



Message From the President

Chuck Wiggins, PhD
NAACCR President

The NAACCR 2015 Annual Conference was a great success. A big thanks goes to Chandrika Rao, PhD, and her colleagues at the North Carolina Central Cancer Registry for hosting the Conference, and to members of the Program Standing Committee for developing an engaging and informative schedule. Kudos, as well, to our professional NAACCR staff for bringing this conference to fruition.

Much of our work at NAACCR occurs under the purview of five Steering Committees. One of my first duties as President was to ensure that we had solid leadership for each of these Committees. This turned out to be a relatively easy job since each Steering Committee either had existing leaders or well-qualified individuals ready to step into such positions. Thus, I'd like to introduce our Steering Committee leaders for the coming year: Laura Ruppert, MHA, and Annette Hurlbut, RHIT, CTR, Co-Chairs, Communications; Nan Stroup, PhD, and Randi Rycroft, MSPH, CTR, Co-Chairs, Standardization and Registry Development; Hanna Weir, PhD, and Susan Gershman, MS, MPH, PhD, CTR, Co-Chairs, Research and Data Use; Mignon Dryden, CTR, and Frances Ross, CTR, Co-Chairs, Professional Development, and Tom Tucker, PhD, MPH, Chair, Strategic Alliances. Information about the Steering Committees, including a list of current members, can be found [here](#).

Finally, I wanted to let you know that I am honored to serve as NAACCR President for the next 2 years. I thought I'd take this opportunity to tell you a little about myself. My introduction to cancer surveillance was as a student intern at the New Mexico Tumor Registry during my spring semester in 1978. I was privileged to work under the direction of Charles Key, MD, PhD and Dorothy "Dottie" Brylinski. After graduating from the University of New Mexico with a B.S. in Community Health Education, I continued to work as a staff member at the Registry for several years. In 1983, I completed an MSPH in Epidemiology at the University of Alabama-Birmingham, where I studied alongside Betsy Kohler, MPH, CTR, our NAACCR Executive Director. I returned to New Mexico in 1984 and worked on registry-affiliated epidemiological investigations.

In 1990, I moved to Seattle to work on my doctoral degree in Epidemiology at the University of Washington. While in Seattle, I worked at the Cancer Surveillance System at the Fred Hutchinson Cancer Research Center, under the direction of Davis Thomas, MD, DrPH, and Mary Potts, RHIA, CPA, CTR. My first position as a newly-minted PhD was Director of the Utah Cancer Registry, where I had the good fortune of working with Rosemary Dibble, CTR, SuAnn McFadden, CTR, Wallace Akerley, MD, and Charles Smart, MD. In 2003, I returned to New Mexico to take the helm at the New Mexico Tumor Registry when Dr. Key retired. Today, I am a Professor in the Department of Internal Medicine at the University of New Mexico School of Medicine. In addition to my registry-related activities, I am a member of our NCI-designated cancer center and coordinate instruction in epidemiology and biostatistics for medical students at our institution. My wife Andrea and I have three teenage sons, Christopher, Jamieson, and Reece.

I look forward to working with each of you in the coming years. Please feel free to contact me via e-mail at cwiggins@salud.unm.edu or by telephone at (505) 272-5541.

Message From the Executive Director

Betsy A. Kohler, MPH, CTR

NAACCR Executive Director



We all hope you benefitted from the NAACCR Annual Conference by learning, networking, and sharing your knowledge with colleagues from across North America. We are already looking forward to St. Louis in June 2016. If you were not able to attend, most of the presentations will be available on the NAACCR website. In addition, we are planning to present some of the key talks as free webinars over the next few months. If you are interested in presenting your talk as a webinar, or attended a talk which you think should be broadcast to the membership at large, please contact Jim Hofferkamp

(jhofferkamp@naaccr.org) as soon as possible.

We are also looking forward to another busy year. Here are a few of the initiatives we will be working on:

- We are hoping to make more progress on our exploration of the XML format to modernize our data transmission methods, and will be looking into ways we can implement the fine work of the NAACCR XML Workgroup.
- We will also be focusing on developing the Virtual Pooled Registry for cohort matching this year.
- Our Professional Development Steering Committee will be working on launching “Understanding Population-Based Cancer Registries” and building out our educational offerings while promoting our venerable webinar series.
- The Communications Steering Committee is polishing a Communications Plan for the membership.
- The Research and Data Use Steering Committee is planning several new Surveillance Webinars and Journal Clubs this year, and will be examining the potential usage of 12-month data, developing cancer control profiles using surveillance data, and revisiting completeness estimates, among other things. They will also be working on a joint-venture with Standardization and Registry Development to address methods for resolving duplicate cases that are reported to more than one state.
- The Standardization and Registry Development Steering Committee will be strengthening our Health IT Advisory Group, working on new best practices in registry operations (consolidation, death clearance work continues, multiple primary resolution will be new), and will continue to envision how registries need to continue to adapt to meet changing needs in the future.
- Our Strategic Alliance Steering Committee is working on Sponsoring Member engagement by recommending a series of new practices.
- In addition, we will be working with our cancer surveillance partners on numerous issues including the transition away from Collaborative Stage, assisting with the development of cancer reporting in the Caribbean, and reinvigorating the National Coordinating Council for Cancer Surveillance.

If any of these initiatives sparks an interest in you, please contact the Steering Committee Chair, or me at bkohler@naaccr.org. We are always looking for new ideas!

NAACCR 2015 Annual Conference Wrap-Up

Chandrika Rao, PhD
North Carolina Cancer Registry



Yes! More than 400 NAACCR members and colleagues celebrated the successful launch of the *New Era in Cancer Surveillance* in the Queen City (Charlotte), North Carolina. For the first time in the history of NAACCR, the 2015 Conference was attended by a record number of cancer surveillance professionals committed to the cause of reducing cancer burden. Had we known better, we could have requested the planet to keep it cooler that week! But the steaming weather did not stop the attendees from discovering the colorful and vibrant streets, and enjoying the music and fine dining of Uptown Charlotte. In addition to the unique attractions close by, many attendees also experienced the thrills of driving on the NASCAR race tracks.

During the Conference, the plethora of talented speakers captivated the audience by sharing their knowledge and expertise in the field of medical research as well as advances in genetics, epigenetics, and biomarkers. The discussions on “Big Data” further highlighted the importance of the registry data. In addition, the linkage between the registry data with the clinical and administrative data proved that our registry data can be made more meaningful for better outcomes.

The positive feedback received from the attendees suggests that this Conference continues to be a great platform for networking and launching more ideas to strengthen the cancer surveillance system and to reduce the burden of cancer.

Post-conference postings are available on the [NAACCR website](#). To access Flickr photos, click [here](#). To access posters, click [here](#). To access presentations, click [here](#).

Honoring NAACCR's Best - Constance L. Percy Award

Recognizing Excellence With the Constance L. Percy Award for Distinguished Service

Narrative Staff

Every year, NAACCR members are nominated by their peers for special recognition in the form of the Constance L. Percy Award for Distinguished Service, which is announced at the organization's Annual Conference. This year's recipients join an impressive collection of cancer surveillance professionals who have dedicated their careers to making every cancer count.

Susan Bolick, MSPH, CTR, and Robin Otto, RRA, CTR, co-chaired the NAACCR Death Clearance Work Group, which recently released a revised version of the *Death Clearance Manual 2014* for use as standard practice for NAACCR member registries. This manual replaced the *Death Clearance Manual 2009* version. When the later manual was released, polarizing opinions regarding the death clearance process still remained. In their role as Work Group Co-Chairs, they worked determinedly to find consensus.

The *Death Clearance Manual 2014* focuses on minimum requirements that every registry should be able to meet. For their leadership, dedication, and perseverance towards standards as well as efficient registry operations, Susan and Robin are most deserved recipients of the Constance L. Percy Award for Distinguished Service.

The Constance L. Percy Award for Distinguished Service recognizes individuals who have contributed exceptional volunteer service to NAACCR during the past 12 months, or sustained, current, and long-term contributions to the organization. The award was created to honor Constance Lebair Percy, a cancer statistics research pioneer and founding member of the International Association of Cancer Registries. Ms. Percy made substantial contributions to public health during her 53-year career as a health statistician and played an integral role in helping establish the link between smoking and lung cancer.

Susan and Robin provided some comments in receiving the award:

Susan Bolick: "Thank you to the NAACCR Board for the distinct honor bestowed on me of receiving the Constance Percy Distinguished Service Award this year. It is indeed my pleasure to work with the members of NAACCR in our effort to meet goals and objectives set to improve cancer registry operations across North America. I look forward to many more years of working together."

Robin Otto: "Since I am now retired and was not registered for the NAACCR meeting, Jim Hofferkamp called me to tell me I was chosen to receive the Constance L. Percy Award for Distinguished Service. I had time to prepare a brief acceptance speech but was too emotional at the time to say what I planned to say. I would like to share it with you now – words of thanks and a fond farewell.

I am truly honored to be one of this year's recipients of the Constance L. Percy Award for Distinguished Service. I could not be more delighted to receive this award along with my dear friend, Susan Bolick.

This award was created to honor a person who made many significant contributions to cancer registration during her 53 years as a health statistician. Constance L. Percy contributed to establishing and updating the ICD-O. The cover of our current ICD-O-3 is in honor of her because everyone who knew her knew that her favorite color was purple. She was a founding member of the International Association of Cancer Registries. And she played an integral role in helping to establish the link between smoking and lung cancer.

I remember Constance Percy in the early days of my cancer registry career. She was one of the "Seniors" when I was a "Junior." I also remember saying I cannot believe I get paid for doing a job that I enjoyed so much. And now, I cannot think of anything better than to finish my career in cancer registration with this award.

Being involved at the national level by serving on NAACCR committees and the NAACCR Board has always been rewarding to me and a highlight of my career. Working with really smart and dedicated cancer registry professionals across the U.S. and Canada made me a better registry manager and more passionate about the work we are doing.

So thank you again to my NAACCR friends and colleagues for choosing me to receive this award and even more for allowing me to be part of this amazing organization and community. It has been a privilege for me to serve an organization that accomplishes so much. I wish you all the best as we launch a new era in cancer surveillance."

NAACCR Member Recognition Awards

Narrative Staff

Congratulations to the following NAACCR members who were recognized during the Awards Luncheon at this year's NAACCR Annual Conference:

2015 Recognition Award Recipients

Leadership Award:

- Melanie A. Williams, PhD
- Glenn Copeland, MBA

Achievement Award:

- Janna Harrell
- Monique Hernandez
- Winny Roshala
- Susana Perez

Merit Award:

- April Austin
- Kim Herget
- Jovanka Harrison
- Christopher Johnson

For further information on NAACCR's Member Recognition Awards, click [here](#).

It's a good way to recognize and encourage each other as we contribute to the NAACCR community!

Honoring Our Retirees

Narrative Staff

During the NAACCR Board of Directors meeting during the 2015 Annual Conference, the Board passed resolutions recognizing five individuals on the occasion of their retirements and for their outstanding contributions to the field of cancer surveillance:

- Susan Capron
- Vivien W. Chen, PhD
- Robin Otto, RRA, CTR
- Shannon Vann, CTR
- Dee W. West, PhD

More information on the substantial contributions made by these individuals (and other NAACCR Board Resolutions) is available [here](#).

In response to the Board Resolution, Dr. Chen wrote the following note:

"Dear NAACCR Family,

Thank you so much for your most generous and kind words, your best wishes and the impressive NAACCR proclamation!

I was delighted to see many of you and to attend one of the best NAACCR conferences ever. The 2015 Conference reaffirmed the importance of population-based registries, highlighted the abundant opportunities for our data use in the era of precision medicine and challenged us to step out of our comfort zone.

Many of you asked about my plan after my "official" retirement in August. I do not have a concrete plan yet but my university will grant me Professor Emeritus status so that I will be affiliated with the Louisiana Tumor Registry and be involved. I will have the same email address (vchen@lsuhsc.edu) and will continue to work on the projects (data analyses and manuscripts) that I have started as well as complete my term on NAACCR and other committees that I currently serve. So I will be interacting with many of you in the coming year.

I have finally figured out my "legitimate" reason for retirement. I am still stuck on "flat file" when everyone else has moved to "XML". So Eric (Durbin), I might have "accidentally" hit my choice of answer (retirement) more than once!

Best regards,
Vivien Chen"

NAACCR Annual Conference Poster Awards

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

Massachusetts Cancer Registry / Chair, Poster Review Committee

Thanks to all the poster authors and judges who participated in the NAACCR Annual Conference Poster Awards. We had 38 posters assigned to either the Registry Operations or Data Use category. There were three awards for each of the categories. And the winners:



Registry Operations

First Place: *KRAS Test Documentation in the Alaska Native Tumor Registry Among People With Late Stage Colorectal Cancer* (Teresa Shade, Alaska Native Tribe Health Consortium, Anchorage, AK)

Second Place: *Looking for Cases in All the Right Places* (SuAnn McFadden, Utah Cancer Registry, Salt Lake City, UT)

Third Place: *Collecting Comorbidities From Statewide Administrative Data* (Robert Martinsen, California Cancer Reporting and Epidemiologic Surveillance [CalCARES] Program, University of California at Davis Health System, Sacramento, CA)

Data Use

First Place: *Racial/Ethnic Differences in Risk of Subsequent Invasive Breast Cancer Among Women Diagnosed with Invasive Breast Cancer and Ductal and Lobular Breast Carcinoma In Situ in New Jersey, 1992-2012* (Karen Pawlish, New Jersey Department of Health, Trenton, NJ)

Second Place: *Ductal Carcinoma In Situ of the Breast: Trends in Incidence and Treatment* (Carol DeSantis, American Cancer Society, Atlanta, GA)

Third Place: *Increase in Rectal Cancer Death Rates Among Young Adults in the United States* (Kimberly Miller, American Cancer Society, Atlanta, GA)

Congratulation to the winners! You can view the posters by clicking [here](#).

25th Edition of CINA Now Available

Glenn Copeland

Director, Michigan Cancer Surveillance Program



The 25th Edition of the publication *Cancer in North America (CINA): 2008-2012* is now available on the NAACCR web site. Please visit www.naaccr.org and select Data and Publications for free access/downloading of the publication.

This publication series presents cancer incidence data as collected by the regional, state, provincial and territorial NAACCR member registries across North America. Incidence data were provided to NAACCR by the NAACCR member registries in the hopes of providing ready access to data across the United States and Canada. This publication is possible due to the ongoing and excellent efforts of our member registries to assemble high-quality and timely cancer incidence data.

The 2015 monograph includes data from 69 central population-based registries: 57 from the United States (50 states, the District of Columbia, Puerto Rico and 5 metropolitan areas) and 12 from Canada (9 provinces and 3 territories).

Volume I includes combined data for the United States, for Canada and for all of North America. The information in Volume I includes leading cancer types by sex and, for the United States, by race and ethnicity. Age-adjusted cancer rates by cancer type, pediatric cancer data and cancer data by stage for selected cancers are also provided. New this year are delay-adjusted cancer incidence rates.

Volume II provides registry-specific incidence data for each of the 69 registries. Volume III will include information on cancer mortality during 2008 through 2012. However, the release of this Volume is delayed pending the release of official U.S. mortality data.

Note that there are other NAACCR products that are available for use in cancer research and data analysis. These include CINA+ Online, NAACCR FastStats, CINA in SEER*Stat, CINA Plus in SEER*Stat, CINA Monograph data in SAS Dataset and CINA Deluxe. Access to NAACCR data is available to NAACCR members.

More information on these additional resources is available at www.naaccr.org under Research.

As always, your comments on this publication are welcome and your thoughts on future publications are always of interest. Thank you for your support of this publication.

NCI SEER Supports Cancer Registrars With a New Tool: The Glossary for Registrars

Jennifer Ruhl, RHIT, CCS, CTR
NCI SEER

The [Glossary for Registrars](#) is an interactive, web-based tool with more than 5,000 terms defined for cancer registrars. Use the glossary to find definitions for anatomy terms, cancer-related terms, common diseases (and not-so-common diseases), physiology terms, surgical procedures, other treatment procedures, and much more.

Resources used to populate the glossary include:

- NCI Data Dictionary
- American Brain Tumor Association
- Cancer Registry Management Principles & Practices for Hospitals and Central Registries
- Cancer Treatments Center of America
- ClinicalTrials.gov
- Fundamentals of Anatomy and Physiology, 3rd Edition
- MD Anderson
- MedicineNet.com

...and many others

The Glossary can be accessed directly from the [SEER website](#) or accessed by clicking on linked terms in the Hematopoietic database and SEER*Rx.

The Glossary is a work in progress. New terms will be added and the tool will be updated quarterly.

If you have questions or comments about the glossary, please submit them to [Ask a SEER Registrar](#) and choose "Glossary for Registrars."

Update on NAACCR Mentorship Opportunities

Betsy A. Kohler, MPH, CTR

NAACCR Executive Director

Several members have asked about the status of the NAACCR Mentorship Program. Under this program, NAACCR members may apply for support to work one-on-one with a mentor member registry to learn a specific procedure, improve data quality, or enhance a specific aspect of registry operations. Many registries took advantage of this opportunity to improve cancer surveillance in their state or province.

This program used to have dedicated funding attached to it, but in recent years this funding has not been available. However, members who would like to apply for a mentorship opportunity may continue to do so and consideration will be given based on merit and funding availability from NAACCR.

Application decisions will be made on the applications by the NAACCR Board of Directors. Please contact Jim Hofferkamp via e-mail at jhofferkamp@naaccr.org for more information and for an application. In addition, over the next year we will be working on ways to revitalize this program to increase learning opportunities for all members.

Registry of the Future

Discussions from the Registry of the Future Open Forum on Data Use Session during the 2015 NAACCR Annual Conference featured discussions on data linkages, real-time reporting, the "ideal" dataset, and shared resources.

This article contains topics/comments assimilated by NAACCR members Susan Gershman and Hannah Weir from the Registry of the Future Open Forum on Data Use Session held during the 2015 NAACCR Annual Conference.

Data Linkages

It was unanimous that we should routinely link to enhance our cancer registry data. Some available files include census, Medicare for non-SEER registries, hospital discharge data sets, all payers claims databases if available, and patient surveys. There was agreement that information technology (IT) resources need to be good and linkage algorithms needs to be standardized. There are two basic linkages for central registries: routine data collection and research studies. There was consensus that we should charge for linkages that involve research projects. One question raised was: can we get beyond the tradition of destroying the data after the immediate project has been completed? In summary, cancer registries can be viewed as the spine to which data can be linked. The cost is minimum but the payoff is large.

Real-Time Reporting

Can we get data into our central cancer registries faster than 6 months? This would require IT resources and more automated data processing. If we could get faster data, then 12-month data could be used as a sentinel indicator of trends (e.g., prostate cancer drop in 2012). The sentinel registry concept is interesting since registries could specialize in difference innovative processes, or collect data items as a pilot before the entire country does.

What do you think of your 12-month data? Maybe it should only be used for surveillance? More timely data makes the registry a participant in the process as it happens, and facilitates interactions with researchers, and subsequently more connection to the clinical community. Frank Boscoe will chair a Task Force on Twelve Month Data. If you are interested in serving on this Task Force, contact Frank at francis.boscoe@health.ny.gov.

“Ideal” Dataset

This topic generated much discussion. The majority seemed to favor collecting more data but there was definitely interest in collecting less data. However, there was a comment that we need a rational explanation for additional data collection. It was also mentioned that a surveillance dataset doesn't need treatment data specifically for NPCR registries since they won't ever be a true research database.

What is the ideal dataset? What are the core data elements that central cancer registries should collect? Public health surveillance core data elements are demographics, disease or condition, and some type of treatment (but not every treatment detail). How do we collect more data without sacrificing quality? It was proposed that efficient linkages for supplementing and adding more data could be the answer.

Some expressed a concern that we need to be thinking about data relevance. However, we need to be flexible in order to be relevant. Should central registries consider dropping information that might no longer be relevant—with an eye to surveillance but also research relevance? Maybe researchers should think of the cancer registry first for assessment in order to help direct the potential research project.

Shared Resources

There was much support for sharing resources. There were two broad concepts:

1. National and regional forums provide the opportunity to share concepts and ideas that need to be discussed across the NAACCR community so those with a common interest can work collaboratively to issue resolution. An example provided was the Virtual Pooled Registry Network which will facilitate cohort matching in states.
2. When working with researchers, make sure that all data collection and any additional work that involves the central registry is included in the grant for funding. This is easier in academically based central cancer registries but might still be feasible in state health departments.

Birds of a Feather Wrap-Up

The "Birds of a Feather" Session during this year's Annual Conference featured a story from David O'Brien of the Alaska Cancer Registry about an Alaska Native community that was concerned about pollution left behind from WWII-era military facilities causing cancer. The Session also featured an in-depth discussion on "Big Data. There were many skeptics regarding Big Data but there was consensus that we should be open-minded to the potential future no matter what it is or becomes.

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

Rich Pinder
*NAACCR Standardization and Registry Development Steering Committee/
Los Angeles County Cancer Surveillance Program*

This year, the NAACCR Annual Conference's **Birds of a Feather** Session migrated south with a discussion on the topic *Using Our Registry Data – What Works and What's Next?* We (Rich and Susan) would once again like to thank those of you who grabbed that cup o' joe and attended this very early morning session. We continued with great attendance at approximately 70 attendees this year.

We began with some history:

'Birds' Over the Years:

- 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?

We then moved on to continue the session with a story from David O'Brien of the Alaska Cancer Registry. There is an Alaska Native community that was very concerned that all the pollution left behind from WWII-era military facilities was giving them cancer from eating traditional foods. David did a study that showed there were no excess cancers and presented the study results in a community open house. The community was so relieved that they shifted their focus on cancer screening and early detection. In January at their conference the Alaska Public Health Association recognized David for his work (see article titled "Alaska Cancer Program Making a Difference in the Community of Yakutat" later in this issue of the *Narrative*).

Next the discussion focused on Big Data. There were many definitions, and Wikipedia states:

"Big Data" is a broad term for data sets so large or complex that traditional data processing applications are inadequate. Challenges include analysis, capture, data curation, search, sharing, storage, transfer, visualization, and information privacy. The term often refers simply to the use of predictive analytics or other certain advanced methods to extract value from data, and seldom to a particular size of data set. Accuracy in big data may lead to more confident decision making. And better decisions can mean greater operational efficiency, cost reductions, and reduced risk."

There were many skeptics regarding Big Data but there was consensus that we should be open-minded to the potential future no matter what it is or becomes. The NCI is focused on Big Data but there is controversy. There was a positive example where merging data on chemotherapy specific to brain tumors that would not have been doable without the merging of datasets.

Another comment reminded us that academic institutions are moving to data warehouses which are centrally managed. This could have promising research opportunities. With all this discussion about Big Data, it sometimes seems like "Big Brother." Is there no concern regarding privacy?

There seemed to be consensus that we need to take a critical look at what we collect, why we collect it, and do we need to collect it. An example provided was the collection of ER, PR, HER2, and then another file that codes them together. Cancer surveillance needs to be relevant so perhaps a new model with a smaller dataset should be under consideration.

In summary, the cancer surveillance community needs to do some rethinking regarding a possible modification of our course over the next decade or so.

We look forward to our next Birds of a Feather topic at the 2016 NAACCR Annual Conference in St. Louis, Missouri.

NAACCR Annual 5K Run/Walk

Recinda Sherman, PhD, MPH, CTR

NAACCR Manager of Data Use and Research

It was a hot and humid morning as a group of nearly 30 intrepid NAACCR members rose early (super early for those from the Left Coast) to participate in our 6th Annual NAACCR 5K Run/Walk. Nearly one-third of the participants have completed the 5K every year since the first event in Quebec City.



We ran/walked around a few fountains along Charlotte's Little Sugar Creek Greenway...I was tempted to jump in!

Frank Boscoe from the New York State Cancer Registry made an excellent executive decision for a last-minute route change so that we could experience the urban section of Charlotte's Little Sugar Creek Greenway. The Greenway is a lovely walking/biking path that connects a number of schools and parks, and it is dotted with public art. After the scenic tour, even the walkers made it back in plenty of time to eat breakfast.



6th Annual NAACCR 5K Run/Walk participants ready to head out for exercise in the wee hours!

We hope you join us next year for our 7th Annual 5K Run/Walk in St. Louis!

National Data Exchange Agreement

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

It's Summer, so Time to Review Your Registry Bucket List and Sign on!

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



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

The registries that have signed the National Interstate Data Exchange Agreement include: Alabama, Alaska, Arkansas, Colorado, Connecticut, Delaware, Guam, Hawaii, Idaho, Indiana, Kentucky, Louisiana, Massachusetts, Michigan, Mississippi, Montana, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, South Carolina, Texas, Utah, Vermont, Virginia, West Virginia, 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 217-698-0188. Jim Hofferkamp provides a listserv announcement to the NAACCR community as soon as a new registry signs on.

Highlights From the Program Manager of Standards

Lori A. Havener, CTR
NAACCR Program Manager of Standards

Standards Volume II, Version 16 - Delayed Release

The NAACCR *Standards for Cancer Registries, Volume II Data Standards and Data Dictionary*, Version 16 is tentatively scheduled for release October 1, 2015. The UDS is working on several new data items and changes to

existing data items to accommodate CS transition. A few new data items have been added for geocoded county; these are different than reported county. There are several data items for which the wording will change to make them less specific, for example, changing “hospital” to “reporting facility.”

Standards Volume II, Version 17

It is time to think about *Standards Volume II, Version 17*! Keep in mind the timeline below as you start thinking about Version 17:

Standards Volume II, Version 17 Timeline

January 1, 2016 – Proposed changes submitted to and approved by the Change Management Board (CMB)

January 1, 2016 – CMB submits request for change to UDS

March 1, 2016 – Volume II Task Force review

May 1, 2016 – Draft submitted to UDS and the S&RD SC for review/approval

June 1, 2016 – Draft submitted to NAACCR Board for review/approval

July 1, 2016 – Post to NAACCR website

January 1, 2017 – Version 17 Implementation

Updates from the Change Management Board (CMB)

The Cancer Surveillance Community Timeline is updated for 2015–2019 (January 2015 to January 2019). The left side indicates the CS transition timeline for CoC, NPCR, SEER, and the Canadian Council of Cancer Registries. The right side of the timeline includes milestones for *Standards Volume II, Multiple Primary and Histology Coding Rules Revisions, AJCC 8th Edition*, etc. Please note that milestones with an asterisk (*) are tentative dates. The updated timeline is posted to the NAACCR website ([click here](#)).

The CMB has developed a Q&A document for the change management process. Changes to the data exchange layout, additions of new codes to existing data items, changes to algorithms for derived variables, and additions of new data elements are time consuming, can affect many aspects of registry operations (data collection, editing, and IT), and are often costly. The Change Management Process Q&A provides the framework for optimal management of change and brings criteria for complete, accurate, and timely preparation to the change process. The Change Management Process Q&A is posted to the NAACCR website [here](#).

NAACCR Education and Training Program Update

Shannon Vann, CTR

Program Manager of Education & Training (Emeritus)

This is the last NAACCR Education and Training Program Update I will write because I am retiring on June 30, 2015. However, instead of an update, this article is the overview of my life in cancer surveillance.

My career in health surveillance began in 1988 with the Illinois Department of Public Health (IDPH). I worked for 3 years as a coder and editor for the Illinois State Cancer Registry (ISCR). During that time I attended my first NAACCR Conference in Chicago. For the next 3 years, I was the manager of the Adverse Pregnancy Outcomes Reporting System (APORS), the IDPH birth defects registry. I returned to cancer in 1994 as the supervisor of the ISCR quality control field staff. I was very involved with training in that role. In a professional sense, I grew up at ISCR. At this point in my career, I became actively involved in NAACCR. I thoroughly enjoyed working with the great cancer surveillance team at ISCR.

In 2001, my husband, Les, was transferred to Iowa. I was hired by the State Health Registry of Iowa (SHRI) as field staff supervisor. Working in a SEER registry was a wonderful, if short-lived, experience. Les was transferred again

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in 2002. This time we were off to Asheville, NC. Again, however, I was lucky to work with dedicated and knowledgeable cancer surveillance professionals that taught me much. Also, at SHRI I was also able to continue to be involved with NAACCR.

Not knowing how long we would live in Asheville, I decided to seek out work-from-home opportunities. I was able to get some contract work, including work with NAACCR. I did this through April 2005. Most of my work was in education and training.

In April 2005 I became the Program Manager of Education and Training for NAACCR. Thankfully, I have been able to do this job remotely from my home. In the 10 years that I have worked full-time for NAACCR I have lived in Manlius, NY, Cincinnati, OH, Savannah, GA, and currently in Indianapolis, IN. For the GIS folks, that is NAACCR Northeast, NAACCR East, NAACCR Southeast, and back to NAACCR East.

Working for NAACCR I have found my niche in education and training. When I entered college at Illinois State University, I planned to study elementary education. At my father's encouragement, the plan changed because of the lack of teaching jobs at the time. I wandered around campus and by accident found health information management (at the time called medical records administration). I was told that jobs were plentiful, and I had no other great ideas so that became my major. After a few years working in hospital health information management departments, I landed at IDPH as described earlier. I feel like I have come full circle. Growing up, I wanted to be a teacher. Although the teaching I do is not elementary education, I still ended up as an educator.

It has been my privilege to work at NAACCR and in education and training. I have met and worked with so many terrific people. I am not naming names because I don't want to miss anyone. You are all the best, and I will miss you very much. Thank you for the great work you do.

NAACCR 2015-2016 Education and Training Calendar



AUGUST 2015

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

SEPTEMBER 2015

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

OCTOBER 2015

10/1/15 - Collecting Cancer Data: Unusual Sites and Histologies
10/6/15 - Session 7; CTR Exam Preparation & Review Webinar Series
10/13/15 - Session 8; CTR Exam Preparation & Review Webinar Series

NOVEMBER 2015

11/5/15 - Collecting Cancer Data: Pharynx

DECEMBER 2015

12/3/15 - Directly Coded Cancer Stage...NOW

JANUARY 2016

1/7/16 - Collecting Cancer Data: Bone and Soft Tissue

FEBRUARY 2016

2/4/16 - Collecting Cancer Data: Breast

MARCH 2016

3/3/16 - Abstracting and Coding Boot Camp: Case Scenarios

APRIL 2016

4/7/16 - Collecting Cancer Data: Ovary

MAY 2016

5/5/16 - Collecting Cancer Data: Kidney

JUNE 2016

6/2/16 - Collecting Cancer Data: Prostate

JULY 2016

7/7/16 - Patient Outcomes

AUGUST 2016

8/4/16 - Collecting Cancer Data: Bladder

SEPTEMBER 2016

9/1/16 - 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).

NAACCR's CoC Liaison Report

Frances Ross, CTR

Kentucky Cancer Registry / NAACCR Liaison to the Commission on Cancer

The Commission on Cancer (CoC) held its Spring Meetings for 2015 in Chicago, IL on May 7-8, 2015. The first day of this 2-day meeting centered on the activities of various committees.

The **Accreditation Committee** first discussed adding new programs for accreditation, which were Oncology Medical Home Accreditation, Rectal Accreditation, and possibly a separate *Pediatric Standards Manual*. These new program ideas were all favorably viewed by the participants, and work on establishing and defining these is ongoing.

Next, the Committee discussed revisions to the *CoC Standards Manual* (v2 2015) regarding new eligibility requirements for palliative care services and risk assessment/genetic counseling. Both of these new requirements were passed by a vote of the Committee members. The palliative care component was added to the eligibility requirements, but members voted NOT to require that these services be given onsite. They felt that a process for referrals to palliative care needed to be better defined, and that the National Cancer Institute-designated programs, which are currently exempt from this requirement, should no longer have an exemption.

There was some debate about increasing the number of cases presented at cancer conferences from 15% to 20-25%. Everyone agreed that this would improve clinical care and increase clinical trial participation, but it would be an added burden to many programs. It was agreed to make this an item for a commendation and not a requirement.

Synoptic pathology reporting was moved from being an item for commendation to being a requirement. The CoC will require that 95% of all path reports be in a synoptic format, and must include at least 95% of the College of American Pathologists required data elements starting in 2016.

Participation in the RQRS program was moved from commendation to a required element, with at least quarterly data submissions to the CoC. Also, programs seeking to move their reference date forward must now keep 10 years of registry data; the previous standard had been only 5 years of historical data. However, the members felt that some flexibility would be needed for integrated programs on this standard.

Finally, this group will be working on new standards development for registry data completeness, follow up, accuracy, and recurrence information. They plan to work with partner organizations on this and specifically mentioned National Cancer Registrars Association. This may be an opportunity for NAACCR to offer support and expertise in the area of data quality standards. An update on these activities will be presented at the October 2015 meeting.

The **Cancer Liaison Committee** heard from Rich Wender, MD, from the American Cancer Society about the transformation of that organization. Mary Milroy, MD, presented metrics and measures for Cancer Liaison Physician activities, and Peter Hopewood, MD, discussed methods to enhance the Cancer Liaison Physician's (CLP) role using a Surveyor-CLP Meeting Guide.

The **Quality Integration Committee** began by discussing nine new cancer care quality measures – three were for bladder cancer, one was for Wilms tumors, and five were proposed for melanoma cancers. All measures were enthusiastically recommended and approved. There were brief updates on the National Cancer Data Base, Cancer Quality Improvement (CQIP) and Public User File (PUF) programs, and the *FORDS Manual* revision work is still underway.

The **Advocacy Committee** meeting included a recap of the American College of Surgeon's Advocacy Summit by William Ward, MD and a recap of the One Degree initiative by Peter Hetzler, MD, liaison for the American Society of Plastic Surgeons. These were followed by lively discussions on the new USPSTF mammography recommendations, e-cigarettes for minors, the rising cost of cancer drugs, and the Breast Cancer Research Stamp Reauthorization bill.

The **Member Organization Steering Committee (MOSC)** voted to add the Society for the Immunotherapy of Cancer as a member organization. Next, it voted to make the MOSC a standing committee of the CoC. It concluded with a discussion of potential criteria for member organizations, possibly stratified by organizational type. Discussion and work assignments will be continued on the next conference call of the Committee.

The **Education Committee** reviewed the suggestions for the Keynote speaker for the October 2015 meeting of the Commission, and discussed the educational needs and content development for the meeting. Dr. Danny Takanishi, Chair of the Speaker Recruitment Subcommittee, reviewed a long list of potential Clinical Congress topics and received thoughtful feedback and comments from the members of the committee.

The **Plenary Session** included several excellent speakers on a variety of informative and inspirational topics. First, Jonathan Irish, MD, Provincial Head of the Surgical Oncology Program at Cancer Care Ontario talked about a quality improvement program which he implemented with remarkable results. The program essentially measured indicators of quality of care (e.g., wait times for clinic appointments) and then provided those measures to the physicians responsible for making changes. Feedback to individual physicians on their own performance inspired change in the desired direction without any other agency directed action invoked. Next, Larry Shulman, MD, Director of the Center for Global Cancer Medicine at the Dana-Farber Cancer Institute, described his successful efforts to bring a cancer clinic to a remote area of Rwanda. Drs. James Connolly and Terry Sarantou presented the National Accreditation Program for Breast Centers first International Accreditation Survey and Helena Gutierrez-Richards, LCSW, explained the work of pediatric oncology social workers at the Nemours Children's Clinic of Jacksonville, FL. Finally, Dr. Janice Zunich, Director of the Genetics Center at Indiana University School of Medicine-Northwest gave an update on the activities of the American College of Medical Genetics and Genomics.

The plenary session was followed by a luncheon and a meeting of the State Chairs and the ACoS staff before the meeting was adjourned.

NAACCR Social Media WG at the Annual Conference

Dan Curran, MS, CTR

NAACCR Social Media Work Group

Leading up to the NAACCR 2015 Annual Conference in Charlotte the NAACCR Social Media Work Group (WG) was busy planning our two main activities: the Twitter Contest and the Twitter How-To Session. The Twitter Contest began one week before the Conference to encourage attendees to begin tweeting their plans for the educational and leisure activities. The winner, Jennifer Kachajian, sent out her first tweet ever to enter the contest. It was a video time machine looking back at past conferences and looking forward to Charlotte:



View Jennifer's video at <http://bit.ly/1LPdS8R> and look for the other contestants on Twitter using the #NAACCRContest hashtag. This year the contestants submitted more frequently and employed more images and videos - even a pet got involved! Thanks to all the participants for your imaginative entries.

During the Conference, the WG sent out a steady stream of tweets as well as LinkedIn and Facebook posts according to the social media plan developed by Benjamin Manthei, the NAACCR intern. Refer to the Twitter Digest article in this issue of the Narrative to view several of the tweets. One notable tweet announced the names of the winners of the Constance L. Percy Award for Distinguished Service, Susan Bolick, MSPH, CTR, and Robin Otto, CTR. Special thanks to for the enthusiastic contributions by David O'Brien and others that participated in this year's contest. Thank you for getting those tweets out there!

Lastly, the WG hosted an educational event at the Conference, our annual Twitter How-To Session. It was an informal gathering of WG volunteers to help NAACCR members log in to Twitter and send out their first tweets. About eight conference attendees were assisted by our WG volunteers Kim Herget, Mindy Young, Annette Hurlbut, and NAACCR's Information Technology Administrator, Dustin Dennison. I offer a big thank you to our Twitter mentors and the participants.

Twitter Digest

Dan Curran, MS, CTR

NAACCR Social Media Work Group

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



@theNCI

The NCI-MATCH trial will link targeted cancer drugs to gene abnormalities
1.usa.gov/1NLg4NO #NCIMatch

@NCIEpi

Struggling to prepare an NIH grant application? View our compilation of grantsmanship resources at 1.usa.gov/1fhDT4m

@CDC_Cancer

Check out our redesigned Web site & let us know what you think! go.usa.gov/3waNe

@NCIEpi

Are estrogen metabolites associated with #ColorectalCancer risk in postmenopausal women? bit.ly/1Jq5vxV #crcsm

@theNCI

Does aspirin reduce cancer risk? There are no easy answers, but here's what the evidence shows
1.usa.gov/1li8MRi

@NAACCR

Constance L. Percy Award for Distinguished Service winners announced at #NAACCR2015: Susan Bolick, MSPH, CTR, and Robin Otto, CTR

@AJCCancer

When the cure causes cancer later on <http://kng5.tv/1J1Dlkr> via @KING5Seattle

@NAACCR

#NAACCR2015 Birds of a Feather starts @ 7am tmrw morning. Located in the Grand Ballroom A lvl 2. Treats for early morning creativity!

@NAACCR

Twitter veterans, come help your colleagues learn how to tweet at #NAACCR2015 during the morning break on Tuesday. ow.ly/OeJKX

@jkachajian

@NAACCR #NAACCRcontest Homage to NAACCR Conferences' "The Afternoon" and evenings 2009 to Charlotte #NAACCR2015!

@CPICaI

CPIC is proud to once again receive the @NAACCR's GOLD certification for excellence in operating Cancer Registry.

@NEDHHS

DHHS' Nebraska Cancer Registry recently received a Gold Standard rating from the @NAACCR. Congrats!

@NAACCR

The 25th edition of Cancer in North America (CINA): 2008-2012 is now available on the NAACCR web site ow.ly/O1Jib

@NAACCR

#CelebrateLife, raise awareness for cancer survivors on National Cancer Survivors Day, June 7 #NCS2015 @SurvivorsDay www.ncsd.org

@NAACCR

NAACCR has earned the CEO Cancer Gold Standard for its strong commitment to employee health ow.ly/NScEb

@NAACCR

May in Review - #NAACCRReview buff.ly/1FPhZxD #breastcancer

@NAACCR

Why are so many men in California dying of hyperplasia of the prostate? Frank Boscoe weighs in buff.ly/1LgJlJq #NAACCRReview

@NAACCR

NAACCR data in the news: Why are Oregon melanoma rates so high among women? ow.ly/MYnN1

@NAACCR

Differing perspectives on what some call the "war on cancer" #NAACCRReview #breastcancer buff.ly/1KJOjD9

@NCIEpi

The April edition of Cancer #Epidemiology Matters E-news is now available! conta.cc/1zgMOvn

@AJCCancer

Did you get your copy of The Brief, a weekly e-newsletter for oncology news + updates from the AJCC? Subscribe at bit.ly/subbrief

@theNCI

T7 Get the basics on cancer clinical trials, including who can participate and ensuring patient safety 1.usa.gov/1HrowzW #abcdrbchat

NAACCRReview

Rebecca Cassady, RHIA, CTR

NAACCR Communications Steering Committee

NAACCRReview was implemented in March 2015 by the Communication Steering Committee as another forum or blog site for NAACCR members to comment on articles in the cancer field as well as on studies relevant to cancer surveillance. Members are invited to share or follow the NAACCRReview on social media using the hashtag #NAACCRReview.

Cancer-related news reviews have included:

1. "Medicare to Cover Annual Lung Cancer Screening for Some Beneficiaries" – Article review by Dee W. West, PhD of the Cancer Registry of Greater California
2. "Breast Cancer Screening Draft Recommendations" – Article reviewed by Kathy Cronin, Ph.D, Deputy Associate Director, Surveillance Research Program
3. "As I Lay Dying" – Article reviewed by John W. Morgan, PhD, CPH, Professor of Epidemiology, Loma Linda University School of Public Health Epidemiologist, Regions 4, 5, 7 & 10 of the Cancer Registry of Greater California (NAACCR Committee Member)

Study Reviews have included:

1. "Misclassification of Sex in Central Cancer Registries" – Overview of study published in NCRA's Journal of Registry Management by Francis P. Boscoe, PhD of the New York State Cancer Registry
2. "Annual Report to the Nation on the Status of Cancer" – Overview of study published in the JNCI's Oxford Journals by Recinda Sherman, PhD of NAACCR

We invite NAACCR members to submit articles that can be used for the NAACCRReview as we want this published website to reflect current information and analysis by our NAACCR community.

Please contact Rebecca Cassady at rcassady@llu.edu to submit content for NAACCRReview.

Please contact Dustin Dennison, NAACCR IT Administrator, at (217) 698-0800, or ddennison@naaccr.org if you have any questions about blogging.

Alaska Cancer Program Making a Difference in the Community of Yakutat

David O'Brien, PhD, GISP

Alaska Cancer Program

In June 2014, Joe Sarcone of the Agency for Toxic Substances and Disease Registry (ATSDR), U.S. Department of Health and Human Services, contacted the Alaska Cancer Program about a cancer concern voiced by the community of Yakutat. In response to this request, the Alaska Cancer Program launched a study of cancer incidence and mortality of this area.

The community has expressed concerns about apparent elevated rates of illnesses, including cancer, and that such illnesses may be caused by wastes left behind from former military installations on the nearby Ankau Saltchucks of the Phipps Peninsula. That area has been traditionally used as a source of subsistence food for the Yakutat community. Yakutat also operated a seasonal Culture Camp there through 2003 to teach children about traditional Tlingit way of life and subsistence foods.

The cancer study resulted in three reports. The first two involved calculating the number of expected cancer cases for incidence and mortality from 1996-2011 and compared them to the number of observed cases reported by healthcare providers over the same time period. The difference between the number of expected and observed cases was small and not statistically significant. The third report reviewed the number of cancer incidence and mortality cases per year as well as the types of cancers. The distribution of cases by year appears to be random and there does not appear to be a high number of uncommon cancers, so the number and types of cancer cases in Yakutat does not appear to be unusual.

Several Alaska Cancer Program staff (Kelly Tschida, Julia Thorsness, Judy Brockhouse, and David O'Brien) presented the results of the study to the community of Yakutat at a community meeting on Wednesday August 27, 2014, via teleconference. Mr. Sarcone was present in Yakutat and moderated the meeting. The presentation was followed by a question-and-answer period. The community had a very positive reception to the study results. A positive outcome of the study was that the tribal leaders of the Yakutat Tlingit Tribe decided to shift their attention from trying to find causes of cancer in their community to screening and early detection of cancer in their community.

The Southeast Alaska Regional Health Consortium (SEARHC) was contacted to check on the availability of screening technology for Yakutat. SEARHC arranged for and funded the transportation of a mobile mammography unit from the Breast Cancer Detection Center in Fairbanks via vehicle and ferry for use in Yakutat. There were 41 women who received mammograms in May 2015. It is planned to continue to send the unit to Yakutat on an annual basis.

Three Presentations on Multi-Race Reporting at the Charlotte Conference

The 2015 NAACCR Annual Conference featured three presentations on the important issues of multi-race reporting and race bridging for cancer incidence and mortality data. These presentations offered valuable information on recent developments in multi-race reporting. It is important that the NAACCR community be aware of the evolving plans for reporting data by race in the United States.

Dave Stinchcomb, MA, MS
Westat

Mandi Yu, PhD, MS
National Cancer Institute

The NAACCR Annual Conference in Charlotte featured three presentations on the important issues of multi-race reporting and race bridging for cancer incidence and mortality data. The National Center for Health Statistics (NCHS) has been working with states to allow multi-race reporting on death certificates since 2003 and expects all states to have converted by 2016. At this time, NCHS will explore reporting death data without the traditional bridged single race groups. The three presentations at the Charlotte conference described the NCHS plans for future death data reporting, evaluated the feasibility of multi-race reporting for cancer incidence data, and discussed challenges in methods of bridging multiple-race population data.

A brief history: U.S. cancer incidence and mortality data are typically reported by four race groups: White, Black, Asian and Pacific Islander (API), and American Indian and Alaska Native (AIAN). These race groups were the standard race categories established by the U.S. Office of Management and Budget (OMB) in 1977 and for many years cancer incidence data, mortality data, and population denominator data have used these race categories. In 1997, the OMB modified the standard to specify five race groups (the API group was split into Asian and Native Hawaiian or Other Pacific Islander) and, more importantly, to allow the reporting of more than one race. The 2000 Census implemented this new standard and began collecting multi-race population data. In response, NCHS developed a provisional race bridging methodology in order to map the multi-race population denominator data back to the original single race categories. Cancer registries have been using these bridged race population denominators for cancer reporting since then. This race bridging technique was intended as a temporary measure until the new OMB standards could be implemented for federal reporting of health statistics.

Elizabeth Arias from NCHS gave the first presentation, entitled "Plans for Multi-Race Reporting of Death Data." This talk described the history of OMB race standards, discussed how the race categories are defined, and presented the 2003 standard death certificate question on race, which allows multi-race reporting (as modeled after the Census race question). This new 2003 death certificate question has been adopted gradually by the states, with 43 states using it by 2013. Arias described the bridging approach used by NCHS and the Census Bureau to modify the census population data with single-race categories; in this bridging approach, people who specify more than one race are assigned a likely "primary" race based on National Health Interview Survey data.

Arias examined the frequency of multiple-race reporting in mortality data for 2013: overall, 0.4% of death certificates specified two or more races. Multiple race reporting was more common for younger ages, with 3.4% of decedents aged 0-14 years having multiple races on the death certificate. Using the reported death rate data for 2013, Arias compared the death rates of the traditional bridged race groups to un-bridged rates where deaths with more than one specified race were reported in a separate category. Arias observed that reporting multiple races separately did not impact the death rates for the individual race groups significantly. The rate for the multiple race group was lower than the others, indicating possible under-reporting for this category. The presentation concluded with a summary of NCHS's plans to explore publication of mortality statistics by multiple races beginning in 2016. Challenges that need to be addressed include the small number of multiple-race deaths and the known misclassification of the AIAN population.

Dave Stinchcomb from Westat gave a talk entitled “Feasibility of Multi-Race Reporting for Cancer Incidence.” The presentation examined the rates of multi-race reporting in SEER incidence data using Census multi-race reporting as a basis of comparison. Overall multi-race reporting in Census 2010 was 2.9% for the U.S as a whole and 3.9% for SEER areas. In SEER incidence data for 2009-2011, the rate was significantly lower: only 0.35% of cases reported multiple races. For the individual states covered by SEER registries, the highest multi-race reporting in Census data occurred in Hawaii, with 23.6 % of residents selecting multiple races. In SEER data, Hawaii also had the highest multi-race reporting rate with 10.8% of cases indicating multiple races. Stinchcomb also observed that more multi-race reporting occurs in younger age groups in the Census data than is evident in the SEER data. This might explain some of the difference in the Hawaii rates because there is less multi-race reporting in the older ages when cancer is more likely to occur. Looking at the trends by year, multi-race reporting increased from 2000 to 2004 and has remained stable since then. In terms of the vital status value in the cancer incidence record, there is more multi-race reporting for cases where the vital status is dead, perhaps reflecting the availability of multiple races on death certificates. The presentation discussed the availability of multiple race information in registry source documents. Stinchcomb also described how cancer rate and trend reporting might be modified for multi-race reporting categories; the key challenge will be in trend reporting. The presentation emphasized that rates of multi-race cases in cancer incidence data are quite a bit lower than the rates in the Census population data. Stinchcomb suggested that additional work may be needed to explore ways to collect multiple races in standard medical record systems and also suggested several alternatives to race reporting as a way to track cancer health disparities.

Mandi Yu from the NCI gave a presentation entitled “Challenges in Bridging Population Race Data for Cancer Surveillance.” This talk described the evolution of race categories and the need for race bridging to ensure comparability between numerators and denominators. Yu pointed out that NAACCR and SEER have developed recoding rules for numerator data, and NCHS and Census have developed methods for the denominator data. The presentation described both the bridging method that the NCHS developed to derive the aggregated county-level population data and the modified regression method that the IPUMS program developed for use with individual data but limited to state-level geographic identifiers. The talk also outlined a method developed for smaller geographic areas such as Census tracts using an Iterative proportional Fitting (IPF) algorithm. Using an example, Yu showed how IPF first assigns the counts of people reporting multiple races using proportions based on the single race counts and then iteratively reassigns counts to ensure that the sum matches tract and county totals. The resulting tract-level population denominator data were evaluated by computing breast cancer incidence data by race using as denominators (1) the proposed tract level IPF results, (2) a similar set of IPF results at the county level, and (3) the NCHS county-level estimates. The results were broken down by area-based SES quintile and showed comparable values for each of the alternative denominator data sources. Yu thus demonstrated the advantage of using finer geographic data in detecting health disparities. The presentation concluded that the IPF methodology is promising but will face prediction challenges as we get further from the most recent decennial census. Yu also noted that we may face additional race bridging challenges with Census 2020 because the Census Bureau is experimenting with alternative race and ethnicity question formats.

These presentations offered valuable information on recent developments in multi-race reporting. It is important that the NAACCR community be aware of the evolving plans for reporting data by race in the U.S. We will need to work to be sure we can continue to report accurate and meaningful cancer statistics broken down by categories that can be used to identify and track cancer health disparities. Additional work is needed to ensure accurate collection of cancer data for multi-race individuals, to explore methods of reporting rates and trends using new multi-race categories, and to develop robust race bridging methods to allow comparison of new data with historical data.

Survivorship Care Plans – The Cancer Registry’s Role

The future will almost certainly involve using cancer registry data to pre-populate Treatment Summary and Survivorship Care Plans (TS/SCPs). Cancer registries have a wealth of information and

can provide at least half of the information recommended for TS/SCPs. Pre-populating TS/SCPs is one way to use registry data beyond traditional surveillance and research activities and it provides a service to cancer survivors and their oncology providers who are tasked with developing TS/SCPs.

Randi Rycroft, MSPH, CTR

Colorado Central Cancer Registry

A Treatment Summary and Survivorship Care Plan (TS/SCP) is a document that is meant to help patients bridge the transition between oncology and primary care at the conclusion of treatment. The TS/SCP is also meant to help patients understand their diagnosis and future care needs and to locate the resources they need to navigate the survivorship phase of their disease. The TS/SCP has two distinct components: (1) the treatment summary provides a concise summary of the cancer diagnosis, treatment, and related health factors; and (2) the survivorship care plan is a guide for patients and their primary care providers to follow that summarizes future care need (e.g. follow-up, provider contact information, health and lifestyle recommendations, etc.).

The idea of providing TS/SCPs to patients is not a new one. As far back as 1996, the National Coalition for Cancer Survivorship advocated for providing these documents to cancer survivors. In 2004, the CDC and LIVESTRONG Foundation collaborated to create a comprehensive action plan addressing cancer survivorship. *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* (available [here](#)) proposes strategies for addressing the needs of cancer survivors, one of which is to provide TS/SCPs for survivors. In its seminal report *From Cancer Patient to Cancer Survivor: Lost in Transition* (available [here](#)), the Institute of Medicine makes its recommendation for TS/SCPs and provides detailed recommendations for the content of the documents.

Despite the calls to action from these nationally recognized organizations, implementation of TS/SCPs has been slow for a number of reasons. A comprehensive TS/SCP is time-consuming to create and to date providers do not have an easy way to bill insurance for reimbursement. Evidence on the effectiveness of TS/SCPs to improve survivorship outcomes is virtually non-existent. Yet, most still agree that TS/SCPs make sense and should be one component of survivorship care. In the United States this is a daunting task. The American Cancer Society estimates that by 2020, the United States will have 18 million cancer survivors.

In an effort to encourage implementation, the American College of Surgeons Commission on Cancer introduced a new program standard for its accredited cancer programs in 2012. Standard 3.3 requires accredited programs to provide TS/SCPs to all their eligible patients by the end of 2019. A similar standard from the National Accreditation Program for Breast Centers requires TS/SCPs for all eligible breast cancer patients by the end of 2016.

What can cancer registries do to contribute to this effort? Plenty! The cancer registry data we routinely and expertly collect can pre-populate 50-60% of the recommended content of a TS/SCP – virtually the entire treatment summary portion. Not only would this save time for providers, but also having the cancer registry involved in the process could lead to improved registry data quality. The cancer registry could capture data supplied by clinicians (e.g. additional treatment or “corrections” to the data supplied by the registry). Furthermore, it’s possible that registrars may be even more diligent in data collection efforts if they knew the information was going directly to patients.

Either hospital or central registry data can be used, but each option presents its own set of benefits and challenges. Some of these are outlined as follows:

Hospital Program

Advantages:

- Data are available sooner.
- Registry data and EHR data are available.

Potential Disadvantages:

- Patients could receive more than one plan.
- Plans could be incomplete if treatment was received at another facility.
- Hospitals may be inclined simply to “tick the box” to meet requirements.

Central Program

Advantages:

- Patients receive only one plan.
- Consolidated data are used from multiple facilities.
- Survivors receive a standardized product.

- It provides a service to hospitals, oncology providers, and patients.

Potential Disadvantages:

- Data timeliness and quality issues?
- Legal issues?

CoC-accredited hospitals are now required to provide TS/SCPs to patients, but when patients are treated at more than one facility, the patient could potentially receive multiple documents which could be confusing for the patient. While the data from a hospital registry would certainly be available sooner than a central registry, TS/SCPs could be incomplete if a hospital is unaware of treatment provided by another facility. Because the task is daunting and essentially unreimbursed, hospitals may be inclined to produce documents meant only to meet the minimum requirement. Such an approach would be of limited value to patients and as such, a waste of already limited time for providers.

Now, let's consider a survivorship program that uses central registry data. A central registry consolidates information from multiple sources which reduces the chance of incomplete treatment summary data. A centralized approach would assure that patients received only one plan and if desired within a given state, would provide a standardized TS/SCP for survivors. Common concerns about using central registry data include timeliness and quality of the data as well as legal concerns. Legal concerns would, of course, have to be addressed by each state. However, timeliness and quality may not be as big a concern as one might think. The Colorado Central Cancer Registry conducted a small pilot survivorship project in which we found that the data were available when requested, and the participating nurse navigators rarely changed any information we had provided.

Where are we now and what's ahead? CDC is working on the WebPlus Survivorship Module (click [here](#) for additional information). Once the survivorship module is incorporated into WebPlus, states that are using the WebPlus software will have access and can begin using the tools and/or making them available to hospitals. CoC and NAPBC facilities are ramping up to meet their respective program standards with varying levels of preparedness. Other survivorship software tools are moving forward to incorporate EHR and/or registry data; registry software vendors are responding in kind. The momentum around delivering TS/SCPs to survivors is building nationwide.

The future will almost certainly involve using cancer registry data to pre-populate TS/SCPs. It just makes sense – cancer registries have a wealth of information and we are cancer data experts. We can provide at least half of the information recommended for TS/SCPs. We can save time for oncology providers. Pre-populating TS/SCPs is one way to use our data beyond traditional surveillance and research activities and it provides a service to cancer survivors and their oncology providers who are tasked with developing TS/SCPs.

Data in Action at its Best!

Registries now have the opportunity to gather and provide essential information to further the research on new drug therapies. They can also part in providing the basis of information used in the summary of care plans as well as the survivorship care plans that catapult the survivor back into the world with a roadmap towards participating in healthy behaviors for an improved quality of life and the prevention of secondary cancers post treatment.

Laura P. Ruppert, MHA
Indiana State Cancer Registry

Wow, the 2015 NAACCR Annual Conference was wonderful this year! For all of us who work in the cancer registry world, the opportunity to come together and share ideas, thoughts, and best practices is essential in this changing environment.

A few days after I returned home and had time to reflect on the Conference as a whole, I was particularly struck with how the presentations this year seemed to offer attendees the opportunity, more than ever before, to consider the cancer patient from diagnosis through the end of treatment and beyond. It was refreshing to have many opportunities to see the fruits of our data at work and the possibilities of its use in cancer care as opposed to just viewing it as a statistical report.

The importance of research and the registries' role in providing a population-based sample set was highlighted throughout the conference. We had wonderful opportunities to hear about the cancer patient's genomic profile and how that plays into the ability to personalize their cancer treatment by identifying the best treatment options, thus allowing the right treatment at the right time for the patient. I thought it was interesting to listen

to the Flatiron presentation on unleashing “Big Data” in oncology and the potential for the registries to play a part in the survivorship care plans.

As I am sure we would all agree that the days are gone when we were only the repository for our state’s cancer data, reporting only incidence and mortality. We now have the opportunity to be registries that gather and provide essential information to further the research on new drug therapies as well as registries that play a part in providing the basis of information used in the summary of care plans as well as the survivorship care plans that catapult the survivor back into the world with a roadmap towards participating in healthy behaviors for an improved quality of life and the prevention of secondary cancers post treatment. In other words, we are now active players in the world of cancer care!

Now this is our “Data in Action” at its best!

Spring 2015 Narrative Poll Results: Social Media

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You may remember that in the Spring 2015 issue of NAACCR’s *Narrative* we polled the membership as to which NAACCR social media accounts are followed. It may come as a surprise to learn that the NAACCR Facebook page was the most popular, followed by Twitter, then a distant third in LinkedIn.

The purpose of this ePoll was twofold, first to see where our members were following NAACCR so that we could more effectively communicate, and secondly to inform those members not already aware of the social media platforms NAACCR is currently using.

A number of respondents reported not following any NAACCR social media accounts. While we understand that in many office environments accessing these sites is not possible, I would like to spend a moment to share what type of information we post on these sites. We hope you will take time to check them out in your free time.

The Communications Steering Committee’s Social Media Work Group works very hard to ensure that we provide our audience with a wide range of topics in the cancer surveillance field. These topics range from research and operations, to widespread coverage of the field in national and international media. NAACCR’s social media platforms are also an easy way to view the latest articles on NAACCR’s blog, NAACCRReview.

We would like to invite you to follow us on social media and give us feedback on anything you would like to see more of in the future!

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

1. Which of the following NAACCR social media accounts do you follow? Please check as many as apply.

- Facebook: **15** (51.7%)
- Twitter: **9** (31.0%)
- LinkedIn: **5** (17.2%)
- Google +: **2** (6.9%)
- Flickr: **1** (3.5%)
- Other: **0** (0.0%)
- None: **9** (31.0%)

2. If you are connected with NAACCR on LinkedIn, which profiles are you following?

- Company Page: **4** (19.1%)
- Membership Group: **1** (4.8%)
- Annual Conference Page: **1** (4.8%)
- N/A: **17** (81.0%)

Be sure to participate in this issue’s poll, which asks what you’d like to see covered in NAACCR’s blog, NAACCRReview!

<http://www.naaccr.org>



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

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