also want to take this opportunity to invite each of you to attend our 2017 Annual Conference to be held in Albuquerque, New Mexico, USA, the home of the New Mexico Tumor Registry. We are also planning a one-day conference that will focus on the Registry of the Future, to be held the day before next year's Annual Conference. Be sure to reserve the dates of June 17-22, 2017 on your calendar!

Enjoy the remaining days of Summer!

Message From the Executive Director

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

What a great meeting in St. Louis! The NAACCR Annual Conference was attended by over 380 cancer surveillance professionals, researchers, students and even some "alumni." The theme, "Gateway to Cancer Discoveries" served to connect the various plenary and break-out sessions. We heard from many national experts, including our own members, on a variety of subjects relevant to the improvement of cancer surveillance in North America, and learned the results of many new studies conducted with cancer registry data. During the next ten months NAACCR plans to host several webinars that will bring some of the most relevant and innovative talks to the broader membership. So stay tuned. And gear up for Albuquerque June 19-27. Next year we hope to sponsor a "Registry of the Future" workshop on Monday June 19 to kick off the Conference, and we are exploring the possibility of hosting a survival methods workshop following the Conference with world-class faculty.

What's happening at NAACCR this summer? We are getting ready to launch another phase of the VPR-CLS pilot project by conducting a linkage with the National Radiology Technicians cohort in August. We look forward to your participation in this project, including the opportunity to use a central IRB approval if you choose to do so. We are also planning to launch our public use data set, and our learning management system with the newly revised cancer registry survey course. If that's not enough, our website re-design is underway and we continue to work with partners to prepare for the staging changes in 2017 and 2018. I am helping to teach a UICC master course this summer, and gearing up for a technical site visit to the Bahamas and Jamaica as part of our work with the GICR Caribbean Hub.

Hope that you all have an enjoyable summer and that it is a little more restful than ours looks like it will be!

Highlights From the Program Manager of Standards

Lori A. Havener, CTR
NAACCR Program Manager of Standards

2016 Implementation Guidelines:

A new version of the NAACCR 2016 Implementation Guidelines and Recommendations is posted to the NAACCR website: (http://www.naaccr.org/StandardsandRegistryOperations/ImplementationGuidelines.aspx). Please use the most current NAACCR 2016 Implementation Guidelines and Recommendations Version 1.5, see Appendix G for a table of the revisions.

Standards Volume II, Version 17:

NAACCR has been notified that there are several new and changed data items forthcoming for 2017 implementation. Unfortunately, these proposed changes will not meet the timeline below and will delay the release of Standards Volume II, Version 17.

Standards Volume II, Version 17 Timeline	
Proposed changes submitted to CMB	October 1, 2015
Proposed changes approved by CMB	December 1, 2015
CMB submits request for change to UDS	January 1, 2016
Volume II Task Force review	March 1, 2016
Draft submitted to UDS and the S&RD SC for review/approval	May 1, 2016
Draft submitted to NAACCR Board for review/approval	June 1, 2016
Post to NAACCR website	July 1, 2016
Version 17 Implementation	January 1, 2017

Standards Volume II, Version 18:
It is time to start thinking about Standards Volume II, Version 18, see the timeline below.

Standards Volume II, Version 18 Timeline	
Proposed changes submitted to CMB	October 1, 2016
Proposed changes approved by CMB	December 1, 2016
CMB submits request for change to UDS	January 1, 2017
Volume II Task Force review	March 1, 2017
Draft submitted to UDS and the S&RD SC for review/approval	May 1, 2017
Draft submitted to NAACCR Board for review/approval	June 1, 2017
Post to NAACCR website	July 1, 2017
Version 17 Implementation	January 1, 2018

NAACCR Research and Data Use Update

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

As usual, I had a wonderful time at the NAACCR Annual Conference in St. Louis (although, admittedly, I ate too much BBQ!). It is always a pleasure to put faces to names (or conference line voices) as well as reconnect with folks I have worked with for years. The NAACCR conference was an event I looked forward to long before moving into my current position with the NACCCR Office, and I know many of you feel the same.

One of the reasons the NAACCR meeting is rewarding is the concurrent sessions. These presentations are generally specific to our field. Our colleagues are presenting their perspective on using the data we all collect, improve, and analyze every day. With this in mind, I would like to remind everyone that the Research and Data Use Steering Committee presents a variety of NAACCR Webinars throughout the year, including webinars of some of the annual meeting concurrent sessions, making them available nationally to the wider NAACCR community. Please let us know which concurrent sessions you would like to see as a free, national webinar (contact me: rsherman@naaccr.org or Susan Gershman susan.gershman@state.ma.us).

My focus in the next couple of years will be on training resources for researchers and analysts. This year, we had two annual meeting pre-conference workshops, *Researcher ToolKit and Introduction to Cancer Surveillance Workshop for Students and Junior Investigators*. We also recently conducted a multi-day, training on GIS and Geospatial Analysis tailored to the specific training needs of one state. We will continue to provide in-person trainings for both experienced and newer researchers/analysts, but will also provide free webinars, materials, and tailored trainings as needed. I would appreciate hearing from both researchers/analysts as well as program managers about what types of training and materials are most needed (contact me: rsherman@naaccr.org or 217-698-0800x6).

I also want to ensure all members are aware that the Standardization and Registry Development Steering Committee has updated the SAS code for reading and writing data files in the NAACCR V16 record format. This tool highlights another reason our annual conference is so much fun (*professional fun!*) because it is often the annual get together with our colleagues that we collaborate with remotely on projects both big and small. This SAS tool, and many others, is developed, refined and tested by collaboration among many NAACCR members each year, spearheaded by Chris Johnson, Board-Member-At-Large from the Idaho registry. The tool is currently available on the Standards and Registry Operations Tab on the NAACCR website and click on the Translation Tools for Vol II to get to the landing page for all years of the SAS tool. You will find many tools and resources developed by NAACCR members on both the Standardization and Registry Operation Tab of the website as well as the Research Tab (Data Analysis Resources, GIS Resources).

Have a fun and productive rest of summer!

NAACCR Education and Training Program Update

Jim Hofferkamp, CTR
NAACCR Program Manager of Education & Training

It has been a busy summer!

Angela and I have been diligently working on the final phases of the new NAACCR Learning Management System (LMS). We hope to have it up and running by the end of the summer. Our next CTR Prep and Review Series will be conducted through the new LMS.

Speaking of the CTR Prep and Review Webinar Series...registration is now open for the October/November Series. The first session is 8/23/16 and we'll meet every Tuesday for eight weeks. We record all of the sessions. If you can't participate in the live session you can still view the recordings. One of the things I really like about the series is the interaction between the participants. Sometimes I think the support and encouragement between participants is just as important as the review of the material! There is still time to **register** if you are interested!

We have finalized our schedule for next season's **webinar series**. We are really excited about the topics we will be covering. We will continue to focus on AJCC TNM Staging, Multiple Primary Rules, and treatment with an emphasis on how each of these are inter-related. In addition to the usual Boot Camp, Coding Pitfalls, and the comprehensive webinars on specific sites, we will also have a webinar that focuses on the general rules and concepts for TNM staging 8th edition. In this webinar we will try to clarify some of the nuances of TNM staging and to bridge the gap between rules for assigning TNM stage and rules for entering the information into your registry database.

Check out the NAACCR Education and Training Calendar for a list of all of the upcoming training activities. Don't overlook the Cancer Surveillance Webinar Series. These are free webinars presented by experts in their fields. On 7/20/16 we have a webinar on Delay Adjustment for Cancer Incidence. If you miss the live session we post the recordings on the **Webinar Recordings** page.

FYI...we'll be moving these recording links to our new LMS in the near future. This will make them easier to access and you will have the ability to track which sessions you have viewed.

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

NAACCR 2016 Education and Training Calendar

July 2016

07/20/2016   NAACCR Cancer Surveillance Webinar Series: Delay Adjustment for Cancer Incidence

August 2016

08/04/2016   Collecting Cancer Data: Bladder

08/23/2016   Session 1: CTR Exam Preparation and Review Webinar Series

08/30/2016   Session 2: CTR Exam Preparation and Review Webinar Series

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September 2016

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09/01/2016   Coding Pitfalls

09/06/2016   Session 3: CTR Exam Preparation and Review Webinar Series

09/13/2016   Session 4: CTR Exam Preparation and Review Webinar Series

09/20/2016   Session 5: CTR Exam Preparation and Review Webinar Series

09/27/2016   Session 6: CTR Exam Preparation and Review Webinar Series

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October 2016

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10/04/2016   Session 7: CTR Exam Preparation and Review Webinar Series

10/06/2016   Collecting Cancer Data: Melanoma

10/11/2016   Session 8: CTR Exam Preparation and Review Webinar Series

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November 2016

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

<div align="center">

December 2016

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12/01/2016   Collecting Cancer Data: Lung

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

Virtual Pooled Registry Update

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

The Virtual Pooled Registry is changing its name to better reflect the full scope of the project. The new name is the Virtual Pooled Registry Cancer Linkage System (VPR-CLS or Viper Class!). VPR-CLS was well-represented at the 2016 NAACCR Annual Conference with a plenary presentation and a breakout session covering linkage software comparisons, results of the ATSDR Camp Lejeune pilot linkage, the Central IRB initiative, and plans for inter-registry deduplication and identification of multiple primaries. All presentations are available for download on the NAACCR website.

In late July or early August, the second pilot test of the VPR-CLS with the NCI Radiologic Technologist cohort study will begin. NAACCR will be confirming participation from the 45 registries that participated in the ATSDR Camp Lejeune linkage and would love to recruit additional participants.

We are excited that two pairs of central registries have volunteered to test inter-registry deduplication using data that has been hashed to protect confidentiality. The results will be compared to internal deduplication performed at the registries using personal identifiers.

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

2016 NAACCR Annual Conference Wrap-up

The Posters and Oral Presentations from the 2016 Conference have been posted to the NAACCR website - http://www.naaccr.org/EducationandTraining/PastAnnualConferences.aspx

Additional posters and presentations will be added to the website as they become available. If you participated in the 2016 program and would like your poster or presentation added to those already uploaded please send a PDF copy to ddennison@naaccr.org at your convenience.

Hope to see you next year in Albuquerque!

NAACCR Member Recognition Awards

Frances Ross
Kentucky Cancer Registry

NAACCR Member Recognition Awards were established to acknowledge and foster the ongoing contributions of time and effort made by so many NAACCR members, and in such a variety of ways. NAACCR recognizes that the active engagement of its membership, in all aspects of cancer surveillance, is the core of its success. To promote continuous participation in NAACCR over many years, the Member Awards are designed as points system, where potentially 40 points may be earned in a year, and awards are given at the 100 level, 200 level, and 300 level of achievement. The 2016 awards were given out at the NAACCR Annual Conference in St. Louis on June 15.

The 2016 Level 1 Merit Award winners were

- **Bobbi Matt**, State Health Registry of Iowa
- **Antoinette Stroup**, New Jersey State Cancer Registry
- **Kim Vriends**, Prince Edward Island Cancer Registry

The 2016 Level 2 Achievement Award winners were

- **Lori Koch**, Illinois State Cancer Registry
- **Jill MacKinnon**, Florida

The 2016 Level 3 Leadership Award winners were:

- **Mei-chin Hseih**, Louisiana Tumor Registry
- **Serban Negoita**, Maryland Cancer Registry

Congratulations and many thanks to all who participated!

NAACCR Annual Conference Poster Awards

Susan T. Gershman
Chair, Poster Review Committee

Thanks to all the poster authors and judges who participated in the 2016 NAACCR Annual Conference Poster Awards. We had forty-eight posters which were assigned to either Registry Operations or Data Use. There were three awards for each of the categories. And the winners:

<u>Registry Operations</u>

First Place: New Jersey Goes QuaCRs! Improving the Quality, Completeness and Timeliness of Hospital Reporting to the Central Registry (Stephanie M. Hill, New Jersey State Cancer Registry, Trenton, NJ)

Second Place: Comparing Electronic Synoptic Pathology Reports to Traditional Narrative Pathology Reports (Cheryl Moody, California Cancer Registry, Sacramento, CA)

Third Place: Operations and Preliminary Results of a Linkage of Cancer Registry Data and HIV Data (Lauren Maniscalco, Louisiana Tumor Registry, New Orleans, LA)

<u>Data Use</u>

First Place: Understanding Theories of Cancer in Population Cancer Surveillance: Genetic and 'epi-genetic' pathways to colorectal carcinogenesis (Bruce Riddle, New Hampshire State Cancer Registry, Hanover, NH)

Second Place: Development and Implementation of a Novel Web-based Application Integrating Cancer Registry Data into Survivorship Care Plans (Robin C. Vanderpool, Kentucky Cancer Registry, Lexington, KY)

Third Place: Impact of Cancer Incidence Reporting Delay on Population-Based Survival Analysis (X Dong, ICF International, Fairfax, VA)

Congratulations to the winners! You can view the posters at:

http://www.naaccr.org/EducationandTraining/2016ACPosters.aspx

2016 Calum S. Muir Memorial Award

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

"..For her many years of service and leadership to the cancer surveillance community and NAACCR including Board Member, Treasurer, and President, and for her unwavering commitment to the establishment of the interstate data exchange."

Susan Gershman -

"I am honored and humbled to have been the 2016 recipient of the Calum S. Muir Memorial Award. My path to cancer surveillance was certainly not a direct one. At the age of 12 my mother told me that I should find a cure for cancer which was a big charge for a little girl who just wanted to play baseball with the boys. I did major in biology but my interest in cancer epidemiology and surveillance was triggered by reading Bertron Roueche's The Medical Detectives which seemed to suit my childhood love of mystery books. Shortly after starting my position at the Massachusetts Cancer Registry (MCR), I had second thoughts. Then I attended my first NAACCR meeting (then called AACCR) and I was hooked. I was astounded by the collegial and collaborative efforts of NAACCR members – always willing to work together, to mentor, and to share all aspects of cancer surveillance. I learned so much about registry operations, information technology, and new ways to use data. I even welcomed our first data audit and assessment of our MCR operations by experts to help improve our registry efficiency.

There are many to thank … to my parents who both died too young from cancer, to my husband Ben Goldberg for his creative inspirations, to my wonderful NAACCR colleagues, to friends and family who have inspired me with their ideas and commitment to cancer surveillance, and to MCR staff for their many years of support and hard work. I truly believe that those of us who work in cancer surveillance have made an impact on the burden of cancer here and around the world. I also know that we must keep working together to continue our successes."

2016 Constance L. Percy Distinguished Service Award

Maureen MacIntyre, MHSA

"..For her deep commitment to NAACCR's principles, members and mission and her thoughtful and diligent leadership as Board Member and President."

Since Maureen was unable to attend the conference this year she instead shared the following message in acceptance of the award:

"In 1998 I attended my first NAACCR meeting which was held in Vancouver, Canada. I can still remember listening to the main plenary address given by Bruce Armstrong from Australia – he was such a compelling speaker who helped me realize how much I needed to learn about the cancer surveillance world. At that time I was a relative 'newbie' to the cancer registration field and I was beyond thrilled to learn about NAACCR and all that it had to offer.

Eighteen years later, I continue to strongly believe in the importance of NAACCR as an innovative and nurturing organization. We all accomplish so much in our local areas, but we all have so much to offer and learn as a collective. Even though I may have grown a bit older and grayer, the fundamental issue of standards will never grow old - even though they will continue to evolve. NAACCR has helped to raise the profile of cancer surveillance at many levels and we need to ensure that cancer registries remain positioned to meet the ever changing needs of the cancer control community.

Thank you to all NAACCR members and the Board for recognizing me with the Constance Percy Distinguished Service Award. I was deeply touched and grateful when Betsy contacted me last week to let me know this was happening. I encourage all NAACCR members to think about how you can contribute to keeping this organization vibrant and relevant in the years to come. Contributions come in all sizes – large and small – don't be shy! You will soon find out that the benefits of 'membership', both personal and professional, will far exceed any expectations you may have.

Kind regards, Maureen"

Birds of a Feather

Rich Pinder
rpinder@usc.edu

Susan T. Gershman
susan.gershman@state.ma.us

This year the NAACCR Annual Conference's Birds of a Feather session headed to the mid-west with an interesting discussion on the topic Is There Anybody Out There? Collaborating for Cancer Surveillance. We (Rich and Susan) would once again like to thank those of you who grabbed breakfast and attended this very early morning session. We continued with great attendance at approximately 50 attendees this year.

This was our ninth "Birds" session so we began with some history:

Birds Over the Years

2008: Efficient Registry Operations

2009: Efficiencies and Challenges in registry Operations

2010: What did we Learn from 2010?

2011: Electronic Health Record – Where is it? What does it mean to YOU?

2012: Information Overload – Any Way Out?

2013: The Future of Cancer Surveillance…or Not?

2014: International Cancer Staging: Can We Develop a System for All?

2015: Using Our Registry Data – What Works and What's Next?

2016: Is There Anybody Out There? Collaborating for Cancer Surveillance

Next, we started with some initial questions:

Q1 Which of the following groups has your registry successfully formed work relationships with? (Local or regional health department agencies, University sponsored research groups, Pharma and/or Bioengineering companies, Other

for-profit research groups, Physician-based clinical practices, College or University graduate programs, Community-based organizations, Other?)

Q2 Has outside collaboration resulted in: (Collaborators working with you, inside the registry, on a volunteer or mentor basis, collaborators working with you, inside the registry on a paid or staff basis, both of above or neither of above?)

Attendees provided many great examples of collaborative efforts. One of the most predominant was working with academic institutions/graduate students to provide internships, cancer surveillance overview, and data projects (**Louisiana, Missouri, New Mexico, Texas**). There are definitely challenges to ensure that students have sufficient mentoring. Also related to academic institutions, the **New Jersey State Cancer Registry** negotiated a management agreement to address registry operations across two different agencies… state agency and academic institution. It was a learning curve for all to get the two groups to work together.

However, these collaborations with academic institutions would have significance as we think about future recruitment of cancer registry staff.

Another great example is working with community groups/consortiums such as the Alaska Native Tribal Health Consortium or a Tribal Epi Center to collaborate on data projects (**Alaska, New Mexico**). These groups are eager to use cancer surveillance data. It is evident how important it is for groups to use their own data … especially underserved populations. **Saskatchewan** Cancer Agency collaborates with First Nation to get demographic information incorporated into the registry database.

Other registries such as the **California Cancer Registry** have developed working relationships with varying programs within their agency such as survey research and wellness groups. The **Louisiana Tumor Registry** does presentations with oncology groups regularly. One example is working with a GI surgery team to provide geo spatial information for high rates of distant stage disease. The **Ohio Cancer Registry** has an excellent collaboration with health department groups. They developed a data user agreement to facilitate statewide, individual, de-identified data release to other groups so they would have access to more timely data. **Massachusetts Cancer Registry** director is a member of the Boston Breast Cancer Equity Coalition. The membership of this coalition includes Boston Public Health Commission, physicians representing Boston hospitals, American Cancer Society, federal office of Women's Health, consumers/survivors to develop a coordinated city response to persistent disparities in female breast cancer mortality between blacks and whites. The **Vermont Cancer Registry** has a strong history of partnering with various organizations such as insurers, cancer coalitions, and community forums.

Below are two examples of excellent national collaborative efforts:

The **Central Brain Tumor Registry of the U.S.** (CBTRUS) is an end user of NAACCR data. There is international interest in starting registries in other countries so mentoring these potential registries was possible because CBTRUS was part of NAACCR.

NAACCR collaborated recently with the entire cancer surveillance community via the Virtual Pooled Registry (VPR) project. The VPR project linked data from forty-five cancer registries to the Camp LeJeune cohort. The VPR was developed by NAACCR with support from the National Cancer Institute. The pilot linkage tested the VPR system and provided ATSDR with information on how the numbers of matched cases distributed among the registries. Following review of the pilot linkage results, ATSDR will then contact selected registries to pursue IRB approval for release of patient identifiers.

In conclusion, a thought for the future of collaboration:

The **Los Angeles Surveillance Program** reminded us that the pharmacology and biotech research companies are an untapped research potential. They almost never have population-based data so tend to rely on short time framed clinical trials. Central cancer registries have the potential to help this for-profit group to report on long term outcomes. It would be ideal for NAACCR to get this message out to this community.

We look forward to our next "Birds of a Feather" topic at the 2017 NAACCR Annual Conference in Albuquerque, NM.

NAACCR CTR Prep and Webinar Series for the October 2016 Exam

The NAACCR CTR Exam Preparation and Review Webinar Series will begin August 23! Have you registered? This series hosted by live instructors offers online interactive instruction with coursework carefully prepared to reflect the changes to the 2016 CTR exam.

For more information and to register click here:

https://netforum.avectra.com/eweb/DynamicPage.aspx?
Site=NAACCR&WebCode=EventDetail&evt_key=d3decdb8-e55a-4f65-b2f2-29c2bd1e609b

Angela Martin
Training Specialist/Project Coordinator
NAACCR, Inc.
Phone: 217-698-0800 ext. 9
Email: amartin@naaacr.org

Ambiguous Terminology Lists: References of Last Resort

Kathleen K. Thoburn, CTR
National Cancer Data Base

The purpose of this communication is to clarify the use of Ambiguous Terminology as listed in *FORDS: Revised for 2016* for case reportability and staging in Commission on Cancer (CoC)-accredited programs. When abstracting, registrars are to use the "Ambiguous Terms at Diagnosis" list with respect to case reportability, and the "Ambiguous Terms Describing Tumor Spread" list with respect to tumor spread for staging purposes. However, these lists need to be used correctly.

The first and foremost resource for the registrar for questionable cases is the physician who diagnosed and/or staged the tumor. The ideal way to approach abstracting situations when the medical record is not clear is to follow up with the physician. If the physician is not available, the medical record, and any other pertinent reports (e.g., pathology, etc.) should be read closely for the required information. The purpose of the Ambiguous Terminology lists is so that in the case where wording in the patient record is ambiguous with respect to reportability or tumor spread and no further information is available from any resource, registrars will make consistent decisions. When there is a clear statement of malignancy or tumor spread (i.e., the registrar can determine malignancy or tumor spread from the resources available), they should not refer to the Ambiguous Terminology lists. Registrars should only rely on these lists when the situation is not clear and the case cannot be discussed with the appropriate physician/pathologist.

The CoC recognizes that not every registrar has access to the physician who diagnosed and/or staged the tumor, as a result, the Ambiguous Terminology lists continue to be used in CoC-accredited programs and maintained by CoC as "references of last resort".

The importance of annual linkage between central cancer registries and state vital records

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

Mortality information is a key component of population-based cancer surveillance. Not only is vital statistic mortality data the main source for tracking mortality rates, but annual linkage between central cancer registries and local vital records is part of standard case-finding. Because the primary uses of central cancer registry data is for surveillance, cancer control, and public health policy, it is imperative that that central cancer registries link to mortality data to identify missing cancer cases. Other public health benefits to linkage with mortality data are updating vital status and other data items required for survival and other outcomes surveillance analysis.

Performing these linkages is a vital and routine part of cancer registry operations and requires the exchange of personal identifiers. But recently, NAACCR has heard from a few members that their states are delaying or restricting the registry and mortality data linkages due to concerns about release of personal identifiers. While we must continue to be vigilant with our data stewardship in all endeavors, there is no reason linkages between central cancer registries and vital statistics should be hampered due to privacy concerns.

Specifically, the Federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) does not limit disclosure of personal identifiers for public health uses such as these and, in fact, encourages and supports the disclosure of such data for the advancement of public health and public health activities, including surveillance. If you are a state having issues obtaining the necessary data for mortality linkage, you may find our HIPAA Information resources useful for clarification (Click Here). You may also find this MMWR article, HIPAA Privacy Rule and Public Health: Guidance from CDEC and the U.S. Department of Health and Humans Services helpful (Click Here). If your state continues to have issues obtaining the required data for mortality linkages, please contact Recinda Sherman (rsherman@naaccr.org; 217-698-0800x6).

Liaison to CoC

Frances Ross
NAACCR Liaison to the Commission on Cancer

The Commission on Cancer held its Spring Meetings for 2016 in Chicago, IL on May 19-20, 2016. The content of this two-day meeting centered on the activities of various committees. Dr. Daniel McKellar, CoC Chair, presented information on his recent studies of survival as a measure of quality of care.

Using data from the NCDB, his analysis concluded that risk adjusted survival is a better measure than observed survival. He compared the four categories of CoC hospitals (community, comprehensive, academic and NCI designated) on observed vs. risk adjusted survival for breast and non-small cell lung cancers. Of all the CoC accredited facilities, only seven hospitals had a statistically better risk-adjusted survival than average; and only five had a worse risk-adjusted survival rate than average. Other findings were that community and comprehensive programs had worse survival rates than academic programs, and NCI designated cancer centers had better survival rates than the other types of programs.

The Member Organization Steering Committee approved an application for membership by the American Academy for Physical Medicine and Rehabilitation. The application will now go to the Executive Committee, and the results will be announced at the Fall CoC meeting.

The Cancer Liaison Committee focused on the Cancer Liaison Physician as a Quality Improvement officer, whose role is to use and disseminate metrics for quality of care measurement, such as the CP3R reports. The group approved a template for CLPs to use to report on activities in their state programs. Again, the emphasis was on analyzing data regarding program/physician practices, identifying outliers, and supporting plans for quality of care improvement. During this session, Rich Wender, MD, Chief Cancer Control Officer for the American Cancer Society, gave a presentation on some of the ACS's goals and accomplishments. From 1990-2015, cancer mortality was reduced by 25%; the goal had been a 50% reduction, so some progress was made but there is more work to do. He outlined a cancer control blueprint for ACS, with two primary objectives: to disseminate practices that work to all cancer patients, and to support the creation of new knowledge for reducing the burden of cancer.

The Accreditation Committee passed a measure to allow pilot programs that participate in the Patient Centered Outcomes Research Institute (PCORI) grant to use these studies for credit as a quality study under Standard 4.7. This item will go to the Executive Committee for approval. Next, the committee discussed a policy to limit the number of programs that will be allowed in an Integrated Network Cancer Program. The suggestion was to limit the size to six programs, primarily because of the burden it presents to the survey and approvals process. This topic generated a great deal of discussion, with concerns for the existing networks which already have more than six facilities, and what impact it would have in general by imposing this arbitrary limit. The topic was tabled for further review. Dr. McKellar then gave an update on the progress for creating an accreditation for Oncology Medical Home as well as a National Accreditation Program for Rectal Cancer (NAPRC). It is a complicated process to launch a new accreditation program, but much needed for rectal cancer, based on outcomes from pilot studies. A NAPRC Steering Committee has been formed to review results of surveys conducted at six hospitals, and present standards and a business plan to the ACoS leadership and Board of Regents. Finally, a proposal to update the Accreditation Appeals Policy was passed and will be sent to the Executive Committee.

The Advocacy Committee is working on a statement to legislators regarding opioid use which would provide an exemption for palliative use with cancer patients. The breast cancer stamp was a big success, earning far more money for cancer research than had been predicted, and will continue to be circulated. This committee is also advocating for Medicare coverage for at-home oral drug parity, as well as tanning bed regulations, and for support of House Resolution 487, which would recognize the importance of the CoC Approvals Program in assuring access to high quality cancer care.

The Education Committee described various upcoming CoC sponsored workshops. There will be an NCDB Data Use Workshop in June, and plans are underway for the Clinical Congress meeting in October. The priority topic there will be breast cancer, gastrointestinal malignancies, and head and neck cancers. ACoS has invited Joe Biden to be the keynote speaker at the Clinical Congress, but has not received a response from him as yet. Finally, the committee developed a 'Toolbox' video presentation for new Cancer Liaison Physicians, to educate them on their new role and provide tools for assessing cancer care in their state programs.

The Quality Integration Committee initiated a Site Specific Leader proposal, to provide clinical resources to NCDB staff to assist in ongoing efforts to develop quality measures. There were 12 cancer sites outlined and members were asked to volunteer to be Leaders, with the expectation that leaders would be directly involved in quality measure development.

The next topic was on Quintiles by Dr. Brian Kelly of Durham, NC. Quintiles is a software company who has been engaged by the ACoS to improve reporting and analytics for their many databases. The College has several databases: the National Surgical Quality Improvement Program, the National Cancer Database, the National Trauma Database, and several surgeon specific registries. These databases are on multiple platforms where there is little data sharing among them; they are dependent on manual data entry; so there was a desire to integrate these databases for improved efficiency in reporting and analysis. Dr. Kelly described a three year blueprint during which Quintiles would develop a complete system architecture which would have the ability to consume, map, and populate data

fields in these various registries from Electronic Health Records (EHRs) and other sources using a C-CDA format. Using a business analytics platform, they plan to build a common application that can take data from EHR files (Cerner, Epic, Meditech, and others) and, using C-CDA, create a data warehouse. In the warehouse, the data will be edited and translated using Natural Language Processing, and then used to populate the various registry databases. From these databases, user intuitive dashboards will report analytics, similar to the quality of care measures. It is anticipated that it will take three years to bring all of the databases on line. NSQuiP and a Bariatric database are scheduled for completion by December 2016; NCDB should be available by September 2017, and Trauma and the other registries are expected to be completed by September 2018. Hospitals will be allowed to continue to use their own local systems, or they may use the College's API, which would automatically pull in data from the EHR system and pre-populate part of the cancer registry abstract. Dr. Kelly estimated that using the College's API would cost a participating hospital about $50,000 to $75,000, but they hoped to lower that cost.

Next, Dr. Matthew Facktor reviewed the 32 quality of care measures approved by the Quality Integration Committee, 23 of which have been implemented into the CP3R reports. This subcommittee is also working on quality measures for the rectal program (NAPRC) and on an Operations Standards Manual for the Alliance collaboration.

The Scientific Review subcommittee provided an update on the Participant User Files (PUFs). These are data files created from NDCB when proposals made by investigators from CoC participating hospitals are approved. The PUFs are HIPAA compliant, de-identified organ specific data files that can be downloaded and translated by SAS and SPSS. In 2013, 182 applications were received and 166 were approved. Now the Call goes out twice a year, and over 200 publications have resulted from PUF projects.

The Alliance for Clinical Trials has partnered with CoC to deliver Cancer Care Delivery research. They are most interested in post-treatment surveillance, where a lack of data persists and guidelines have not changed in the last 15 years. The Alliance is taking a stratified tailored approach to surveillance in four cancer sites, looking for recurrence data. From this effort, the investigators found that, in all four cancer sites, the number of 'unknown recurrence' cases to known recurrence cases dropped by 50%. They also learned about the challenges to collecting recurrence data: finding out where the patient received follow up care, getting information from outside providers, finding data available in paper format only, and taking extra time to enter recurrence data. In spite of these challenges, 80% of the registrars felt that recurrence data was important or vital.

The FORDS manual revision project continues, as the project seeks to realign data collection standards and procedures with contemporary medical practice. Input was obtained from the AJCC 8th edition panels, as well as from clinicians, cancer registrars, and NCDB PUF users. CoC staff are reviewing all of the suggested changes and hope to have the new manual (renamed STORE) ready for implementation on January 1, 2018.

After all of the committees had reported on their activities, the Executive Committee met to discuss and vote on the recommendations that had been approved by the committees. Their decisions will be reported at the Annual meeting held in conjunction with the Clinical Congress.

AJCC Announces Disease Site Webinars

Donna M Gress, RHIT
American Joint Committee on Cancer

Announcing AJCC Disease Site Webinars.docx and add Module I of the AJCC Curriculum provides for central registry staff the basic principles of staging, terminology used, and how it is different from Collaborative Stage. https://cancerstaging.org/CSE/Registrar/Pages/Disease-Site-Webinars.aspx

Modules II through IV are the staging rules, and nuances and exceptions to those rules. Each module builds upon the last.

The new "Timing is Everything" graphic explains how timing is key to AJCC clinical and pathologic staging, understanding the use of the "c" and "p." The AJCC stage classification timeframes match the points in time in a patient's care based on their treatment. The graphic represents the patient care continuum with treatment choices and the resulting stage classifications. The arrow indicate the starting and ending points for information included in that stage. https://cancerstaging.org/CSE/Registrar/Pages/default.aspx

Status Report: Guidance for Stage 3 Meaningful Use Public Health Measures in 2017

The Centers for Medicare and Medicaid Services (CMS) published the final rules for Stage 3 Meaningful Use (MU3) and Modifications to Meaningful Use in 2015 through 2017 (Modified Stage 2) in the Federal Register on October 16, 2015. Detailed guidance for Central Cancer Registries, developed by the Stage 3 MU Public Health Task Force, is available in Public Health Agency Readiness for Meaningful Use, 2015 - 2018.

Declaration of Readiness

Eligible Providers (EPs) will have the option of attesting to the Meaningful Use Stage 3 measures in 2017. The reporting period for these 2017 early adopters of Stage 3 will be 90 days. Public Health Agencies (PHAs) must declare readiness to the Stage 3 measures and 2015 Edition Certified Electronic Health Record Technology (CEHRT) criteria at least **six months in advance of the reporting period**. If a PHA declares Stage 3 readiness later than July 1, 2016, an EP can still choose to submit the data, and the cancer registry can still accept the data starting on January 1, 2017. But if an EP wants to take an exclusion, they would have that option if a PHA declares less than 6 months in advance.

CEHRT Requirements: Which Implementation Guide (IG) needs to be used?

The IG that is used is only determined by the stage the EP is in. EPs that are in Stage 2 must use the August 2012 IG; EPs that are in Stage 3 must use the April 2015 IG. The August 2012 IG, Implementation Guide for Ambulatory Healthcare Provider Reporting to Central Cancer Registries August 2012, is the version cited in the Office of the National Coordinator for Health Information Technology (ONC) "2014 Edition" for certification. The April 2015 IG, HL7 CDA ® Release 2 Implementation Guide: Reporting to Public Health Cancer Registries from Ambulatory Healthcare Providers, Release 1, DSTU Release 1.1 – US Realm, is the version cited in the ONC "2015 Edition" for certification.

EDITS50 Beta Release available (Edit Engine, EditWriter, SQLite meta le)

Joseph D. Rogers
Division of Cancer Prevention and Control, NCCDPHP, CDC
(Submitted by Wendy Blumenthal)

The National Program of Cancer Registries (NPCR) announces the availability of **beta release versions** of the Edit Engine and EditWriter. Volunteers are invited to evaluate and test the new tools.

What Has Changed in EDITS50

EDITS50 is a from-the-ground-up rewrite of the EDITS suite of tools. The changes include:

- The database system of the EDITS metafile is a SQLite database.

- The syntax for interacting with the EDITS metafile (the EDITS API) has been redesigned to be more powerful, extensible and user friendly.

What Has NOT Changed

The flexibility of the EDITS tools has been retained.

- Registries will still write their own registry-specific edits. Metafile authors do not have to be programmers to write most edits; the EDITS Language is powerful, yet easy to learn.

- Syntax in edit logic will not change. All existing edits will roll forward into the new metafile structure with little or no modification.

- Registry-specific edit sets are easy to create.

- EditWriter and GenEDITS Plus will continue to support special-purpose projects (e.g., NPCR-CER).

Documentation/Help Files

The EditWriter help file is comprehensive and context-sensitive. Press the **F1-Help** key from anywhere in the program, and the help file will open to the page that is relevant to the task at hand.

The EDITS API documentation includes sample source code (C++) for all functions. We encourage programmers to submit versions of the samples in whatever programming language they use. We will include those samples in future releases of the official API documentation.

GenEDITS Reports

The EDITS50 version of GenEDITS Plus is in early stages of development. However, a GenEDITS-style report can be run from within EditWriter.

In a recent test, a central registry ran their Call for Data edits using GenEDITS Plus v4, and then again using EditWriter v5 against 2.6 million cases. **The EW5 version ran more than twice as fast as the GEPv4 version**. This result is consistent with test findings in our lab.

How to Obtain a Copy of the Beta Package

Contact Susan Capron <exi2@cdc.gov> and ask for the link to the installers for Microsoft Windows. The Engine and EditWriter are available in 32-bit and 64-bit versions.

For Windows
The Windows installers provide:

- EDITS50.dll and the programmer documentation EDITS_API.chm

- EditWriter.exe and the user help file EditWriter.chm

- EMFtoSMF.dll, used by EditWriter to convert EDITS40 metafiles to EDITS50 format

- MetafileBrowser.exe and the user help file MetafileBrowser.chm (programmer's tool)

For Linux
For those registries running on Linux, a package is available containing these binaries:

- libedits50.so -- the Edit Engine built for Linux.

- libcstage0205.so -- the CStage0205 library built for Linux.

- RunEdits50 -- a console app that runs edits using a SQLite metafile and a data file. It generates a simple Html report. The package includes source code (C++) for this app as a programmer's ai

NIH Approves Single IRB Review for Multi-Site Research

Dennis Deapen, DrPH
Director, Los Angeles Cancer Surveillance Program

Citing the importance of accelerating multi-site cancer research when based on a common protocol, Francis S. Collins, MD, PhD, Director of the National Institutes of Health, introduced new policies for Institutional Review Board approvals. "Today, the time it takes to go from a sound research idea to the launch of a new, multi-site clinical research study is too long. A major contributor to the delay is that too many institutional review boards (IRBs) are reviewing the protocol and consent documents for the same study, often with no added benefit in terms of the protections for research participants" states Dr. Collins.

The new policy was created to establish the expectation that all sites participating in multi-site studies using the same protocol involving non-exempt human subjects research funded by the NIH will use a single IRB (sIRB). This move to a single IRB model is expected to reduce cost, burden and delays.

In 2014, NIH published a proposed draft sIRB policy for public comment and received 167 comments from a range of stakeholders, including individual researchers, academic institutions, IRBs, patient advocacy groups, scientific societies, healthcare organizations, Tribal Nation representatives and the general public and carefully considered those comments in the development of the final policy. A discussion of those considerations is included with the announcement of the final policy. Commenters, especially individual researchers, scientific and professional societies, and patient advocacy organizations, generally agreed that the use of a single IRB for multi-site studies involving the same protocol would help streamline IRB review and would not undermine and might even enhance protections for research participants. "This move to a single IRB model also presents a unique opportunity to harmonize the standards and agreements used in clinical research" notes Dr. Mike Lauer, NIH Deputy Director for Extramural Research.

Many population-based cancer registries participate in multi-state NIH funded research, so investigators are likely to want to comply with this policy in the future. NAACCR is considering how to support researchers and registries during this transition. The effective date of the new policy is May 25, 2017. The full policy announcement can be found at https://grants.nih.gov/grants/guide/notice-files/NOT-OD-16-094.html, with additional related links (https://www.nih.gov/about-nih/who-we-are/nih-director/statements/single-irb-policy-streamline-reviews-multi-site-research;
http://osp.od.nih.gov/sites/default/files/NIH_sIRB
_Policy_Multi_site_Research_UPDATED2016.pdf and frequently asked questions (http://osp.od.nih.gov/under-the-poliscope/2016/06/accelerating-clinical-research-streamlining-multi-site-review-human-subjects-research.

NIH states that additional information and resources will be forthcoming.

Comprehensive 2016 Ontario cancer statistics report released by Cancer Care Ontario

Zeinab El-Masri, MPH
Surveillance and Ontario Cancer Registry

Cancer Care Ontario, a provincial cancer agency in Canada, has compiled more than 30 years of data from the Ontario Cancer Registry to produce the Ontario Cancer Statistics 2016 report.

In this first comprehensive look at the state of cancer in Ontario, OCS 2016 provides a clear picture of cancer, focusing on the incidence, mortality, survival and prevalence of the disease in Canada's largest province.

For the first time, statistics on clinically relevant indicators for select cancers, using stage at diagnosis, cancer histology and biomarker data are also reported. ... (READ MORE)

NAACCR Walkers - Come Walk with Us

Jane E. Braun, MS, CTR, MNCEM
Individual Member

NAACCR Walkers Looking for Sponsors as They Tackle the Boston Marathon Route

After a year off for most of the members in 2015, the NAACCR Walkers team will be undertaking the half-marathon trek along the Boston Marathon route for the eighth time on September 25. The team, made up of current and former NAACCR members, participates in the Jimmy Fund Walk to support cancer research at the Dana Farber Cancer Institute (DFCI) in Boston. The DFCI is known for its innovative studies, myriad of clinical trials, and extremely efficient use of funds. The NAACCR Walkers have raised over $38,000 so far, and we would love for you to help us keep that number growing.

Please consider sponsoring someone on the NAACCR Walkers team. Go to http://www.jimmyfundwalk.org/2016/naaccrwalkers and choose a walker to sponsor. Because each walker needs to meet fundraising goals, we prefer you select ANY member rather than using the "general team donation" category.

Please sponsor the NAACCR Walkers! Your support is greatly appreciated. For more information, you can contact team captain Jane Braun at jane.braun@state.mn.us.

Sharon Whelan Memorial

SHARON WHELAN 1948-2016

Sharon was born in London England in 1948. After completing an Arts degree at Sussex University, she trained as a secretary, and it was in this capacity that she was recruited to join the young International Agency for Research on Cancer in 1974.

At IARC, her first long term appointment was working as secretarial assistant to Dr Calum Muir. Dr Muir, one of the founding scientific staff of IARC, was head of what became known as the Descriptive Epidemiology Programme (DEP), and in his professional work, collecting and analysing cancer data from around the world, and especially from cancer registries, relied upon the assistance of his small staff, including Sharon. Recognising her capacities in analysis of epidemiological data, he encouraged her to join the MSc programme in Epidemiology and Public Health at the University of Birmingham, where she was supervised by Dr John Waterhouse and Ms Jean Powell. Sharon graduated in 1982.

When she returned to IARC, Sharon joined the scientific staff of DEP, and worked under the supervision of Dr Calum Muir (1981-1986) and then Dr Max Parkin (1986-2004) until her retirement in 2005. Although she worked

on several projects – including a major editorial input to the International Classification of Diseases for Oncology (ICD-O), Sharon will be best remembered for two major roles, and contributions. ... ([READ MORE](#))