Message From the Executive Director

Betsy A. Kohler, MPH, CTR
NAACCR Executive Director
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We had a "stellar" Annual Conference in Albuquerque this year! Many thanks to Chuck and the planning committee for a successful conference. We had over 400 delegates at the Conference this year. Nearly 100 experts attended the Registry of the Future pre-conference workshop and voiced their opinions on how to chart the future of cancer surveillance. A summary report of this meeting and a plan of action will be distributed shortly. Additionally, our other workshops were well attended as well. The survival course taught by our international team provided hands-on opportunities to 22 students. The post-conference workshop hosted by METRIC was attended by 32 specialists and our Introduction to Cancer Surveillance attracted 21 junior scientists. In total we had 9 workshops educating 243 professionals in the field. This year we were able to host three breakout sessions specifically for student presentations, and another dozen students presented posters at the meeting.

This year we introduced a special feature, the Young Talks, in honor of John L Young Jr, a pioneer in cancer surveillance in the U.S. Four special talks were presented during breaks featuring topics of great interest to all. Kevin Ward (GA) presented the inaugural talk on Essential TNM. Other topics included "Characterization of Sexual Gender Minority Cancer Cases" by Frank Boscoe (NY) and Scarlett Gomez (CA); "WHO Classification of Central Nervous System Tumors- An Opportunity for Cooperation and Collaboration across Disciplines" by Carol Kruchko, of the Central Brain Tumor Registry of the U.S.; and "An Online Interactive Tool to Improve the Understanding of Cancer Survival Statistics" by Paul Lambert.

It is a special year for the NPCR Program which is marking its 25th Anniversary. NAACCR presented NPCR with a plaque "in appreciation for their leadership in fostering nationwide cancer surveillance in the United States and supporting central cancer registries in the collection of accurate and timely cancer incidence data to effectively address the local cancer burden."

NAACCR's Calum Muir Award was given to Dr. Heather Bryant of Canada for her enduring vision, expertise and leadership in cancer surveillance and control. Dr. Bryant was one of the inaugural members of the senior management team, of the Canadian Partnership Against Cancer working to implement and steward the Canadian Cancer Control Strategy. She has provided exceptional leadership to the cancer control community through the effective engagement of health leaders in many networks and collaborations. Her leadership and contributions have also been recognized, by the international community as a three-term member of the UICC Board of Directors and as one of Canada's Top 100 Most Powerful Women of 2015, all testaments of her exemplary leadership and expertise.

Mary Potts of Seattle was awarded the Constance Percy Award for her significant contributions to improvements in registry operations, data quality and the development of educational tools that have benefited the cancer surveillance community. Under Mary's guidance Seattle has been able to deploy SEER*Educate and develop coding exercises designed to teach registrars how to use and apply the coding guidelines published by the standard setters. SEER*Educate has also become a valuable tool for identifying omissions and ambiguities in the standard setters' coding guidelines, resulting in questions being sent to the appropriate standard setters for clarification for the registry community.

Congratulations also to our NAACCR Member Awardees! These awards are given to members who have provided sustained and notable service to NAACCR. Please check the Awards section of the website to learn how to track your points to earn these awards. Thanks to all of you for your support of NAACCR!

Highlights From the Program Manager of Standards

Lori A. Havener, CTR
Program Manager of Standards, NAACCR

Standards Volume II, Version 18:
The release of NAACCR Standards Volume II, Version 18 is delayed. There are many new data items that will be added for the implementation of AJCC Cancer Staging Manual, 8th Edition. As soon as all new/revised data item requests for 2018 have been reviewed by the UDS WG a list of all new/revised data items will be released with the 2018 Implementations and Timelines document. The timeline below reflects what we hope to achieve for the release of Standards Volume II, Version 18.

Standards Volume II, Version 18 Updated Timeline

All new data items requests submitted to UDS	August 1, 2017
UDS final review of Standards Volume II, Version 18	October 24, 2017
Draft submitted to NAACCR Board for review/approval	November 1, 2017
Post to NAACCR website	December 1, 2017
Version 18 Implementation	January 1, 2018

2018 Implementations and Timelines:

NAACCR and the standard setting agencies developed the 2018 Implementations and Timelines document that includes the timelines for the 2018 implementation of:

- AJCC 8th Edition Chapters Updates to Histologies
- ICD-O-3 Histology Revisions
- Standards Volume II, Version 18
- New and revised histology terms and/or codes
- CoC 2018 STORE Manual
- SEER Summary Stage 2018
- SEER EOD 2018
- MP/H Rules (solid tumor manual)
- EDITS
- 2018 Implementation Guidelines

All agencies are diligently working to meet the deadlines in the timeline. Updates to the *2018 Implementations and Timelines* will be submitted via the NAACCR ListServ. A list of all new and/or revised data items for Standards Volume II, Version 18 will be released soon with the 2018 Implementations and Timelines document.

Standards Volume II, Version 19:

There is so much activity for 2018 right now it seems crazy to even think about what is coming for 2019! The basic timeline below is a simplified version for Standards Volume II, Version 19 to let folks know when new and/or revised data item requests should be submitted to the Change Management Board.

Standards Volume II, Version 19 Timeline

All new/revised data item requests submitted to the Change Management Board	November 1, 2017
Standards Volume II draft submitted to NAACCR Board for review/approval	June 1, 2018
Post to NAACCR website	July 1, 2018
Version 19 Implementation	January 1, 2019

Research and Data Use Update

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

Well, another high energy (and hot!) NAACCR Annual Conference has come and gone. I hope many of you were able to enjoy beautiful Albuquerque and the surroundings. As usual, it was an invigorating whirlwind of meetings, meet-ups, introductions and re-connections for me. And this time I was not "all work and no play." I braved the heat and was able to see a Shakespeare production in the square and visited the Grand Canyon for the first time—both incredible (although not equally so) experiences.

With the conference behind us, we have moved on to a variety of other things including releasing the 1995-2014 CiNA datasets to researchers. We continue to have great response to our CiNA Public Use File and, despite being available less than a year, we now have multiple publications using it as source data. We are also in the midst of scheduling a number of NAACCR Talks in the Cancer Surveillance Series. Look for the listserv announcements or you can check them out as we schedule them here (they are free sessions): NAACCR Talks Registration

NAACCR Geocoder

On July 20th, one of our NAACCR Talks was on the recent updates to the NAACCR Geocoder. As you know, we have spent the past six months improving the geocoder and will continue to modify as needed. The recording of the Webinar will be accessible soon, but here are the take home points:

- Estimated accuracy of updated NAACCR geocoder match >99% (based on results from NY & NJ).
- Increased accuracy results in an increase in unmatched cases (guesstimated 2-5%).
- Match Score – you can now select your minimum match score.
- Micro Match Status – for tract-level analysis, the geocoder now returns a variable indicating the case was "Match"—high quality geocode; "Unmatched"—will require manual review; and "Needs Review"—pretty good match but requires manual review of the matched data before accepting the match for use below the county-level.
- Exhaustive Search—this is a new feature to be used for "Needs Review" cases. The "Needs Review" cases must to be re-run (or in the case of SEER*DMS viewed) in a batch mode using Exhaustive Search criteria. This will output all potentially matched addresses and their associated metadata. A user will manually review and select the correct address match or make a "No Match." The capacity to review these multiple matches is currently built into SEER*DMS. Around September 1, NAACCR will release an interface to handle these cases for on-line users.
- Due to issues with the quality of a data source release, cases geocoded using the NAACCR Geocoder 2012 forward are lower quality and need to be re-geocoded. However, states that are impacted by issues with address renumbering under the E911 initiative need to be conservative when re-geocoded historic cases. Impacted states are in NE and South—West and Midwest states are largely unaffected. Within impacted states, rural counties are affected.
- If you know your state was unaffected by E911 renumbering (West or Midwest states) or have not yet standardized address numbers (Arkansas), please re-geocode from 1995 forward. This will increase your geocoding accuracy due to better underlying data and improved geocoder algorithm.
- If you do not know when your state standardized address numbers and your state has re-numbered, please re-geocode all cases diagnosed or geocoded from 2012 forward. This will greatly improve your geocoded data and reduce the potential to introduce error based on address changes for historical data.
- While there is no central location with information on the dates E911 re-numbering occurred by county/state, you may be able to find state-specific information through your state GIS or Planners offices.
- We have updated the NAACCR Geocoder Data Dictionary and Tutorial. All geocoding resources are available here: https://www.naaccr.org/gis-resources/.

Zip code level Geocoding

After the Geocoding Webinar, we received feedback that users could no longer easily geocode zip code level matches. This is because we set our minimum match score to 88, and a zip code level match score ranges from 51-60. We have updated the minimum match score to allow zip code level matches. Users can use the match score ranges to understand the scale of their match.

Updates and Guidance

I will continue to present Geocoder information here, in the NAACCR Narrative, but I will move to the NAACCR Forum to present technical details and facilitate discussion among members. There is currently a forum dedicated to the NAACCR Geocoder. Access to the Forum requires a MyNAACCR account. You can access the Forum from our homepage under useful links. The content is currently old, but I will be providing periodic updates as we move forward and you can ask questions.

Please do not hesitate to contact me if you have any questions.

NAACCR 2017 Education and Training Calendar

August 2017

08/03/2017	Collecting Cancer Data: Central Nervous System
08/22/2017	CTR Exam Preparation and Review Webinar Series Session 1
08/29/2017	CTR Exam Preparation and Review Webinar Series Session 2

September 2017

09/05/2017	CTR Exam Preparation and Review Webinar Series Session 3
09/07/2017	Coding Pitfalls
09/12/2017	CTR Exam Preparation and Review Webinar Series Session 4
09/19/2017	CTR Exam Preparation and Review Webinar Series Session 5
09/26/2017	CTR Exam Preparation and Review Webinar Series Session 6

October 2017

10/03/2017	CTR Exam Preparation and Review Webinar Series Session 7
10/10/2017	CTR Exam Preparation and Review Webinar Series Session 8

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

Virtual Pooled Registry Update

Castine Clerkin, MS, CTR
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It has come to our attention that there may be some confusion about how the piloting of NCI's U.S. Radiologic Technologists Study (USRT) is contributing to the development of the larger Virtual Pooled Registry (VPR) initiative. It is our hope that the information below will provide clarification.

The VPR group initially identified two cohort studies to pilot test several of the processes critical for a scaled VPR process. These processes included: ability to link behind the registry firewall, development of a standard input data file, and ability to provide numeric match data back to the investigators. Thus, when the USRT linkage was first initiated as a pilot test of the VPR, the goal was to have registries perform a standardized, automated linkage and provide a report of match counts to the researchers. This initial phase was so successful (linking with 45 registries!) that the USRT Principle Investigator volunteered to help us evaluate several additional key features for the next phase of the VPR. These include understanding and testing the Registry/IRB data request process and release of information on matched cases following Registry/IRB approval.

For this second phase of the USRT pilot test, registries will receive official applications requesting release of individual-level data on the high quality matched cases that were identified by the BigMatch linkage software during the first phase of the pilot. Registries will not be required to relink their data, nor will they be expected to manually review the potential matches. For this pilot project, the researchers are interested in the high quality matches only.

While this second phase of pilot testing does not incorporate all future aspects of the VPR (templated forms, Central IRB, etc.), it will provide essential information to justify funding to support the VPR as a comprehensive system. The specific information that USRT is gathering includes the following:

- Real and concrete estimates of cost efficiencies and savings that can be accrued by the Federal Government (especially the NCI) through the development and support of the VPR
- Comparisons to the USRT usual methods of data collection (i.e. self-report and medical record validation) in terms of the following benefits:
  - Case ascertainment improvements (i.e. early data indicate nearly doubling the number of cancer cases reported)
  - Increased detail of information gathered and data item completeness
  - Cost savings specific to this project and type of research activity
- Collection of information that will inform additional VPR efficiencies to facilitate the registry/IRB application processes, including:
  - Which registries might accept a central IRB
  - How to best complete a research request when the registry linkage is just a portion of a larger study
  - Unique registry/IRB needs and processes
- Refinement of resources (monetary, technical, instructional, etc.) necessary for the registries and NAACCR to support full implementation of the VPR system.

This information will be compiled into a report and presented to NCI senior leadership to request long-term support for the VPR. This support will include direct funding to the registries for future VPR linkages, which we anticipate to occur either through NCI SEER or CDC's NPCR program.

While we recognize that participation in the second phase of the USRT pilot testing may pose an additional burden, we wanted you to understand the objectives of this second phase and why your contribution is so essential. The results of this second phase will provide NCI with real and concrete benefits of VPR linkages and help secure ongoing funds for registries to participate in future VPR activities.

As the pilot linkage is being completed, we continue to develop all the systems necessary for full VPR implementation in 2018, including new linkage software that will be available to you shortly, an NCI-sponsored Central IRB, templated forms for IRB and Data Use, and an online system for researcher application, review, and exchange of files with registries. Detailed webinars on these initiatives will be provided in the coming months, so stay tuned!

We realize that registry support is absolutely vital for the success of this project, and deeply appreciate your willingness and patience in working with us to date. With your help we are working towards obtaining the resources necessary for future VPR participation. In the meantime, THANK YOU for your contribution, dedication, patience, and good will as we fine-tune the VPR!

2017 Percy and Muir Awards

- The Constance L. Percy Award for Distinguished Service -

Established to recognize an individual who contributed exceptional volunteer service to NAACCR during the past 12 months, or sustained, current, and long term contributions to the organization.

Mary Potts, RHIA, CPA, CTR

"For her significant contributions to improvements in registry operations, data quality and the development of educational tools that have benefited the cancer surveillance community."

- The Calum S. Muir Memorial Award -

Honor someone who has made substantive and outstanding contributions in cancer registration.

Heather Bryant, MD, PhD, CCFP, FRCPC

"For her enduring vision, expertise, and exemplary leadership in cancer surveillance and cancer control"

NAACCR Member Recognition Award Winners

The purpose of the NAACCR Member Recognition Awards program is to celebrate and foster the ongoing contributions of time and effort made by NAACCR members in a wide variety of ways.

Members accumulate points by participating in NAACCR activities, then submit points annually to NAACCR via a web based application. Award levels include: Merit (100) Achievement (200) Leadership (300).

Level 1 Merit Award winners:
- Kyaw Soe Aung, Cancer Care Ontario
- Baozhen Qiao, New York State Cancer Registry
- Laura Ruppert, Indiana Cancer Registry
- Heather Stuart-Panko, Saskatchewan Cancer Agency

Level 2 Merit Award winners:
- April Austin, New York State Cancer Registry
- Jack Finch, Colorado Central Cancer   Registry
- Sandra Gamber, Elekta
- Paulo Pinheiro, Nevada Statewide Cancer Registry
- Deirdre Rogers, Mississippi Cancer Registry

Level 3 Merit Award winners:
- Maria Celaya, New Hampshire State Cancer Registry
- Paulo Pinheiro, Nevada Statewide Cancer Registry
- Deirdre Rogers, Mississippi Cancer Registry

Congratulations to all the recipients!

If you have any questions, please call or email Frances Ross at (859) 218-3181 fer@kcr.uky.edu.

Annual Conference Materials

Dustin Dennison, M.MIS.
Information Technology Administrator, NAACCR

The 2017 Annual Conference page has been updated with the following materials:

- Final Program
- Abstract Program
- Oral Presentations
- Poster Presentations
- CE Form
- 2017 Photos

NAACCR Annual Conference Poster Awards

Thanks to all the poster authors and judges who participated in the 2017 NAACCR Annual Conference Poster Awards. There were three awards for each of the categories, Registry Operations and Data Use. And the winners:

Registry Operations

First Place: *Improving Completeness of Treatment Documentation Through 15-Month Resubmission of Data in New Jersey* (Stephanie M. Hill, New Jersey State Cancer Registry, Trenton, NJ)

Second Place: *Improving the Accuracy of Type of Reporting Source Data Field at the New Jersey State Cancer Registry* (Suzanne Schwartz, New Jersey State Cancer Registry, Trenton, NJ)

Third Place: *Meaningful Use Cancer Reporting: How Meaningful is it? An Analysis of Data Submitted to the Maryland Cancer Registry* (Diane Ng, Westat, Rockville, MD)

Data Use

First Place: *Hot Spotting Preventable Cancers: Done Right* (Abby Holt, Arkansas Department of Health, Little Rock, AR)

Second Place: *Time Between Breast Cancer Diagnosis and Treatment Among Alaska Native People* (Sarah Nash, Community Health Services, Alaska Native Tribal Health Consortium, Anchorage AK)

Third Place: *Colorectal Cancer Incidence Trends in Massachusetts by Tumor Location, 1995-2014* (Annie MacMillan, Massachusetts Cancer Registry, Boston, MA)

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

https://www.naaccr.org/2017-annual-conference-oral-poster-presentations/#PosterListing

Susan T. Gershman
Chair, Poster Review Committee

NAACCR Student Award Program

Oral Presentation and Poster Awards

Thanks to all the poster authors and judges who participated in the 2017 NAACCR Student Award Program. This year we had thirteen oral presentations and ten poster presentations. First, second and third place awards were given in both categories. And the winners:

Oral Presentations

First Place: *The accuracy of the HPV status site-specific factor 10 variable for head and neck cancer cases in Iowa: 2010-2014* (Amanda Kahl, University of Iowa College of Public Health & the Iowa Cancer Registry, Iowa City, IA)

Second Place: *Developing a RESTful HTTP Service as a Frontend for the CDC TNM Staging API* (Roger Chui, Kentucky Cancer Registry, Lexington, KY)

Third Place: *The excess treatment-related incidence of diseases of the circulatory system in patients diagnosed with Hodgkin lymphoma* (Caroline Weibull, Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm, Sweden)

Poster Presentations

First Place: *Estimating the impact of a cancer diagnosis on life expectancy by socioeconomic group for a range of cancer types in England* (Elisavet Syriopoulou, University of Leicester, Leicester, Great Britain)

Second Place: *The impact of a prior HIV/AIDS diagnosis on the survival of cancer patients* (Ben Hallowell, University of Georgia, Athens, GA)

Third Place: *Racial/ethnic differenced in thyroid cancer incidence in the United States, 2007-2013* (Kristin Weeks, University of Iowa Carver College of Medicine Medical Scientist Training Program, Iowa City, IA)

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

https://www.naaccr.org/2017-annual-conference-oral-poster-presentations/

Castine Clerkin, Jeannette Jackson-Thompson, Angela Meisner
Student Award Committee

Birds of a Feather

This year the NAACCR Annual Conference's **Birds of a Feather** session headed west with an interesting discussion on the topic *Attrition In Our Workplace – Affect, Attitude & Acceptance*. We (Rich and Susan) would once again like to thank those of you who attended the late afternoon session. We had over 70 attendees this year!

This was our Tenth Anniversary of the "Birds" session so we have provided some Birds history below:

Birds Over the Years

2008: Efficient Registry Operations
2009: Efficiencies and Challenges in Registry Operations
2010: What did we Learn from 2010?
2011: Electronic Health Record – Where is it? What does it mean to YOU?
2012: Information Overload – Any Way Out?

2013: The Future of Cancer Surveillance…or Not?
2014: International Cancer Staging: Can We Develop a System for All?
2015: Using Our Registry Data – What Works and What's Next?
2016: Is There Anybody Out There? Collaborating for Cancer Surveillance
2017: Attrition In Our Workplace – Affect, Attitude & Acceptance

For this session Rich started with a brief description of the topic and some initial questions.

Many of us have seen our registry workforces shrink over the past years. Whether it's by work scope, cuts triggering layoffs, loss of funding, outsourcing workload to private contractors, or retiree's positions not being filled – we can't help but notice 'Empty Desk Syndrome' when looking around our workplaces.

We'd like to hear your thoughts on how this has affected you – not from the budgetary, workscope or annual planning perspective which we usually discuss – rather on how you personally have dealt with it.

- What kind of effect has it had?
- How have you handled the changes?
- Are there personal tips to help keep a positive attitude in the midst of change?
- How are we preparing and promoting our field for the next generation? (or perhaps ARE we preparing ???)

This was arguably one of the best "Birds" with representatives from a number of states presenting some personal and troubling issues. Let's start on the positive side though, move to the negative, and then conclude with thoughts for the future. We began the session with a number of remarks regarding maintaining a positive work environment. Comments included that we need to work smarter with less staff, develop a "work family", take advantage of all opportunities, share with our colleagues and remember that no need to reinvent the wheel. New employees often arrive with infectious enthusiasm so employers need to ensure that the enthusiasm continues forward. Does the employer offer training, 'innovate' time to keep the new employee motivated? Employers need to invest in staff in order to make sure they feel good about their work environment.

Now let's move to some of the negative issues. First, working at home seems to be one of the issues affecting hiring for central cancer registries. Hospitals and contract agencies have greater flexibility regarding the working at home issue. Is this really a solution that we all work at home? Are there studies regarding productivity, collaboration, networking that make this such a positive alternative to an office environment for tumor registrars? Second, it seems that there are states (registries that are located in departments of public health) that have issues such as declining staff with little hope of replacement and minimal institutional support or appreciation of cancer surveillance. Some are even afraid to retire with the fear that their cancer registry will cease to exist. This creates such poor morale that we all need to reflect on what type of assistance we can provide for this type of situation. Perhaps this would be a great topic for a future Birds of a Feather session !

For the future we should all remind ourselves of the support we receive from NAACCR and its member organizations. I doubt if there's another profession that provides so much opportunity for networking, education, subject matter expertise, collaboration, and encouragement. For example, I (Susan) can't even begin to count the number of times I've contacted my colleagues all over the country for assistance in dealing with work place issues. They've always provided their ideas, support and encouragement that have helped me to move forward! Our work environments will continue to transform but if we work collaboratively, we can hope for an even greater influence for cancer surveillance.

And speaking of the future, after ten years, Rich and Susan have decided that it's time to move on as leading the "Birds of a Feather". We want to thank you for attending the sessions, for your wonderful ideas, thoughts, and visions as we continue the fight to reduce the burden of cancer all over the world! Rumors are the flock will continue, led by new faces – so stay tuned in Pittsburg to see where we fly next!

-Rich Pinder
rpinder@usc.edu

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

Photos from Bike Ride at 2017 Annual Conference

Photos from the afternoon ride along the Rio Grande, on Albuquerque's Paseo del Bosque Bike Trail at the 2017 NAACCR Annual Conference. Submitted by Rich Pinder.

View the full gallery here: http://vue.usc.edu/RioGrande2017/

Report on COC 2017

Frances Ross
NAACCR Liaison to the Commission on Cancer

The Commission on Cancer held its Spring Meeting for 2017 in Chicago, IL on May 11-12, 2017. The content of this two-day meeting centered on the activities of various committees. Dr. Larry Schulman, CoC Chair, welcomed everyone and gave a brief overview of his outlook on the future of cancer care. He stressed that the value of care is equal to the Benefit gained by the patient divided by the Cost and Toxicity of the care. He questioned whether the Commission should be looking at the factors of the denominator of this equation. He stated that future priorities of the CoC should be 1) exploring areas where care and outcomes are variable, 2) ensuring that actions taken truly assess and improve the quality of care, and 3) becoming a leader in driving the improvements of cancer care and outcomes in the United States.

The Accreditation Committee, headed by Dr. Danny Takanishi, reported on the activities of the Program Review Subcommittee. Their responsibilities are to implement and evaluate standards for the Approvals Program, to oversee the survey process and review the results, and to promote CoC accreditation.

There was an analysis and discussion about the Survivorship Care Plans (SCP) (Standard 3.3). There were 411 surveys conducted in 2016 on 2015 data. For the surveyed hospitals, there were 9,918 patients reported as eligible to receive SCP, and anywhere from 0 to 7572 actually received a SCP. Nationally, it was estimated that over 400,000 patients would be eligible for an SCP, and 79,120 received them (about 20%). This standard is creating the most deficiencies of the 3 new standards for cancer programs. The subcommittee recommended the following considerations:

- Retain the compliance levels to emphasize the importance of the SCP.
- Eliminate confusion on the timing of delivery of SCPs.
- Clarify compliance percent calculation language.
- Add language to allow those not in compliance to pass the standard if the Cancer Committee creates a comprehensive action plan; executes, monitors, and evaluates the plan; and demonstrates progress toward achieving compliance within a timeframe to be determined by the committee.

The Member Organizations Harmonizing Standards Workgroup proposed a structure (outline) for all Standards Manuals. If accepted, this would make the Manuals for the National Accreditation Program for Breast Cancer (NAPBC) and the National Accreditation Program for Rectal Cancer (NAPRC) and any other specialty accreditation programs more uniform and in line with the overall CoC Accreditation Program Standards. To support this effort, Asa Carter at CoC developed a table comparing the standards of CoC with those of NAPBC.

The Oncology Medical Home Accreditation Committee is looking for surveyors for its new programs. The NAPRC has 6 pilot programs and they are reviewing their standards, following the process of the NAPBC. They will require new programs to have their standards met for 12 months before they can be surveyed.

Various Standards Workgroups addressed specific problematic standards. One group discussed standards 4.7 (Studies of Quality) and 4.8 (Quality Improvement), and recommended merging these two standards and clarifying what needs to be done to achieve compliance. They would like CoC to help institutions design studies, provide examples, provide education in data analysis, and possibly create some 'CoC suggested Quality Studies.'

Another workgroup considered standards 1.8 (Outreach), 4.1 (Prevention Programs, and 4.2 (Screening Programs). They determined that these standards do result in improvement of patient care, but they are redundant and should be merged into one standard, emphasizing all three activities. More clear, concise and straightforward measures need to be developed for this standard, and the group is considering if this category should have a commendation level as well as a compliance level.

Finally, another workgroup considered standard 1.5 (Cancer Program Goals). They questioned how it was different from standards 4.7 and 4.8 (Quality Studies) and determined that it was important to have programmatic goals clearly articulated. However, these goals do not need to be new each year; rather they should be evaluated and programs should demonstrate by progress towards the goals.

The Quality Integration Committee implemented the Site Specific Leader proposal, to provide clinical resources to NCDB staff to assist in ongoing efforts to develop quality measures. They also re-initiated measure development with the Measures Subcommittee, continued to assist NCDB with planning and prioritizing work, and reviewed proposals for collaboration for research within CoC.

Work continued on the Registry Platform Project, which seeks to unify the various databases within CoC into a new infrastructure being developed by Quintiles, a software development company. The NCDB and RQRS re-structuring is in its first phase, planned for 2018. The second phase would move registries to real time reporting and the eventual goal is to import EHR data directly into the NCDB to create various analytic files (Quality measures, Survival data, Participant User Files, CQIP, etc.).

This committee also participates in the development of the cancer care quality measures. New measures were proposed for rectal and kidney cancers, and the group was asked to vote within the week to accept or reject these new measures – 4 for rectal cancer and 3 for kidney cancer.

The FORDS Manual has been revised for 2018 and will be renamed the STORE Manual. The number of data items has risen from 250 to 375, as each site specific factor from the Collaborative Staging System, if retained, will be named as an individual data item. Other changes will be made to accommodate the implementation of AJCC staging 8th edition in 2018. And there will be additional data items for capturing radiation treatment and follow up information.

The Scientific Review Subcommittee reported impressive growth in the Participant User Files (PUF) program. In the first year (2013) the number of PUF files disseminated was 166 and that number has doubled every year since, with 872 files distributed in 2016. This group is eager to promote research collaboration with NCDB data and was soliciting ideas to expand and evaluate new research projects.

The Education Committee described various upcoming CoC sponsored workshops. There will be a Quality of Care conference in September, and plans are underway for the Clinical Congress meeting in October. The priority topic there will be approaches to asymptomatic neck cancers, innovations in pancreatic cancer treatment, and treatment options for non-small cell lung cancer in high risk patients. Nine topics are being considered and six keynote speakers have been suggested for later voting by the group during the Executive Committee meeting. The chair of this committee, Dr. Hisakazu Hoshi, outlined a framework for the foundation of any effective educational program. The framework involves first, a needs assessment, then goal setting, determining the educational methods, creating educational materials, then teaching students, and finally evaluating the effectiveness of the process.

The Advocacy Committee has been focused on several important and topical issues: access to care and the health care reform act (ACHA), cancer research funding, graduate medical education requirements, drug use, particularly opioid use, and the importance of immigrants in health care delivery. At the Committee's February in person meeting at the Capitol, members made 36 visits to congressional representatives, three visits to leaders in childhood cancers, and they spoke in support of several bills in Congress. Specifically, they sent letters of support for One Voice Against Cancer (OVAC) research programs, removing barriers to colorectal cancer screening, cancer care payment reform, cancer drug coverage, and active treatment planning.

In addition to the issue of health care reform, the committee made recommendations for legislation to support effective use of sunscreen in schools. Several organizations have developed position statements (AMA, ACS, and the American Dermatological Society) and recommend uniting with CoC to introduce a bill to allow the application of sunscreen in schools. Currently, most states prohibit the possession and application of sunscreen in public schools, and only 5 states allow it.

Distress screening was another area of focus for the Advocacy Committee. They mentioned specifically the screening of clinical trials participants for aspects of distress – disruption to work life, home life and family. A bill

has been introduced in the House called the Patient Experiences in Research Act, which, included with the Drug Use Act, seeks to get patient experience metrics from different clinical trial arms to measure these disruptions.

At the state level, they reported that 5 states have bills pending to ban tanning beds for minors (2 states have banned them); 3 states have active bills to allow sunscreen in schools; 2 states have palliative care councils (1 has enacted this law); and 20 states have active bills prohibiting tobacco use in public places, (2 states have passed a tobacco ban). On another topic, the Massachusetts Board of Registration has proposed a change requiring doctors to have specific conversations with patients discussing all forms of treatment and documenting compliance with the law in the patient's medical record. The patient must sign a written consent or refusal of treatment form, acknowledging the discussion of treatment possibilities. There were strong opinions both for and against this proposal. Some physicians said, 'Of course, this is how we practice anyway.' Other said it would set a bad precedent for legislators to mandate specific conversations between doctors and patients, and it would just invite lawsuits, with its ambiguous language.

There was a brief tutorial on physician payment systems, the latest of which is a merit-based fee for service system, based on performance measures. Finally, the committee reported on a survey they had conducted regarding advocacy efforts by the CoC Member Organizations. Nearly 80% of the member organizations participate in advocacy activities, mostly in regard to federal legislation and regulatory requirements.

The Member Organization Representative Committee continued discussion on 4 'hot topics' from this committee's meeting last spring: Advocacy, Harmonizing Standards Requirements, Survivorship Care Plans, and Distress Screening. Advocacy recommendations were presented by the Advocacy Committee, and the report of the Harmonizing Standards Workgroup was addressed by the Accreditation Committee. For distress screening (Standard 3.2), the committee recommended having the necessary measurement data incorporated into the Electronic Health Record. These would be: name of the person providing the screening, the interval for follow up, any non-English resources, and any best practices. Currently, EPIC, Cerner, and Meditech can capture distress screening information in their systems; it was felt that Varian and Elekta could develop this as well. Recent accreditation surveys found that, out of 469 facilities, 443 were compliant with this standard, 2 were deficient but the deficiencies were resolved, and 21 were deficient. The group will monitor the results of 2017 surveys and make any recommendations to the Accreditation Committee.

The purpose of the Survivorship Care Plans is to provide a list of treatments received, enhance communication about continued care, and inform the patient about the possibility of late effects. Of 464 surveys, 16% had a deficiency for this standard. There was concern among the attendees that there is not currently enough evidence from outcomes to confirm the value of having this standard. There were numerous challenges to meeting this standard cited: lack of technology to create the care plans, limited staff to create and deliver the plans, lack of support from hospital leaders, and difficulty in identifying 'eligible' patients. The group recommended clarification of the standard, the development of an SCP education and dissemination plan, and an assessment of the outcomes showing the benefit of providing these plans. There was concern that the SCPs were really not being used by either the patient or by their primary care providers. They recommended revisiting this standard, focusing not on the percentage of patients receiving them, but rather on the resources needed to produce these documents, and on the impact of these plans to empower patients to regain their lives and take charge of their continued care.

The Cancer Liaison Committee recommended keeping cancer liaison physicians (CLP) who are State award winners, but no longer CLPs, involved in the CoC by inviting them to become part of the Advisory Group. Next, the American Cancer Society provided an update of their new Regional Model map, reducing 11 divisions down to 6 regions. They are taking a market center approach with 46 markets led by volunteer boards who will focus on delivering their services to the customers in their communities. Their strategic plan is to define the future of cancer control in the U. S. and to develop new tools for fighting cancer through investment in research.

Brainstorming Sessions – Friday's meeting started with 3 separate brainstorming sessions focused on 1) CoC accreditation standards, 2) specialty accreditations, and 3) patient centered care. The conclusion of the discussions was that each standard needs to emphasize its purpose to improve a particular problem and to let individual programs demonstrate efforts to address the problem and develop measures of progress. They also concluded that the survey process needs to be more uniform across programs and suggested better training for surveyors, more objective measures of compliance, and more pre-survey preparation. The surveyor can then spend his or her on-site time on verification, education, and CoC promotion. The patient centered standards need to emphasize their focus on processes, outcomes, and documentation.

NPCR Releases XMLExchange Plus/XMLPlus.dll for NAACCR XML Data Exchange

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The National Program of Cancer Registries (NPCR) has published XMLExchange Plus and XMLPlus.dll, implementing v1.2 of the NAACCR XML Standard for data exchange. The NAACCR XML Implementation Guide is available here: https://www.naaccr.org/xml-data-exchange-standard/

Installers

Installers for 32-bit and 64-bit Microsoft Windows environments can be downloaded from the CDC-NPCR website: https://www.cdc.gov/cancer/npcr/tools/registryplus/xml-exchange-plus.htm

Features

XMLExchange Plus is a tool for working with NAACCR XML data exchange files. It is designed to demonstrate the capabilities of the NPCR XML parsing library, XMLPlus.dll. Our goal is to provide a gentle introduction to the complexities of writing and reading NAACCR XML dictionaries and data files. The intended audience for XMLExchange Plus includes programmers and EDITS metafile administrators.

XMLExchange Plus performs these tasks:

- **Dictionary Maintenance**. This module cross-references data items defined in the base and user dictionaries to help IT staff produce valid NAACCR XML dictionaries. User dictionaries may be created and modified, including a selection of registry-specific items defined in a custom metafile.
- **Convert**. XML data files can be created from flat-format files, optionally including items from one or more user dictionaries.
- **Validate**. Validation compares the contents of each item in the NAACCR XML data file to the definitions for those items in the dictionary file(s) named in the header of the data file. Errors are reported as they occur.
- **Run EDITS**. It is not necessary to convert a NAACCR XML data file to flat-buffer format in order to run EDITS. This module reads the XML, prepares it for editing on-the-fly, and creates a GenEDITS-style report.

Context-sensitive help is readily available; press the **F1-Help** key from anywhere in the program to open the help file to the section that is relevant to the module you are viewing.

For Programmers

The NAACCR XML Standard defines strict rules for writing data exchange files. NAACCR offers a library written in Java, with source code, for programmers who can incorporate Java into their development environment.

XMLPlus.dll is a C-interface library. This is the calling convention used in the Edit Engine and the Collaborative Stage library. The "C" linkage makes the library accessible, without requiring the installation of additional frameworks, from software developed in managed programming languages (e.g., Java, C#, VB.NET) or unmanaged languages (e.g., C++, Delphi).

The XMLExchange Plus help file contains programmer documentation for the XMLPlus API, including sample code that demonstrates how to use the features of the Edit Engine to run EDITS against an XML data file.

Request for Feedback

The NAACCR XML Task Force expects vendors and central registries to implement support for NAACCR XML data exchange based upon reading the documentation. The documents are detailed and complicated. As publishers of software for reporting facilities and central registries, NPCR is working to ensure that Registry Plus applications will be able to read incoming XML data files from any source, and produce XML data files that can be read by others.

Therefore, if you are creating NAACCR XML data exchange files, please try running the features of XMLExchange Plus, and let us know your results. We want to iron out inconsistencies as early as possible.

As always, we are available to answer questions. Contact us at cancerinfo@cdc.gov

http://www.naaccr.org

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