



Message From the President

Chuck Wiggins, PhD

NAACCR President

Having turned 60 earlier this year, I am acutely aware of being caught between the old and the new. For example, I keep a copy of the American Cancer Society's annual Cancer Facts and Figures at my desk. This classic publication is the perfect tool for responding to inquiries regarding new cancer cases and deaths for the current calendar year (and more). Nonetheless,

I'm constantly on the look-out for new tools for accessing and presenting Registry data. If you have not already done so, check out the Cancer Statistics Center at the following URL: <https://cancerstatisticscenter.cancer.org/#/>. This website is like the tried and true Cancer Facts and Figures – but online and on steroids. Cancer incidence and mortality data are available by state and by type of cancer. The site also displays basic information on cancer screening, survival, and risk factors. Congrats to our colleagues Ahmedin Jemal, Rebecca Siegel, and Kimberly Miller at the American Cancer Society for a job well done. Thanks to cancer registries from coast-to-coast for providing data that contribute to this useful resource.

On another topic, I am really looking forward to our Annual Conference in June. Thanks go to Dr. Jeannette Jackson-Thompson, her colleagues at the Missouri Cancer Registry and Research Center, and members of the 2016 NAACCR Annual Conference Program Committee for assembling a stellar agenda for this meeting. St. Louis will be a terrific venue for this annual gathering. I look forward to seeing you there!

Message From the Executive Director



Betsy A. Kohler, MPH, CTR

NAACCR Executive Director

bkohler@naaccr.org

The NAACCR Certification program has been in existence since 1998, when 18 U.S. and 4 Canadian registries met certification requirements for 1995 data. The certification criteria have remained unchanged since inception of certification. NAACCR intended for the criteria to be a benchmark of basic data quality that would ensure the calculation of reliable incidence rates by race, sex, and geographic area, had face value, and that the criteria were not variable over time. In recent years nearly all states and provinces achieve gold or silver certification using these original criteria.

In the near future we anticipate the development of a new and powerful tool that could greatly improve the data quality in North America. This tool has not been available to us in the past, and therefore could not be used in setting certification criteria, or measuring compliance by registries. With the development of the VPR, we are moving toward the development of processes that will allow states to identify duplicate case reports between jurisdictions. In addition we are establishing a NAACCR task force to develop a protocol to adjudicate the ownership of duplicate cases between states. Soon, we will have the ability to de-duplicate among registries, which will greatly improve the accuracy of cancer rates by state, and for the U.S. (Canada already has de-duplication methods in place). In addition we will be able to improve the ascertainment of multiple primaries which may occur in different states, and potentially improve data quality of other variables (treatment for example). These processes have the potential to improve the quality of cancer registry data exponentially. Therefore, NAACCR is considering the development of a "Platinum" certification level.

Platinum certification would be issued to states and provinces who demonstrated that they had matched their files against other states, and resolved matches according to NAACCR protocol (yet to be developed). While

some registries may not have the capacity or the authority to participate in deduplication, platinum level is being considered, since the quality of the data in the states that do participate will be notably better. Further, our experience with certification has shown that over time, registries develop the capacity and authority to achieve the highest level of certification, and overall the national and North American data are improved. A platinum certification level would provide further incentive to registries to participate in inter-jurisdictional de-duplication and resolution.

The Board has voted to consider the option of creating a Platinum certification level due to the development of new tools and the potential for these tools and processes to vastly improve data quality. A Taskforce will be created to develop the specific and measurable criteria for this level of certification. Additional Platinum Certification criteria should also be explored by the Taskforce.

We would like the Taskforce to begin working now, well in advance of an implementation date. The concept of the original certification process was introduced before the methods were established, which allowed registries to participate in the development of the criteria and to prepare for the assessment. We anticipate that we will be able to test methods of deduplication between jurisdictions in the next year or so, and it will take that long to work out the protocol for the resolution of the duplicates. NAACCR does not plan to certify registries at the Platinum level until two or more years from now.

As always, we welcome your thoughts and comments. We will be seeking volunteers for the working group(s). If you are interested in working on developing a Platinum Certification level, please submit your name to Recinda Sherman at rsherman@naaccr.org.

Highlights From the Program Manager of Standards

Lori A. Havener, CTR

NAACCR Program Manager of Standards

2016 Implementation Guidelines:

There is a new version of the NAACCR 2016 Implementation Guidelines and Recommendations posted to the NAACCR website. Please use the most current NAACCR 2016 Implementation Guidelines and Recommendations Version 1.4, see Appendix G for a table of the revisions.

Standards Volume II, Version 17:

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

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

NAACCR Narrative

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

There are several revisions to the 2016 Implementation Guidelines and Recommendations, Version 1.4. Please see Appendix G of this document for the revisions: <http://www.naaccr.org/StandardsandRegistryOperations/ImplementationGuidelines.aspx>

NAACCR Research and Data Use Update

Recinda Sherman, MPH, PhD, CTR

NAACCR Program Manager of Data Use and Research

Along with Spring, March brought us two major cancer surveillance reports: 1) Annual Report to the Nation on the Status of Cancer, 1975-2012, Featuring the Increasing Incidence of Liver Cancer; and 2) Cancer in North American Volume Four: Cancer Survival in the United States and Canada. These two reports represent the concerted efforts of both individual and organizational NAACCR members and are the definitive picture of the burden of cancer in North America.

This year's Report to the Nation was spearheaded by CDC with contributing authors from ACS, NAACCR, and NCI. The Report marks the 18th annual, collaborative effort to produce comprehensive trends in cancer incidence and mortality. The Report was published in Cancer on Wiley Online Library ([link to publication](#)) and details an overall decline in cancer incidence and mortality among men. Although cancer incidence among women remained stable, mortality rates declined for women as well.

However, despite successful reductions in the occurrence and mortality among the most common cancers, rates for some cancers are increasing, like liver cancer, the focus of the Report's special section. Deaths from liver cancer increased at the highest rate of all cancer sites for both men and women, and incidence rates increased sharply, second only to thyroid cancer. The Report suggests that the rise in liver cancer rates is likely due to the prevalence of Hepatitis C infection (HCV), particularly among people born between 1945 and 1965. The curtail the increasing incidence of liver cancer, CDC recommends appropriate testing and treatment for HCV in people born during this time period, as well as getting a Hepatitis B vaccination, reducing tobacco use, maintaining a healthy weight, and using alcohol moderately for all populations.

The second report released in March was the long awaited CiNA Survival Monograph ([link to monograph](#)). NAACCR has been publishing the CiNA monograph series for 25 years, and this is the inaugural publication of the 4th Volume of CiNA. The production of the CiNA Survival Monograph was a priority under NAACCR's 2011-2016 Strategic Management Plan (SMP) and was brought to fruition by the tireless efforts of NAACCR volunteers from the Survival Taskforce, which laid the groundwork for this analysis by improving the data quality and standardization of key variables needed for survival analysis.

The monograph includes data from 41 registries on nearly 7 million cancer cases diagnosed among North Americans between 2005 and 2011 and provides crucial, population-based statistics needed, along with incidence and mortality, to comprehensively assess the burden of cancer in North America. CiNA Survival includes data from 8 of 13 Canadian provinces/territories, 28 of 50 U.S. states, and specific metropolitan regions in Michigan and Washington—covering approximately 62% of North America. For registries to be included in CiNA Survival, they need to meet certification standards as well as data quality criteria specific to the variables required for survival analysis.

With the publication of the monograph comes the release of an additional CiNA Deluxe Analytic File, CiNA Survival Analytic File, which is available to researchers through the CiNA Deluxe data release process. Please note, inclusion in the data release requires active consent by the individual registries. And, currently, the dataset will only be approved for research using variables that have been determined to be "fit for use" in survival analysis. Determining data quality fitness is still ongoing.

Both the CiNA Survival Monograph and CiNA Survival Analytic File will be updated annually with the most recent data submission. If you have any questions or feedback about either report or the CiNA datasets, please contact me: rsherman@naaccr.org

NAACCR Education and Training Program Update

Jim Hofferkamp, CTR

NAACCR Program Manager of Education & Training

Angela and I have been busy building the new NAACCR Education and Training Learning Management System. We hope to have it up and running early this summer!

We have also been updating all of our materials for the next CTR Prep and Review Webinar Series. This is the one for registrars planning on taking the exam in June/July. Still time to register if you are interested!

We have just about finished with 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, treatment with an emphasis on how each part of the abstract is 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 for TNM staging 8th edition and updates on the new Multiple Primary Rules.

We also will be announcing three cancer surveillance webinars that will be presented May-July. These webinars are presented by experts in the cancer surveillance field and are free to the entire NAACCR Membership.

If you have any questions, send Angela or me an email at jhofferkamp@naaccr.org or amartin@naaccr.org.

NAACCR 2015-2016 Education and Training Calendar

April 2016

04/19/2016 Session 1: CTR Exam Preparation and Review Webinar Series

04/26/2016 Session 2: CTR Exam Preparation and Review Webinar Series

May 2016

05/03/2016 Session 3: CTR Exam Preparation and Review Webinar Series

05/04/2016 Cancer Surveillance Webinar Series: An In-Depth Study of KRAS Biomarker Testing in Colorectal Cancer Patients

05/05/2016 Collecting Cancer Data: Kidney

05/10/2016 Session 4: CTR Exam Preparation and Review Webinar Series

05/13/2016 Cancer Surveillance Webinar Series: Data Imputation

05/17/2016 Session 5: CTR Exam Preparation and Review Webinar Series

05/20/2016 Cancer Surveillance Webinar Series: Use of Imputation Technique for Modeling Missing Information in Population-based Cancer Registry Data

05/24/2016 Session 6: CTR Exam Preparation and Review Webinar Series

05/31/2016 Session 7: CTR Exam Preparation and Review Webinar Series

June 2016

06/02/2016 Collecting Cancer Data: Prostate

06/07/2016 Session 8: CTR Exam Preparation and Review Webinar Series

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).

National Data Exchange Announcement

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

Spring Has Arrived, Grab Your Baseball Caps and Sign-on - National Data Exchange Agreement

Thirty-eight registries, the District of Columbia, Guam, and Puerto Rico have signed the modified National Data Exchange Agreement. For registries needing to re-sign and registries that are now ready to sign:



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.

Go to www.naaccr.org. Click on "Standards and Registry Operations"; click on "National Interstate Data Exchange Agreement." Then follow the instructions below.

The registries that have signed the National Interstate Data Exchange Agreement include: Alabama, Alaska, Arkansas, Colorado, California, Connecticut, Delaware, Georgia, 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, Washington DC, 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 have emailed all registries that have not signed the agreement so expecting that 5-6 more states will soon join our team. Check our updated map at:

<http://www.naaccr.org/StandardsandRegistryOperations/DataExchangeAgreement.aspx>

Thanks for your help.

Susan T. Gershman, Director, Massachusetts Cancer Registry

Virtual Pooled Registry Update

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

The Virtual Pooled Registry (VPR) project is now an ongoing NAACCR activity and the project is progressing nicely. Two large research cohorts (the ATSDR Camp Lejeune Study and the NCI Radiation Technician Study) have volunteered to participate in the initial VPR pilot linkages that will test the VPR system, including a standardized linkage protocol. All linkages will occur at the registry. Researchers will receive a count of high quality and manual review matches from each participating registry. This information will help researchers focus their efforts in applying for IRB review and release of identifiable data on the matched cases. The Camp Lejeune linkage was initiated on March 28th and is being performed by 48 registries around the U.S. NAACCR would like to thank these registries for their support of the VPR.

A beta site for the VPR Linkage Coordination Center (LCC) has been developed in conjunction with IMS, Inc. The LCC will be a one-stop-shop where the researcher submits an application to link with cancer registries, a Research Review Committee assesses and votes on the request, researcher and registries are notified of approved projects, researcher files are uploaded, edited, and shared with participating registries, and linkage results are exchanged. The LCC will provide automated process notifications, as well as notification back to the researcher of final match results by registry.

In an effort to facilitate the use of valuable cancer registry data, NAACCR is committed to streamlining the IRB application and review process across registries. The use of a templated IRB form and establishment of a Central IRB for review of cancer registry linkage studies are two methods that are being explored. A VPR Working Group

has been established to provide overall scientific direction, technical expertise, guidance, and input in the development of the VPR system, including IRB activities, data security, research, and state registry operations, The VPR Working Group membership includes registries, standard setters, researchers, and other key partners.

NAACCR continues to identify researchers that may benefit from future participation in the VPR once it is fully operational and welcomes suggestions from NAACCR member registries. In addition, individuals interested in serving on the VPR Research Review Committee, which will evaluate the research linkage proposals for scientific merit and feasibility, are encouraged to contact Castine Clerkin, the VPR Manager, at cclerkin@naaccr.org.

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*:

- Best Practice document, a supplement to the Communications Plan, is under review by the NAACCR Board.

Recent Reports/Publications:

- Press Release: The North American Association of Central Cancer Registries (NAACCR) is pleased to present the inaugural publication of Cancer in North America Volume Four: Cancer Survival in the United States and Canada. NAACCR has been producing Cancer in North America incidence and mortality publications for over 15 years. <http://www.prweb.com/releases/2016/03/prweb13274893.htm>

Other News to share with the NAACCR Community PAN interests:

- NAACCR Review (<http://news.naacr.org/>)
 - [The effect of multiple primary rules on cancer incidence rates and trends](#) -February 19, 2016
 - [Cancer incidence among Asian American populations in the United States, 2009–2011](#) -February 8, 2016
 - [Cancer Mortality Among Recipients of Solid-Organ Transplantation in Ontario, Canada](#) -February 2, 2016
 - [Cancer kills Kentuckians at highest rate](#) -January 27, 2016
- Planning underway for our Committee's participation at the annual conference including decision on giveaways for the registration bag and booth items. Input always appreciated for future conferences!

Professional Development Steering Committee (PDSC)

Co-Chairs: Frances Ross and Mignon Dryden

The NAACCR Professional Development Steering Committee has been focused on creating web-based learning modules for the survey course: "Understanding Population-Based Cancer Registries." The content, formerly presented as the NAACCR Short Course, is being updated in Powerpoint™ presentations with audio included for independent viewing. NAACCR staff are concurrently working on implementing a web-based Learning Management System (LMS), and integrating this new system with WebEx, which is currently used for NAACCR webinars. Jim Hofferkamp and Angela Martin have also been working with Camtasia™, another software application used to incorporate PowerPoint™ presentations into an LMS.

The Committee hopes to integrate the Survey Course modules into the new LMS and make them available by the Annual Conference in St. Louis. This course will require user names and passwords in order to track user progress and award certificates of completion for the various courses to be included.

NAACCR Narrative

All of the Steering Committees have recently revisited and updated the Strategic Management Plan (SMP). After reviewing the document for the Professional Development Steering Committee, the members present agreed with the following changes and accepted the additional activities with enthusiasm. These include:

- Work with other Steering Committees on Global Initiative
- Include Evaluations and an open-ended survey question of what other educational topics participants are interested in at the end of each webinar.
- Include a webinar on “NAACCR 101” information, such as, how to sign up for NAACCR listserv, etc.

Finally, the committee would like to publicize the workshops planned in conjunction with the 2016 Annual Conference. There will be five workshops: Basic and Advanced SEER*Stat Training, a Researchers Toolkit Workshop, an Introduction to Cancer Registration for Students and Junior Investigators, and Conducting Survey Research in Central Cancer Registries and Optimizing Recruitment.

Committee Highlights since last *Narrative*:

- Work continues with updating Survey Course, “Understanding Population-Based Cancer Registries” to web based learning modules.
- NAACCR staff continue to implement a web-based Learning Management System (LMS) that will incorporate webinars and the Survey Course. Release is scheduled for early June.

Other News is share with the NAACCR Community PAN interests:

- Five workshops are planned in conjunction with the 2016 Annual Conference:
 1. Basic SEER*Stat
 2. Advanced SEER*Stat
 3. Researchers Toolkit
 4. Introduction to Cancer Registration for Students and Junior Investigators
 5. Conducting Survey Research in Central Cancer Registries and Optimizing Recruitment

Research and Data Use Steering Committee (RDUSC)

Co-Chairs: Hannah Weir and Susan Gershman

Training/Education:

- NAACCR Webinars
 - An In-Depth Study of KRAS Biomarker Testing in Colorectal Cancer Patients scheduled for May 2, 2016, 2:00 pm Eastern Time.
 - Data Imputation scheduled for Friday, May 13, 2016, 2:00 pm Eastern Time.

Other News to share with the NAACCR Community PAN interests:

- Cancer Control Indicators Task Force (co-chairs Recinda Sherman and Susan Gershman) continued to meet to review the data for their state/ province cancer indicators report; modifications to the model are still in progress.
- The Survival Analysis Work Group will be replaced with the CINA Survival Work Group to produce the CINA Survival Volume and a new task force to develop life tables for Hispanics.
- The RDU Steering Committee will be doing presentations to recruit volunteers for work groups in a breakout session at the NAACCR Annual Conference.
- If you have a suggestion for a journal club or surveillance webinar topics, please contact Hannah Weir (hweir@cdc.gov) or Susan Gershman (susan.gershman@state.ma.us).

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](#)):



[NCI Cancer Stats @NCICancerStats](#)

Population-based cancer research helps improve public health <http://go.usa.gov/cesC4> #NationalPublicHealthWeek

[NCI Epidemiology @NCIEpi](#)

Keep up-to-date with the latest [#funding](#) opportunity announcements by subscribing to our monthly newsletter <http://conta.cc/1UX2sp4>

[CDC Cancer @CDC_Cancer](#)

Video abstract: [#Cancer](#) rates are going down but number of cases & deaths will keep going up <http://bit.ly/1pIj9YN>

NAACCR, Inc. [@NAACCR](#)

AHIMA's Advocacy and Policy Efforts- Petition for removal of restriction of national patient identification solution <http://buff.ly/1q9TmbD>

[American Cancer Soc @AmericanCancer](#)

We're fighting [#cancer](#) disparities & working to improve access to screening & treatment <http://goo.gl/6HHAl>
[#MinorityCancerAwareness](#)

[ONC @ONC_HealthIT](#)

[#ONC2016](#) Annual Meeting, 5/31 – 6/2, 2016 at the Walter E. Washington Conv. Ctr. in Wash, DC
<http://ow.ly/ZW28Z>

[Cancer Registrars @NCRANews](#)

NCRANews is seeking volunteers for three positions: NAPBC Liaison, Journal of Registry Management Associate Editor,... <http://fb.me/2icmAEzzO>

[NCI Cancer Stats @NCICancerStats](#)

What cancers are rising and falling in your state? See our easy-to-use tool to find out <http://statecancerprofiles.gov>

[CDC Cancer @CDC_Cancer](#)

Caregivers for [#cancer](#) patients & survivors: who are they & what do they do? <http://go.usa.gov/csv39>

[National Cancer Inst @theNCI](#)

With Early Drug Development Opportunity Program, NCI expands early-phase [#clinicaltrials](#)
<http://1.usa.gov/1XgGKKx>

NAACCR, Inc. [@NAACCR](#)

Video: Why cancer is so hard to fight in rural Kentucky | Watch PBS NewsHour Online <http://buff.ly/1PBqw92>
[#Cancer](#) [#Research](#)

NAACCR, Inc. [@NAACCR](#)

Comments on the increasing incidence of liver cancer [#ARN2016](#) [#NAACCRReview](#) [#Cancer](#) [#Research](#)
<http://buff.ly/22zefv1>

NAACCR, Inc. @NAACCR

Great video by our friends at @CDC_Cancer #Cancer #CancerResearch #BreastCancer <http://buff.ly/1TDX08s>

NAACCR, Inc. @NAACCR

Cancer in North America Volume Four: Cancer Survival in the United States and Canada <http://story.cd/AAEUdD> via @PRWeb

NAACCR, Inc. @NAACCR

Overall #cancer death rates are dropping, but #LiverCancer rates are rising in US <http://buff.ly/1pxqz0u>

NAACCR, Inc. @NAACCR

The effect of multiple primary rules on cancer incidence rates and trends <http://buff.ly/1SFuzrY> #NAACCRReview

NAACCR, Inc. @NAACCR

Cancer: Planning for the Future - video by @CDC_Cancer #Cancer #CancerResearch #BreastCancer <https://www.youtube.com/watch?v=h7GBxZ9oSPI>

NAACCR, Inc. @NAACCR

On January 15, 2016, three new sets of SEER*Educate practical application exercises will be released. <http://buff.ly/1o6JVcA> #NAACCRNews

NAACCR Election Results

Hello NAACCR Community The NAACCR Nominating Committee is pleased to announce the results of membership voting for officers. **Nan Stroup, New Jersey has been elected as President-Elect.** The new Representatives-at-Large are **Frank Boscoe, New York State, Chris Johnson, Idaho** and **Heather Stuart-Panko, Saskatchewan.** The Committee thanks all of the candidates who were nominated this year and the member registries for their participation.

Thanks.

NAACCR Nominating Committee members:

Bobbi Jo Matt, BS, RHIT, CTR

Jim Martin, PhD

Kyle Ziegler, CTR

2016 Annual Conference: Final Pre-conference Update

Jeannette Jackson-Thompson, MA, MSPH, PhD

Director, Missouri Cancer Registry and Research Center

Chair, Program Committee, 2016 NAACCR Annual Conference

Theme: Gateway to Cancer Discoveries

Venue: Hyatt Regency St. Louis at The Arch

Dates: 11 – 16 June 2016

I hope conference attendees and presenters are as excited about the upcoming 2016 Annual Conference as we are. By “we” I mean members of the Program Committee, NAACCR staff and staff of the Missouri Cancer Registry and Research Center (MCR-ARC).

This will be the third and final *NAACCR Narrative* update prior to the conference. In the Fall 2015 issue (28 October 2015), we introduced the conference theme (“Gateway to Cancer Discoveries”); identified keynote and plenary speakers; provided a Call for Abstracts link (with a later deadline for student abstracts); and identified

several pre-conference workshops. In the Winter 2016 issue (28 January 2016), we focused on activities (Komen Race for the Cure, NAACCR bike ride, Cardinals baseball game and the NAACCR 2016 Walk/Run) and entertainment (award-winning step team/stomp troupe “Gentlemen of Vision” and multi-talented vocalist Kim Massie). In this issue, I’ll focus on conference deadlines and provide a few program/activity updates. I’ll close with some acknowledgments.

Dates, Deadlines and Opportunities

- Early Bird discount for conference and workshop registration ends 30 April 2016
 - The Early Bird registration fee for members and hospital registrars is \$495 (\$595 for non-members) and includes one ticket for the Opening Reception and the Awards Luncheon.
 - The Early Bird registration fee for retired/inactive professional members is \$125 does not include tickets; these may be purchased onsite for \$60 per ticket.
 - The registration fee for students is \$125, regardless of when purchased, and does not include tickets (available as above for \$60 per ticket). Use of the student registration fee must be approved by NAACCR.
- Exhibit/sponsor registration is open – reserve a spot soon
 - Exhibitors – Standard or Double Booth packages are available
 - Sponsorship opportunities range from \$1,000 to \$20,000; visit the NAACCR website (<http://www.naacccr.org/educationandtraining/annualconference.aspx>) and download “Prospectus 2016” to see all the sponsorship opportunities.
- Reserve your hotel room at the Hyatt Regency St. Louis while rooms are still available at the conference rate (<https://aws.passkey.com/event/11552621/owner/988/home>)
- Poster presenters who want to be considered for a Poster Award must upload their poster by Friday, 20 May; go to the NAACCR conference website and click on “Poster PDF Submission” for details.
- The deadline for student abstract submissions closed on 4 April. However, I heard from a couple of potential attendees that they are still awaiting travel approval. *If anyone knows of a student who missed the deadline, please contact me (jacksonthompsonj@health.missouri.edu); an extension may be possible for student poster (not oral) submissions.*

Activity Updates

- Find out more about fun events by scrolling to the bottom of the NAACCR 2016 Annual Conference page -
 - “Group Outings.”
 - 18th Annual Susan G. Komen Greater St. Louis Race for the Cure – Saturday, 11 June. Thanks to Shari Ackerman, we now have a NAACCR team! For more information or to register, click on the link. If you register to run or walk, you get a free T shirt! If you aren’t going to be in St. Louis by Saturday morning, you can still support the Komen Foundation and the NAACCR team by making a donation. Hint: If you want to do both, register first, then donate.
 - NAACCR Night at the ballpark! Baseball fans – watch the St. Louis Cardinals take on the Houston Astros. Field box tickets are only \$25.00. The game begins at 6.15 pm on Wednesday, 15 June. Click on the link to see “NAACCR Night” and then click on “Buy Now” to purchase your tickets. Be sure to use the NAACCR coupon code to get the discount. For those of you who want to celebrate early (and pay an additional fee), Cardinals Nation will host the Official Pre-Game Party of the St. Louis Cardinals. The pep-rally style party starts 2 ½ hours before the game and features a DJ or live music along with a full ballpark-style buffet.

Program Updates

Pre-conference Workshops

Five pre-conference workshops will be offered. A registration fee is charged for each workshop.

- Basic SEER*Stat Software Training (\$250) – Saturday, 11 June, 8:30 am – 5:30 pm
- Advanced SEER*Stat Software Training (\$250) – Sunday, 12 June, 8:30 am – 5:30 pm
- Researcher Toolkit Training (\$230) (New) Sunday, 12 June, 10 am – 5:30 pm
- “How Did You Get My Name?!” Conducting survey research in central cancer registries and optimizing recruitment (\$250) (New) Monday, 13 June, 8:30 am – 4:30 pm
- Introduction to Cancer Surveillance – Workshop for students and junior investigators (New) \$75, Monday, 13 June, 9:00 am – 12:00 pm, 1:30 pm – 4:30 pm (Breakfast not included)

See Preliminary Program for details: http://naaccr.org/AC2016/2016_PreliminaryProgram_032216.pdf

Plenary Session Changes

- “Natural language processing – From information to data” will be presented by Paul A. Fearn, PhD, Director, Biomedical Informatics, Fred Hutchinson Cancer Research Center, rather than by Lynne

Penberthy, MD, Associate Director, Surveillance Research Program, NCI, as previously announced (Plenary Session 3)

Plenary Session Updates

- Melissa Jim, MPH, Division of Epidemiology and Disease Prevention, CDC, will join the “Gateway to Diversity” Panel (Plenary Session 2); her topic will be “American Indian and Alaska Native Populations.”
- A. Lindsay Frazier, MD, Associate Professor of Pediatrics, Harvard Medical School (“Consensus-based principles and classification systems for collecting pediatric cancer stage in population-based cancer registries”) and Frank Bove, ScD, Senior Epidemiologist, Agency for Toxic Substances and Disease Registry, CDC (“Camp Lejeune environmental cancer assessment: Necessity of population cancer data”) will join Michael LeFevre, MD, MSPH as speakers in Plenary Session 1, “Gateway to Implementation and Results.”
- Chesley Richards, MD, MPH, FACP, Deputy Director, Office of Public Health Scientific Services, CDC, will join Eduardo J. Simoes, MD, MSc, DLSHTM, MPH and Kevin Stavely-O’Carroll, MD, PHD as a speaker in Plenary Session 4, “Gateway to Scientific Discovery.”
- Clay Anderson, MD, FACP, NorthCare Hospice & Palliative Care, North Kansas City, MO is currently the sole speaker for the final plenary session (# 5); his topic will be “How population-based cancer data influences palliative care and end-of-life decision making.” A half-hour slot (4:00 - 4.30 pm) is being held for a possible late breaker.

Concurrent Session Updates

There will be five concurrent sessions spread over three days, one each on Days 1 (Tuesday, 14 June) and 2 (Wednesday, 15 June) and three on Day 3 (Thursday, 16 June)

- Each concurrent session will have five or six breakout sessions
- Most breakout sessions will have four speakers; a few will have three speakers
- All breakout sessions are based on the Gateway theme but there is a wide variety of sub-themes, including Research, Innovative Data Use, Cancer Control, Improved Stage Data, Global Initiatives in Surveillance, Vulnerable Populations, Geospatial Applications and others; the most intriguing title is “Gateway to Zombies and Immortals.”
- One hundred general abstracts were accepted for oral presentation; to date, only one oral presenter has withdrawn.
- Two students who submitted by the general deadline have been accepted for a Student Oral Presentation session; additional student presenters may be added to this session.
- Two breakout sessions will feature four NAACCR Steering Committees (Standardization & Registry Development and Data Use; Professional Development and Communications); attendees are invited to participate in these sessions to learn more about the activities of each Steering Committee.

Acknowledgments

More detailed acknowledgments will appear in a post-conference submission to *The NAACCR Narrative*. I want to take this opportunity to thank a few individuals and groups without whose involvement, assistance and support I could not have managed to serve as Chair of the NAACCR 2016 Program Committee and meet my many commitments as Director of the Missouri Cancer Registry and Research Center (MCR-ARC) and a University of Missouri faculty member.

- MCR-ARC staff, particularly Shari Ackerman, Electronic Communications Coordinator and a Program Committee member who took responsibility for Conference entertainment (Gentlemen of Vision and Kim Massie), formed a NAACCR team for the Komen race and arranged for “NAACCR Night at Busch Stadium; Nancy Rold, CTR, Operations Manager, who assumed some of my responsibilities; and Chester Schmaltz, PhD, who participated in planning the Introduction to Cancer Surveillance Workshop.
- Kimberly Johnson, PhD, Washington University in St. Louis, for taking primary responsibility for organizing the pre-conference workshop “Introduction to Cancer Surveillance for Students and Junior Investigators.” (Congratulations, Kim, on your promotion to Associate Professor!)
- Members of the 2016 Annual Conference Program Committee. I’m grateful to all of you for your support and want to thank everyone who agreed to moderate a session; Jim Martin for his work with abstracts and Susan Gershman for her work with posters.
- NAACCR staff, particularly Charlie Blackburn for his prompt and cheerful support and Betsy Kohler for brainstorming with me about the conference and allowing me to participate in NAACCR’s successful NCI conference grant application.
- Venue West staff, particularly Kat Duda, for their support and expertise.

The ever popular Birds of a Feather will be recording its ninth flight at the NAACCR Annual Conference Gateway to Cancer Discoveries. Hosts Susan (Massachusetts) and Rich (Los Angeles) are ready for another energetic early morning adventure! Please grab your breakfast and don't forget that "cup of joe" and join us for another engaging session on Wednesday, June 15th, 7:00am-8:00am. This year the topic is "**Is There Anybody Out There? Collaborating for Cancer Surveillance**".

To start off the session we pose these questions for your consideration:

- Who are your collaborators?
- Have you had any new collaboration requests?
- Which collaborations have been successful and which have not been successful?
- What have you learned?
- Is there any group with whom you would like to collaborate?
- Are there some groups out there we should all be working with?

Come join in this informal discussion so we can share unique, interesting and productive ideas. Don't forget that there are always special treats from Los Angeles and Boston to fuel your creative ideas!

Rich Pinder

Susan Gershman

NAACCR works with Partners in the Caribbean



Betsy A. Kohler, MPH, CTR
NAACCR Executive Director
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Over the past year NAACCR has taken an active role with its partners, NCI, CDC, IACR, and the Caribbean Public Health Agency (CARPHA) to improve cancer surveillance in the Caribbean. The International Agency for Research on Cancer (IARC), a specialized agency of the World Health Organization, working with key partners, launched the Global Initiative for Cancer Registry Development (GICR). As a key partner, NAACCR has been supportive of the GICR and developing six Regional Hubs for cancer surveillance in different areas of the world. The soon to be launched Caribbean Hub will be located in Trinidad and Tobago at CARPHA's headquarters. NAACCR was part of the trans-agency team that visited CARPHA in January 2015 to confirm the siting of the hub in this location. CARPHA has agreements with at least 24 Caribbean nations to conduct disease surveillance and has an established epidemiology presence in the region.

In May 2015, NAACCR provided faculty (Kevin Ward, PhD, Atlanta/Georgia Registry) to a Cancer Control Leadership Forum in Barbados, sponsored by the International Cancer Control Partnership [<http://www.iccp-portal.org/>] and the NCI. This workshop provided background on cancer surveillance and the role of population-based cancer registries in the development of cancer control plans in low- and middle-income countries of the Caribbean.

Last June, the South Carolina Central Cancer Registry hosted a one-day technical information meeting for staff from CARPHA to help them learn first-hand what it takes to establish and run a population-based central cancer registry. Susan Bolick and her staff provided background on their challenges within the government, medical community, and public to develop and maintain a high-quality registry that is integral to cancer control and research. Susan shared South Carolina's experience of building a registry with scarce resources and the progress they have made over time to become a gold certified registry. Following the knowledge-sharing visit in South Carolina, CARPHA had its first taste of NAACCR at the annual conference in Charlotte, including the pre-conference SEER*Stat workshop and a recognition of the Caribbean Hub through a contributed presentation.

In the fall of 2015, Hilda Razzaghi, PhD, an Epidemic Intelligence Service (EIS) Officer, CDC, began an analysis of cancer mortality data for the Caribbean, as collected by CARPHA, and these data will be published in an upcoming edition of the MMWR. Some of the challenges of using country-specific regional vital statistics included not having complete single year data from each country for a comparable period of years, and the high percentage of unknown or invalid cause of death codes (about 10%).

In late September, NAACCR and CDC visited the U.S. Virgin Islands to assess their newest efforts using Department of Interior funding to establish population based cancer reporting on these islands. Future site visits under the aegis of the Caribbean work-plan include two days in Barbados and three days in Trinidad and Tobago later this spring.

NAACCR is in the process of ensuring that our new learning management system will be accessible and useful for our Caribbean neighbors, as well as registries around the world, particularly countries with limited resources. We are working on a portal that will provide information to new registries about how to establish and staff a population-based cancer registry. Many educational tools and references will be posted to the site along with many of our webinars. In addition, we plan to host discussion boards and share information on how to access the wealth of knowledge amassed by NAACCR members. NAACCR and its constituencies have always been enthusiastic about sharing their knowledge and expertise. It is exciting to participate in these new opportunities to improve cancer surveillance on a global level.

Audit Findings from the NC Central Cancer Registry

*Dianna Stucky, BS, CTR, Quality Assurance Specialist
North Carolina Central Cancer Registry*

The North Carolina Central Cancer Registry (NCCCR) is partially funded by the National Program for Cancer Registries (NPCR) and is governed by its program standards. These standards require that the NCCCR have a comprehensive quality assurance program in place that includes the conducting of re-abstracting and or case-finding audits from an assortment of source documents and/or internal audits within the database.

In July of 2015, the NCCCR conducted an internal database quality audit to review the accuracy of the sex field coded to male for Breast Primaries. The Central Cancer Registry database had approximately 1,550 breast cases with sex coded to male from the Diagnosis year 2003-2014. After manual review of all of these cases, it was found that 600 of these cases were incorrectly coded to male. So, 38% of the male breast cases in our database were misrepresented! We were able to determine that they were females by reviewing supporting text of the case in question (or other admission records from hospitals that had the case already correctly coded to female with text documenting the correct sex), review of the SSDI website in some cases, the NC voter's registration website, and review of first and middle names.

There were a few cases that were questionably female, but there was no supporting documentation or information that could help us to determine this, so those cases were left coded to male.

Based on the results of this audit, the NCCCR recommends that facilities include supporting race/sex text for all cases, especially for the cases that are out of the ordinary, such as male breast cancer. Since male breast cancer is relatively rare, (compared to female breast cancer), you can see where this could skew the statistical findings if there was a 1,550 patient incidence of male breast cancer for this time period. (Doctors might start ordering mammograms for all their male patients). So you see how text is essential (and required) by the NCCCR and is used to validate codes in the abstract for accuracy (and not have it all depend on whether you accidentally clicked on "1" instead of "2"). Sex/Race text is just as important as pathology, operative, histology and treatment text fields! So your validation in the text field is enabling us to ascertain the best possible data for North Carolina (and CDC and the NPCR).

CARCA and its Conference

The Chicago Area Cancer Registrars Association (CACRA), organized in 1975, provides its members with multiple opportunities for education, networking, professional enrichment and representation to the state and national organizations. CACRA hosts one fall and one spring educational conference per year. By having these educational conferences in the Chicagoland area CACRA keeps down the travel costs for its membership. CACRA members can attend these nearby meetings to learn and network while still earning nationally approved continuing education hours. We wanted to share the details of our most recent conference which was a huge success! The CACRA Fall Educational Conference of 2015 took place on November 13th at the Northwestern Medicine Warrenville Campus. Topics included brain tumor management, proton therapy, ICD-10-CM, resources for patients, breast surgery options, and breast reconstruction. We were also fortunate enough to take a tour of the Northwestern Medicine Chicago Proton Center itself, which was fascinating. CACRA's membership got a behind-the-scenes look at how proton treatment is done, what we usually only encounter in the medical record.



Cancer in North America Volume Four: Cancer Survival in the United States and Canada

[View The Cancer in North America Volume Four: Cancer Survival in the United States and Canada Press Release](#)

The North American Association of Central Cancer Registries (NAACCR) is pleased to present the inaugural publication of *Cancer in North America Volume Four: Cancer Survival in the United States and Canada*. NAACCR has been producing Cancer in North America (CINA) incidence and mortality publications for over 15 years. This is the first time that NAACCR has published cancer survival data for North America. Along with incidence and mortality data, information on population-based cancer survival is necessary to understand the burden of cancer. The CINA Survival publication includes data from 41 registries on more than 6.7 million cases diagnosed among North Americans between 2005 and 2011.

In terms of national coverage, CINA Survival includes data from 8 of 13 Canadian provinces/territories, 28 of 50 states, and sub-state areas in Michigan and Washington. National population coverage by CINA Survival is about 62% for the United States and 63% for Canada. For registries to be included in CINA Survival, they need to meet data quality criteria.

The results show stark differences in survival for many cancer sites by race in the U.S., a finding seen also in the latest population-based survival statistics published by the National Cancer Institute (SEER Cancer Statistics Review 1975-2012).

Reference:

Johnson CJ, Weir HK, Mariotto AB, Nishri D, Wilson R (eds). *Cancer in North America: 2008-2012 Volume Four: Cancer Survival in the United States and Canada 2005-2011*. Springfield, IL: North American Association of Central Cancer Registries, Inc. March 2016.

Link to report: <http://www.naacccr.org/DataandPublications/CINAPubs.aspx>

Annual Report to the Nation: Cancer Death Rates Continue to Decline; Increase in Liver Cancer Deaths Cause For Concern

NAACCR is pleased to announce the publication of the *Annual Report to the Nation on the Status of Cancer, 1975-2012*. CDC took the lead on the publication this year, which is a long-standing collaborative effort between ACS, CDC, NAACCR, and NCI. The report features a special section on liver cancer.

Both CDC and NCI have produced useful materials for understanding and promoting the report. Please share #ARN2016!

[Click here to view report](#)

[Press Release](#) | [Questions and Answers](#)

New Frontiers in Cancer Treatment

Allen D. Austin, III, BA, CTR

North Carolina Central Cancer Registry

“Cancer can be wily because it does everything possible to dodge destruction. But viruses are equally tricky in their mission to invade cells and propagate.”

— Frederick Lang, M.D.

There is a field in cancer research called virotherapy, using oncolytic viruses to treat cancer, which involves using viruses to infect the cancer cells while sparing normal cells. This research, although in practice since the mid 1950's, has exploded in the last ten years. Initial research revealed that the immune system defeated the virus before it could take effect, but by adding immunotherapy it became more effective. For example, researchers at Queen Mary University of London armed the Vaccinia virus with a copy of the interleukin-10 (IL-10) gene to dampen the immune response, thus hiding the virus from the host's immune system, in order to treat pancreatic cancer.

The following are some exciting examples of this research:

- Patients with melanoma are being treated with a genetically engineered derivative of herpes called T-VEC with more than 16% showing a positive response. This virus attacks the melanoma, multiplying vigorously inside the cancer cells until they burst open, triggering a secondary immune reaction against the tumor. It basically “unmasks” the cancer, waking up the host's immune system to attack the cancer cells.
- When Doctors at the Mayo Clinic gave patients with multiple myeloma a single IV dose of a variation of the measles virus (MV-NIS) their cancer retreated. (The measles vaccine has an affinity for certain types of tumors and treats the multiple myeloma as food, turning the diseased cells into machines to make copies of the virus). Most people have been inoculated with the vaccine, rendering it vulnerable to their immune system. But patients with multiple myeloma often have suppressed immune systems, thus allowing the virus to do its work. In one landmark case, they injected a 50-year old patient suffering from multiple myeloma with enough measles vaccine to inoculate 10 million people! The patient's cancer went into complete remission.
- Researchers at the University of Pennsylvania reported that Doctors using a deactivated HIV virus caused patients with acute lymphoblastic leukemia to go into remission. The process involves removing the genes from the HIV virus that cause the disease and those that make it infectious. Then the patient's T-cells are extracted, reprogramming them with the genetically modified HIV, and then infused back into the patient's body. Normally T-cells don't see cancer cells, but with the genetically modified HIV virus, the T-cells become serial killer cells literally going from one tumor cell to the next to kill them.
- Doctors in Neurosurgery at Maryland have genetically programmed a type of common cold virus (Adenovirus Delta-24-RGD) to attack glioblastoma multiforme. Without treatment, a glioblastoma doubles in size every two to three weeks, so, even though neurosurgeons think they've removed the entire tumor, hidden cancer cells remain seeded in the brain to inevitably grow back. This new treatment involves injecting an altered cold virus through a hole in the skull directly into the patient's tumor. This altered virus (named Delta 24) detects a cancer cell, enters the cell, and begins making copies of itself nonstop. The malignant cell fills with viral particles until it explodes, then burst forth and moves forward to infect other cancer cells, until all tumor cells have burst.
- Doctors at Duke are using a genetically engineered polio virus (PVS-RIPO) to combat brain tumors. Using the genetic code of cold-causing rhinovirus and splicing it into the poliovirus genome removes its disease-causing ability, then by injecting it directly into the tumor; the PVS-RIPO infects and kills the tumor cells.

We've known for a long time that some viruses may cause cancer, like the HPV virus leading to cervical cancer or the Epstein - Barr virus (EBV) which increases the risk of nasopharyngeal cancer or Burkitt lymphoma. But now, due to technological advances in genetic engineering of viruses, we have finally learned how to make viruses work **for** us instead of **against** us.

Dr. Allemani to receive inaugural Global Public Health Award

Dr Claudia Allemani to receive the inaugural Global Public Health Award from the Faculty of Public Health in the U.K.

[Dr Claudia Allemani](#), Senior Lecturer in Cancer Epidemiology at the London School of Hygiene and Tropical Medicine, U.K., has been named as the first ever recipient of the Global Public Health Award by the U.K.'s

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prestigious Faculty of Public Health. The award, which will be formally presented at a ceremony during the Faculty's annual conference on 14 June 2016, is in recognition of her work on the CONCORD programme, the world-wide collaboration that established global surveillance of population-based cancer survival in 2015 (The Lancet), and in which almost all the NAACCR registries are participating.

Claudia is a member of the LSHTM's Cancer Survival Group, which focuses on research to explain trends and inequalities in cancer survival at regional, national and international level, including in socio-economic, racial and ethnic groups of the population. The results help policy-makers to target investment in cancer services to improve survival and reduce inequalities in outcome.

Submitted by Michel Coleman

<http://www.naacr.org>



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

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