THE NAACCR NARRATIVE

President's Message

Winny Roshala, BA, CTR
NAACCR President

I hope you all had a wonderful holiday season and that you can look back upon 2022 as a year filled with new challenges, but also many unexpected opportunities. As we all prepared our data files for the annual Calls for Data, the challenges from the impact of the pandemic came into play and establishing fair expected case counts completeness percentage for 2020 cases was no easy feat. Standard setting agencies worked to come up with fair and reasonable estimates for these unprecedented circumstances. We know it will take years to fully determine the impact of the pandemic on cancer surveillance efforts. We continue to forge ahead, despite the challenges. Early indications of 2021 data reflects a slow increase of cancer cases. Again, it may take several years to fully assess the impact of the pandemic on cancer surveillance including incidence and stage at diagnosis, impacting outcomes. Only time will tell.

The NAACCR Board and Steering Committee Chairs, in collaboration with the NAACCR staff have been working diligently to develop a Strategic Initiative Priorities roadmap for NAACCR. You will hear more about this in the next edition of the *NAACCR Narrative*.

I'm so excited that the 2023 NAACCR Annual Conference will be held in-person again in historic and vibrant New Orleans, LA! The NAACCR Program Committee has been working hard to provide a diverse and dynamic program agenda, to inspire attendees and promote networking and collaboration in familiar as well as new, innovative environments! Birds of a Feather will also be making a return flight to New Orleans, LA (aka NOLA)! Look for more details regarding NAACCR in NOLA!

I also want to take a moment to thank the members of the NAACCR Nominating Committee, consisting of Devbani Raha, (Nova Scotia) Chair, April Austin (NY) and Heather Stabinsky (NJ). The committee did a tremendous job putting together a full slate of candidates for the office of Treasurer, 3 Representative- at-Large positions and 3 Nominating Committee member positions. Kudos to them all for a job very well done!

I also want to encourage you all to consider nominating a colleague for the Calum Muir Award or the Constance Percy Award. There are so many colleagues who have served as leaders and mentors in the cancer surveillance community. Let's honor those who are so deserving of this recognition!

Wishing you all a bright New Year, filled with good health and many new exciting opportunities and adventures!

I also want to encourage you all to consider nominating a colleague for the Calum Muir Award or the Constance Percy Award. There are so many colleagues who have served as leaders and mentors in the cancer surveillance community. Let's honor those who are so deserving of this recognition!

Wishing you all a bright New Year, filled with good health and many new exciting opportunities and adventures!

Please contact me should you have any questions, comments or suggestions at wroshala@crgc-cancer.org

---

NAACCR 2023 is Live and In-Person

Sound the Trumpets! The NAACCR Annual Conference is going to New Orleans, Louisiana.

Registration is Open!

Join us: Thursday, June 20-22, 2023

New Orleans, Louisiana

See the Conference Website **naaccr23nola.org** for information on:

- Exhibits/Sponsorships
- Schedule/Agenda
- Travel information
- Hotel information
- Registration

Check back frequently; new information is added as it becomes available.

If you have any questions, please contact the NAACCR Office. (217)698-0800 or questions2us@naaccr.org

---

The NAACCR Board of Directors is seeking nominations for the Constance L. Percy and Calum Muir Awards

In March, the NAACCR Board of Directors considers nominations for two of the most prestigious awards in the cancer surveillance community, The Calum Muir Award, and the Constance L. Percy Award. These awards, described below, will be presented at the NAACCR Annual Conference in New Orleans in June. Please take the time and nominate a NAACCR member who has demonstrated leadership and commitment to cancer surveillance.

Nomination Deadline: March 1, 2023

The Calum Muir Award

The purpose of the Calum Muir Award is to honor someone who has made long-term, substantive contributions in cancer registration. Preference is for the recipient to be an active member of NAACCR with a long-term commitment to the organization. The intent is that it not be a posthumous award. The award will be bestowed each year at the NAACCR Annual Conference to a recipient selected by the Board of Directors.

The Constance L. Percy Award for Distinguished Service

The purpose of the Constance L. Percy Award for Distinguished Service is 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. The award may be bestowed once each year, usually at the NAACCR Annual Conference, to a recipient selected by the Board of Directors. More than one award may be given in any year. No limit is placed on the number of times an individual may be recognized by a Constance L. Percy Award for Distinguished Service

Past Award Recipients

Please include information about why you think your candidate should be considered for the award. This information will be distributed to the Board and serve as the basis of voting. Nominations should be submitted in writing to bkohler@NAACCR.org by MARCH 1. Thank you for your participation.

New Resources Available on NAACCR's Data Security and Confidentiality Issues Website

Heather Zimmerman and the Data Security & Confidentiality Workgroup

Over the last 2 years the Data Security and Confidentiality Workgroup has produced several resource documents to assist the cancer surveillance community with navigating this important and sometimes confusing area. You can find these valuable resources, along with older but still relevant materials, online at https://www.naaccr.org/data-security-confidentiality-issues/ .

We would like to highlight some of these resources:

National Death Index Fact Sheet

This factsheet covers the key facts central registries need to know about linking with the National Death Index and how the data can be utilized. It also covers limitations and requirements association with the use of NDI data.

Indemnification Primer

We've all seen data use agreements that contain an indemnification clause, but do we really know what it means? This primer covers indemnification as a legal term of art and aims to help central registries understand why it is often included and sometimes negotiated out of DUAs.

HIPAA Resources for Cancer Registries

HIPAA and its regulations including the Privacy Rule rank among the most commonly cited laws dictating how individually identifying health and personal information must be protected. But how should central cancer registries interpret HIPAA regulations? How do provisions for public health surveillance and research activities apply to registries and their operations? This handy guide explains how HIPPA applies to central registries.

Requests from or on behalf of Patients for Individual-Level Information from Central Cancer Registries

Are central cancer registries required to release individual-level information directly to patients or their family? Is it even a good idea to release this kind of information? These guidelines can help central registries understand what laws may apply to these types of requests and to determine whether to honor such requests.

Data Destruction Primer

Data Use Agreements almost always include a requirement to destroy the data once the project is complete or the DUA expires but what does data destruction even mean? This primer covers how to properly destroy data and how to ensure that your data is destroyed through good planning.

Multi-Factor Authentication Factsheet

Most of us have had to switch to multi-factor authentication in both our personal and professional accounts but is the hassle really worth it?? This factsheet covers what MFA is and why it is important.

Data Encryption and Hashing Primer

Protecting data from unauthorized access is the primary goal of data security, and encryption and hashing are tools we hear about all the time, but do we actually understand what they are and how they should be used? This primer provides a basic description of encryption and hashing to help central registry staff understand when they should and should not be used.

The Data Security and Confidentiality Workgroup is currently working on even more resources so keep an eye out for their release in the coming months!

Spotlight on Registries: Jetty Alverson, Michigan Cancer Surveillance System

Spotlight on Registries is a relatively new feature for the *Narrative* Newsletter and presents a series of articles that highlights a registry's special activities or achievements. This Edition spotlights the Michigan Cancer Surveillance Program's 2021 NPCR Success Story, which describes their successful linkage between their registry database and the LexisNexis database in order to update several demographic data items. Georgetta "Jetty" Alverson from the Michigan Cancer Registry and lead-author on the Success Story spoke with the Narrative recently about their experience.

To see the original 2021 NPCR Success Story, click here.

NAACCR Narrative Interviews Jetty Alverson, Michigan Cancer Surveillance System. Some responses were edited for clarity.

NAACCR Narrative **(NN):** What do you think was your greatest challenge in implementing this new procedure for updating SSN and related patient demographics?

Ms. Alverson:

- The amount of time involved to review the LexisNexis linkage results and determine which instances of the results should be updated in the registry database.

- Updating the patient's missing SSN with a known SSN was not as labor-intensive as updating the patient's name and/or demographics.

- Manual review of the file results for best patient information for name and demographics was time consuming. Typos could easily be spotted, and scripts were written for auto-updating the registry database. Manual review was needed when there was a difference in first and/or last name. If the patient was alive in the registry database but LexisNexis indicated the patient was now deceased, the patient's name was updated based on the LexisNexis results.

- Middle name was updated with the LexisNexis linkage result if the patient's middle name was missing and/or if middle initial was reported instead of the patient's middle name.

- Date of Last Contact was updated when the patient's vital status was alive in the registry database but identified as deceased in the LexisNexis results.

NN: What do you think was your greatest success in this implementation?

Ms. Alverson:

- MCSP saw an increase in the annual number of cases reported to the registry with missing SSN and/or invalid/masked SSN reported by Michigan reporting facilities. This is an issue that goes beyond the edits that need to be performed on a regular basis. Therefore, we needed to identify changes in facility reporting of SSN.

- MCSP's state-specific reporting requirement for reporting the patient's full SSN requires that facility follow-back be conducted in attempt to obtain it if it is not readily available.

  - The registrar/facility should determine if the facility collects the patient's SSN and if so, if the reason the registrar does not have access to the patient's SSN is due to a user access rights issue. If user access is needed, the registrar should contact the applicable facility admin/IT staff to request user access.

  - If the facility no longer collects the patient's SSN, it is recommended that the registrar (facility cancer registry) communicate this state-specific reporting requirement to the applicable administrative staff at the facility.

  - If the patient's SSN is not collected or not available, facility follow-back with applicable physician(s) is required by MCSP.

- To sustain success, MCSP created a new state-specific data item, MI100 Reason SocSoc Unknown beginning with v22 (diagnosis year 2022 cases and forward). This state-specific data item serves to act as a reminder to facilities that MCSP requires the patient's SSN and of MCSP's state-specific reporting requirement that facility follow-back be conducted in attempts to collect the patient's SSN. Use of this state-specific data item is required (2022 cases and forward) if the patient's SSN is reported as unknown.

NN: Do you have anything else you would like to share with the NAACCR community as part of this article on your Success Story experience?

Ms. Alverson: MCSP cancer registry staff has been using LexisNexis on a regular basis for approved research studies/linkages and patient look-up for SSN when reported as unknown, invalid, or masked. Regular use of LexisNexis for missing SSN is what prompted the quality assurance review to identify the reason for the increase in the number of cases with missing SSN and for registry batch look-up of cases in the registry database to determine if the SSN could be identified.

Mapping cancer registry processes to collect and process cancer pathology data in Canada

Authors: Cancer Registry Process Mapping Task Force, a task force of the Canadian Council of Cancer Registries

Introduction

Canadian cancer surveillance consists of 13 provincial and territorial population-based cancer registries (PTCR) that collect information on all reportable tumours among Canadian residents according to Canadian and international coding standards. Although PTCR practice may differ across the provinces, most of the information collected is ascertained from provincial/territorial level health information systems attributed to universal health care systems in Canada[1].

Canadian cancer registries typically report over 90% of tumours as pathology confirmed. To facilitate data quality, timeliness, and complete ascertainment of pathology confirmed cases, improvements in electronic reporting from pathology laboratories continue in many jurisdictions in Canada and the United States.
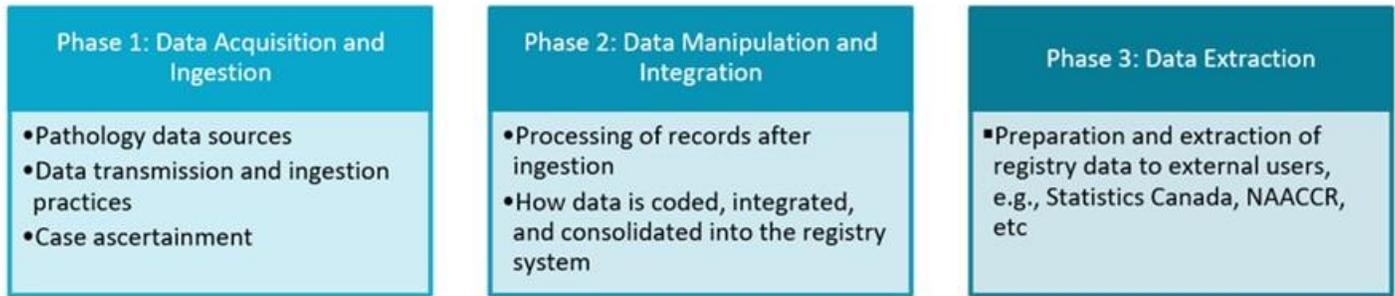
Some PTCRs rely on manual processes including but not limited to, filtering electronic reports for reportability status, storing and processing massive volumes of data, and maintaining these systems. Although some advances have been made, we are far from fully realizing the benefits of real-time electronic reporting of cancer pathology. NAACCR, along with cancer registry experts and students from Rutgers University, recently published work in this area titled: *A Six Sigma Lean Green Belt Analysis of Electronic Pathology Reporting in Central Cancer Registries[2]*.

Canadian cancer registries are reporting common experiences. Data volume and complexity of data are increasing, human resource capacity is limited, and there is increased pressure to improve on data timeliness. In response to these challenges, and in light of advances in electronic pathology reporting, the Canadian Council of Cancer Registries (CCCR) created a task force (Cancer Registry Data Process Mapping Task Force) to lead an environmental scan of electronic reporting of pathology information across PTCRs. This effort was designed to facilitate additional discussions among PTCRs, not necessarily providing a written compendium of solutions. The overarching objectives of this work were to:

- Enable comparison of pathology data sources, systems, processes and tools across PTCRs.

- Facilitate the capacity to:

    o leverage systems, processes, tools and knowledge from other PTCRs;

    o identify and compare strengths, weaknesses and pain points;

    o identify opportunities for improvements, enhance collaboration and share advancements.

- Prove the opportunity to identify challenges in ascertaining, integrating and consolidating pathology information, and contribute towards Pan-Canadian solutions, registry practices and data standards.

Engagement with PTCRs

The environmental scan is currently underway and will be conducted in three phases, corresponding to the different stages of cancer registry operations. Under each phase, a questionnaire was developed by the Task Force in collaboration with cancer registry experts across Canada to gather key information about electronic reporting of pathology. The phases and topic areas were as follows:

Phase 1: Data Acquisition and Ingestion	Phase 2: Data Manipulation and Integration	Phase 3: Data Extraction
• Pathology data sources • Data transmission and ingestion practices • Case ascertainment	• Processing of records after ingestion • How data is coded, integrated, and consolidated into the registry system	▪ Preparation and extraction of registry data to external users, e.g., Statistics Canada, NAACCR, etc

In partnership with Statistics Canada, follow up interviews were held with PTCR registry teams to discuss responses to the questionnaire and develop key project outputs: (1) a data metrics table and (2) cancer registry data process maps. The data metrics table compares high-level information on systems, processes, and data that characterize electronic reporting of pathology across PTCRs. The cancer registry process maps (i.e., flow diagrams as shown below) incorporate information on systems and processes, areas that rely on manual work, pain points, challenges, and opportunities.
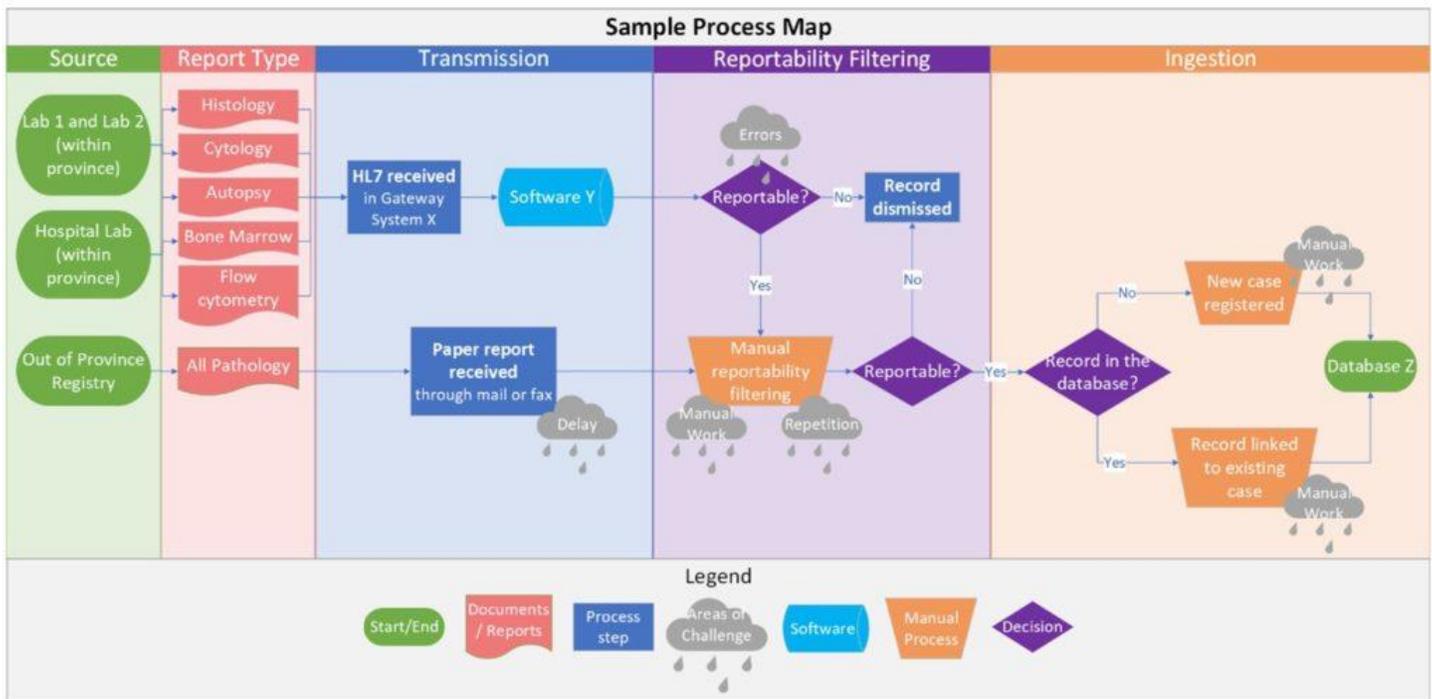
Sample Process Map

Early Findings and Key Messages

To date, the Task Force in partnership with Statistics Canada, completed Phase 1, and was able to engage nearly all PTCRs. Cancer registry process maps illustrating where we rely on manual work, common challenges, and opportunities, were shared with all PTCRs through the CCCR Web Portal. Additionally, a data metrics table was produced summarizing electronic reporting across all Canadian cancer registries. At this time, we are excited to share early findings of our work:

- Many PTCRs are in early phases of transitioning or recently transitioned to electronic reporting. In most cases, electronic reporting includes complete coverage of pathology information in the province.

- Even though all registries have established electronic reporting, the way those reports are fed into the system, the format of the reports, and technical solutions to process the information are significantly different.

- Many PTCRs are looking to explore data science in order to deal with the demands associated with volumes, timeliness, and human resource (registrar) shortages, but this is not traditionally an area within the cancer registries.

- Some registries are actively collaborating with data science teams in using natural language processing and machine learning to support operations.

The current work provides some early examples of successes, but the exercise was designed as proof of concept work; it provides limited direction on standards and methods for registrar practice. The second phase of this initiative is underway and will focus on the processing, consolidation, and integration of pathology data into the cancer registry dataset.

We want to acknowledge the great work done by our NAACCR and US colleagues in this space as reported in the *A Six Sigma Lean Green Belt Analysis of Electronic Pathology Reporting in Central Cancer Registries*[2]. We are looking forward to engaging with US partners to explore new opportunities that arise from electronic reporting and harnessing the power of data science to modernize cancer registry practice.

---

[1] NAACCR Editorial Review Board. Central Cancer Registries in Canada: Strong Integration with Canadian Health Information Systems and a Single Standard Setter. NAACCR Narrative [Internet]. 2021 Sep [cited 2023 Jan 10]. Available from: https://narrative.naaccr.org/article/central-cancer-registries-in-canada/

[2] North American Association of Central Cancer Registries. A Six Sigma Lean Green Belt Analysis of Electronic Pathology Reporting in Central Cancer Registries. [Internet]. IL (US): NAACCR; 2021 [cited 2023 Jan 10]. Available from: https://20tqtx36s1la18rvn82wcmpn-wpengine.netdna-ssl.com/wp-content/uploads/2021/03/A-Six-Sigma-Lean-Green-Belt-Analysis-of-Electronic-Pathology-Reporting-in-Central-Cancer-Registries.pdf

---

Birds of a Feather

Are you the top dog, the cool cat, the big bird??
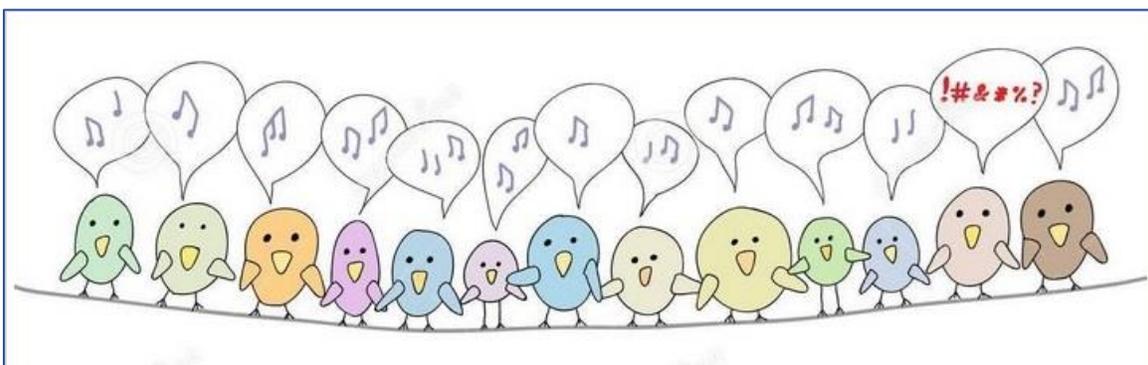
We need two moderators for our Birds of a Feather (BOF) session at the Annual Conference. BOF has become a NAACCR tradition of sharing ideas and tips with other members. This year's theme will be "Bouncing Back!" Come and share your ideas about bouncing back from COVID-19 and new data requirements. Have you always wanted to be the one in control of the mic and handing out the "fabulous prizes"? Now is your chance! If you are interested in being a moderator, send your name to Monica mthornton@naaccr.org with a brief statement about why this would be your jam!

NAACCR Education and Training Program Update

Jim Hofferkamp, BA, CTR
NAACCR Program Manager of Education & Training
jhofferkamp@naaccr.org

NAACCR WEBINAR SERIES

We just wrapped up our "Data Item Relationships" webinar. During the webinar we focused on how to spot inconsistencies between data items while abstracting. It was a fun webinar and interesting webinar. We had some great tips from our participants. One of our guest hosts, Angela Costantini, is a pediatric registrar. She did a great review and provided excellent tips on abstracting pediatric cases.

Next up is Boot Camp! We have Nancy Etzold and Elaine Bomberger-Schmotzer. They are both excellent trainers with extensive experience working in CoC-accredited facilities. During this webinar the participants work! Nancy and Elaine will develop a series of quizzes that help reinforce the core concept of cancer registry. We have minimal lecture and maximum quizzes!

For more information or to subscribe see the NAACCR 2022-2023 Webinar Series page at https://education.naaccr.org/next-year-webinar-series.

2022-2023 WEBINARS AT A GLANCE

- Breast 2022 Part 1 10/06/22
- Breast 2022 Part 2 11/10/22
- Esophagus 2022 12/01/22
- Head and Neck 2023 1/12/23
- Data Item Relationships 2/2/23
- Boot Camp 2023 3/02/23
- Prostate 2023 4/06/23
- Lower GI 2023 Part 1 5/04/23
- Lower GI 2023 Part 2 6/01/23
- IT Worked for Me: In"FUN"matics in the Cancer Registry 7/13/23
- Melanoma 2023 8/03/23
- Coding Pitfalls 2023 9/07/23

NAACCR CTR PREP AND REVIEW

The CTR Prep and Review Series for the March test started on February 7. There have been significant changes made to the content of exam this year and we have been busy updating our materials to reflect these changes.

Additional information is available at https://education.naaccr.org/ctr.

V23 UPDATE: ICD O, SOLID TUMOR RULES, SSDI

The v23 Update on ICD O, Solid Tumor Rules, SSD, and Surgery Codes was on January 11, 2023. We had nearly 3,000 attendees! A recording of the session is available at https://education.naaccr.org/updates-implementation. Individuals that view the webinar recording are eligible for 2 CEs.

For information about free upcoming webinars see the NAACCR Upcoming Events page https://education.naaccr.org/upcomingevents.

NAACCR TALKS RECORDINGS

Recordings of all NAACCR Talks can be found at: https://education.naaccr.org/freewebinars.

PRINCIPLES OF CANCER REGISTRIES

Our latest educational product is titled *Principles of Cancer Registries*. These asynchronous training modules are targeted at international registries. The first module looks at sources of cancer data and the process for collecting cancer data. The second module focuses on Assessing the quality of data collected within a cancer registry. A third module will be posted this summer. It will review the basic registry operations that occur once data is submitted to a central registry.

The modules are available at https://education.naaccr.org/international.

As always, if you have any questions about the plethora of NAACCR Education and Training products don't hesitate to contact Jim Hofferkamp or Angela Martin!

Highlights from the Program Manager of Standards

Lori Havener, CTR
Program Manager of Standards
lhavener@naaccr.org

NAACCR Data Standards and Data Dictionary v24 Implementation Timeline

For version 24 there are several proposed revisions (new data items, changes to existing data items, retired data items, etc.). Field testing has been completed on the proposed revisions for version 24 that require field testing, and the results will be shared with the Mid-Level Tactical Group (MLTG) at their February 2023 meeting. The next step in the change management process will be for the MLTG, and then, the High-Level Strategic Group (HLSG) to vote on whether to move forward with implementation of the proposed revisions.

NAACCR Data Standards and Data Dictionary Version 24 Implementation Timeline		
Activity	**MLTG Deadlines**	**Comments**
Proposed requests for new data items and revisions requiring field testing submitted to the Mid-Level Tactical Group (MLTG). *Note*: most new and some changed data items require field testing.	July 1, 2022	
Field testing initiated	October 1, 2022	
Proposed requests for changes to existing data items that do not require field testing submitted to MLTG for final review. Other planned changes (e.g., staging, ICD-O-3.2, SSDI schemas, etc.) reported to MLTG.	October 1, 2022	MLTG may elect to require field test on changes*

NAACCR Data Standards and Data Dictionary Version 24 Implementation Timeline		
Activity	MLTG Deadlines	Comments
MLTG informs the High-Level Strategic Group (HLSG) of all planned changes for 2024.	January 1, 2023	
Field test results reported to MLTG.	March 1, 2023	
HLSG reviews/approves changes to be implemented in 2024.	April 1, 2023	
MLTG transmits new standards approved for implementation to UDS WG.	April 1, 2023	NAACCR Data Standards and Data Dictionary is updated.
Standard setters provide their requirements for the Data Standards and Data Dictionary, Required Status Table (Chapter 8) and the Reportability table (Chapter 3).	May 1, 2023	
UDS WG final review/approval of the Data Standards and Data Dictionary	June 1, 2023	
UDS WG submits NAACCR Data Standards and Data Dictionary, Version 24 to the Standardization and Registry Development Steering Committee for review/approval	June 15, 2023	
NAACCR Data Standards and Data Dictionary, Version 24 Released	July 1, 2023	

*Changes to existing data items that result from experience in collecting the data, questions received from registrars or reliability studies generally will not require field testing. However, changes to codes made for other reasons may require field testing to ensure that the new codes and coding instructions can be accurately applied in registry settings. Change requests made in October that the MLTG determine need to be field tested may postpone the implementation year.

2022 National Childhood Cancer Registry (NCCR) accomplishments

Fernanda Silva Michels, MSc, PhD, CTR
Program Manager of Data Quality and Integration
fmichels@naaccr.org

2022 was a year of exciting growth and development for the National Childhood Cancer Registry! As we kick off the new year, the NCCR project staff at NCI and NAACCR would like to highlight just a few of the many accomplishments brought about by the collective efforts of everyone involved in making the NCCR a successful reality.

This year marked the **first coordinated NCCR call for data,** with 24 central cancer registries submitting full NCCR files as part of the annual SEER and NAACCR calls for data. The NCCR now covers more than two-thirds of all U.S. children, adolescents, and young adults ages 0-39, with plans to expand further in 2023.

We also saw the completion of the **first linkage between the NCCR and the Virtual Pooled Registry (VPR)**, matching the NCCR patients (age 0-39) against the VPR files (all ages) from NCCR registries plus nine VPR-only registries. Subsequent cancers will be added to the NCCR database to form a complete picture of the patient's cancer history. NAACCR's Interstate Case Ownership Task force (a subgroup of the NAACCR Standardization a Registry Development Steering Committee) has been developing standard rules for addressing duplicate cases between states, and we plan to test

these rules using duplicate cancers identified through the NCCR-VPR match. This process will observe patient confidentiality protocols and will require the involvement of the registries. More information will be provided once the cancer matching has been completed.

Great strides have been made in developing mechanisms to make data available to end users through several avenues, including an NCCR version of SEER*Stat and an NCI cloud-based data platform. The **NCCR Data Platform** will enable researchers to perform cohort discovery and to explore data available at an aggregate level. The platform will also support requesting access to patient-level data through a robust authentication, authorization and review process including, where necessary, IRB review and approval.

HemOnc.Org is a one-stop shop for detailed information about oncology treatment regimens with links to relevant literature for evidence-based therapy. Practicing clinicians from various oncology specialties are the editors for the content. While HemOnc.Org is not an accredited guidelines entity, they do offer valuable information on trial and medication abbreviations and names, dosing, evidence, and therapy options for patients, clinicians, pharmacists, and researchers. Until recently, pediatric regimens and their evidence were not well documented. SEER and the NCCR have funded a team of pediatric oncologists to better describe pediatric oncology therapies, add missing details to existing regimens, add missing guideline-recommended regimens and protocols, and perform landscape analysis for missing historic regimens and protocols. The HemOnc.Org team has re-organized information to make it easier to find pediatric oncology regimens by cancer, created new pages for different cancers, and added more detail about regimens. https://hemonc.org/wiki/Main_Page#peds

The **Pediatric Proton and Photon Consortium Registry (PPCR) linkage project** enabled a linkage between NCCR registries and the PPCR for eventual deposition into the NCCR and to identify patients who live in the US and are treated with radiotherapy at PPCR sites (around 2,700 patients treated by approximately 20 PPCR sites). The patient-level portion of the linkage is complete, with additional work ongoing into the new year. Look for more information and linkage results later this year.

The NCCR is envisioned as a connected data infrastructure to enable sharing of childhood cancer data, not just from central registries, but from myriad data sources. Twelve **NCI-designated Cancer Centers** were awarded supplemental NCI funds to aggregate, integrate, and submit existing data beyond the traditional cancer abstract, with the goal of expanding that infrastructure and ultimately supporting improved understanding of childhood cancer. In 2022, nine of the 12 NCI-designated Cancer Centers completed their data submissions to the NCCR.

Members of the NCCR Data Quality and Metadata Working Groups collaborated with NCI on a structured approach to developing new Site-Specific Data Items (SSDIs) for generating pediatric cancer stage according to the **Toronto Staging** Guidelines. The recommended SSDIs have been collated into one document titled "Implementation Guide for Toronto

Staging." The proposed new data items are based directly on Toronto Staging, and many are already collected by CTRs at pediatric facilities, but in a non-standardized way. Field test has been happening in the Kentucky Cancer Registry, and the SSDIs have been proposed for implementation in 2024.

NCCR*Explorer, the interactive web application for statistics based on NCCR data that was first launched in 2021, received some significant updates in 2022:

- A new feature was added to the Recent Trends graph for Incidence statistics. An information panel can now be displayed next to the graph that shows the Annual Percent Change (APC) estimates for the trend lines shown on the graph. To show the APCs, check the 'View APC' checkbox located above the graph.

- Data update to the NCCR*Explorer application including incidence and survival estimates based on North American Association of Central Cancer Registries (NAACCR) and Surveillance, Epidemiology, and End Results (SEER) Program registry submissions through diagnosis year 2019.

- The dataset used for this release represents 69% of the U.S. population and includes the following 24 NCCR cancer registries: California (3 registries: Greater Bay, Greater California, Los Angeles), Connecticut, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Kentucky, Louisiana, Massachusetts, Michigan, New Jersey, New Mexico, New York, Ohio, Pennsylvania, Seattle (Puget Sound), Tennessee, Texas, Utah, Wisconsin.

And finally, the **NCCR is drawing international attention, with presentations** at the UICC World Cancer Congress, in Geneva, Switzerland, and at the IACR 2022 Virtual Conference.

We wish to extend a heartfelt thank you to all those who have worked so diligently to make 2022 a success for the NCCR, and we look forward to working with you in the coming year as we continue to realize the full potential of this innovative initiative!

Virtual Pooled Registry Update

Castine Clerkin, MS, CTR
NAACCR Program Manager of Virtual Pooled Registry
cclerkin@naaccr.org

Welcome to 2023! I'm so excited to share the below updates on the Virtual Pooled Registry (VPR).

Happy Anniversary! February marks the first anniversary of the VPR's official launch! We have accomplished so much in the past year and couldn't have done it without the support of NCI, IMS, VPR workgroups and consultants, eager researchers, and most importantly the central cancer registries that have supported VPR linkages. Thank you all! I'd like to take a moment to share some noteworthy highlights from the past year:

- 45 registries, representing 95% of the U.S. population, participated in the VPR.

- Eight studies were reviewed and approved for Phase I linkage.

- Six studies, ranging in size from 14K to 10.9M, completed their Phase I linkages for a total of ~11.1M cohort members linked and ~564K high quality cancer matches identified.

- 38 registries currently use the Templated IRB/Registry Application (TIRA) for all or part of their review process, thereby reducing the number of individual applications from 58 down to the TIRA plus nine different applications.

- 24 registries have adopted the VPR Templated DUA in lieu of their existing registry DUA, thereby simplifying DUA completion and compliance.

- 12 registry IRBs ceded review to the NCI-funded Central IRB operated by the Biomedical Research Alliance of New York (BRANY), with more registries to follow.

- BRANY reviewed and approved six VPR studies, with each review taking two to three days to perform.

VPR Linkages for 2023

Eight new studies have been selected to use the VPR for registry linkage in 2023. In addition, the VPR will facilitate up to five outstanding study linkages from 2022 and relinkages for the Transplant Cancer Match Study and the Childhood Cancer Survivor Study.

New Central IRB (CIRB) website

As the CIRB for review of VPR studies, BRANY has a new website that provides an overview of the CIRB review process and activities to date, as well as guidance for local IRBs wishing to learn more about ceding review to BRANY. More information can be found here: https://www.brany.com/forms-downloads-vpr-cls-cirb/

VPR Templated DUA

The VPR Templated DUA has been posted on NAACCR's VPR webpage: https://www.naaccr.org/vpr-fact-sheets/ .

Secondary Data Sharing Initiatives

The NAACCR Secondary Data Sharing Task Force has been meeting monthly since April 2022 and recently finalized a Secondary Data Sharing Fact Sheet, which will be distributed through the NAACCR ListServ and posted to the NAACCR VPR webpage. The Task Force is also planning a secondary data sharing webinar for Wednesday, March 29, from 1-2:30 Eastern. **Please Save the Date!**

Wishing you all the best for the New Year!

Castine Clerkin
NAACCR VPR Program Manager

Winter 2023 Research & Data Use Update

Recinda Sherman, MPH, PhD, CTR
NAACCR Program Manager of Data Use and Research
rsherman@naaccr.org

We all know the about the Nobel prize, but some of you may not be aware of the satirical Ig Nobel Prize that honors unusual scientific achievements. In September 2022, the Ig Nobel Prize in Medicine was awarded to a group of researchers who showed that when patients go through chemotherapy for autologous hematopoietic stem cell transplantation, they may suffer fewer harmful side effects if eating ice cream is part of the procedure. Perhaps we need a NAACCR Taskforce to investigate how we might collect the dosage of ice cream?

Read all about it here: https://www.nature.com/articles/s41598-021-02002-x.

NAACCR Call for Data (CFD)

This year we had 68 of 70 registries successfully submit the NAACCR Call for Data, and all submitted in the XML format. All but one US registry has or plans to submit the 12-month data for cases diagnosed in 2021. This was an extremely tough year for many registries for myriad reasons, underscoring the on-going need for additional registry support and resources. We are still in the data quality evaluation process, and we will provide an update on how we will handle 2020 Completeness as soon as the evaluation is complete.

During CFD, the new Match*Pro Patient-level Deduplication protocol was a success based on the goal of deduplication, but there was a significant time investment for many registries. This year, we have not yet made the decision about whether we will require the update, tumor-level deduplication protocol for CFD. I strongly encourage you to attend the training webinar *Match*Pro Tumor-Level Deduplication Training for NAACCR Certification* on March 6. Here is the link to

register: https://naaccr.zoom.us/webinar/register/WN_6RVvEFgCSdG1Ci7FE6yBFA. For the past several months, we have been testing the update on a variety of registries. Will Howe at IMS is incorporating feedback into improving the program and providing resources to best support the registries. As you begin to work with this update, please reach out to me with any issues and concerns, so that we can use that information to inform our decision of when to make the Match*Pro Deduplication Tumor-level Protocol mandatory.

2020 Data

As expected, the impact of the pandemic has resulted in changes in cancer rates that do not reflect changes in actual burden. At this time, we do not plan to include 2020 rates in trend data. We are working with our partners to develop standardize language that will provide critical context to users about interpretation of the rates. As mentioned above, we will accommodate for the impact of pandemic related disruption of medical services on our completeness assessments for the purpose of Certification. But, again, we are still in the evaluation process.

Annual Report to the Nation

NAACCR and our collaborators are still working on the Part II publication for the Annual Report to the Nation covering data through diagnosis year 2018. This publication is an early assessment of the 2020 data, and it will be published late winter or early spring. NAACCR is the lead author for the next annual report, but due to intense interest in post-covid data by the public and the media, we have skipped an Annual Report for the data through diagnosis year 2019. The next ARN will be a special focus on 2020 data, and we hope the publication will help provide context for interpretation of results for local and regional data as well.

NAACCR Geocoder

As you are hopefully aware, we have been undergoing various security assessments for the NAACCR/TAMU Geocoder. We have materials regarding the TAMU/NAACCR Geocoder Security Assessment available for registries to review at: https://geo.naaccr.org/About/SecurityAssessment.aspx (this link requires a MyNAACCR sign-in). At this link (which is also available under the About Tab in the TAMU/NAACCR Geocoder Platform https://geo.naaccr.org/About/), we have posted:

- Results of the 2022 security assessment
- Written Executive Summary
- Oral overview of results (video presented to the NAACCR Geocoder Technical WG)

There is also general security information in the Data Confidentiality and Security section, also on the About Tab. We continue to monitor and assess the TAMU/NAACCR geocoder for security weaknesses and will release updated annual assessments.

If you or your registry would like additional details, please contact me. Because detailed security information is both proprietary and has the potential to identify vulnerabilities, we will need a signed NDA before we can release additional information.

****

For more information or to get involved in one of these issues, please contact me. And, as always, if you have any questions, concerns, or revolutionary ideas in any other part of the NAACCR Research and Data Use area, please contact me rsherman@naaccr.org.

Upcoming Webinar Presentations

Angela Martin, CTR
NAACCR Trainer/Project Coordinator

Feb 2023	
02/21/2023	NAACCR CTR Exam Prep and Review Webinar Series Session 3
02/28/2023	NAACCR CTR Exam Prep and Review Webinar Series Session 4
Mar 2023	
03/02/2023	NAACCR Webinar Series: Abstracting and Coding Boot Camp 2023
03/06/2023	NAACCR Talk: Match*Pro Tumor-Level Deduplication Training for NAACCR Certification
03/07/2023	NAACCR CTR Exam Prep and Review Webinar Series Session 5
03/14/2023	NAACCR CTR Exam Prep and Review Webinar Series Session 6
03/21/2023	NAACCR CTR Exam Prep and Review Webinar Series Session 7
03/28/2023	NAACCR CTR Exam Prep and Review Webinar Series Session 8
April 2023	
04/06/2023	NAACCR Webinar Series: Prostate 2023
May 2023	
05/04/2023	NAACCR Webinar Series: Lower GI 2023 Part 1

For more information about NAACCR education and training opportunities, or to register online, go to the Education and Training site https://education.naaccr.org/upcomingevents or contact Angela Martin (amartin@naaccr.org).

Publication Information
NAACCR Board of Directors, 2022-2023