



Delaware Cancer Consortium
Delaware Cancer Registry Advisory Committee (DCRAC)
Monday, July 8th, 2024
Approved Meeting Minutes
Location:
Thomas Collins Building
540 S. DuPont Hwy.,
Dover, DE 19901
Time: 10:00am – 11:00am

Attendance

Members

Attended	Robert Hall-McBride, Christiana Care Health Systems
Did Not Attend	Stephanie Guarino, Nemours
Attended	James M. Monihan, MD, Allied Diagnostic Pathology Consultants, PA
Attended	Nicholas Petrelli, MD, Helen F. Graham Cancer Center
Did Not Attend	Rishi Sawhney, MD, Bayhealth Medical Center
Attended	John D. Shevock, Bayhealth Medical Center
Attended	James Spellman, MD– Beebe Healthcare - Tunnell Cancer Center

Staff

Attended	Wilhelmina Ross, Delaware Cancer Registry/Westat
Attended	Jason Lawson, Delaware Division of Public Health
Did Not Attend	Sumitha Nagarajan, Delaware Division of Public Health

Welcome

Attendance was recorded of committee members participating in the hybrid meeting.

Old & New Business

Approval of Minutes

The DCRAC reviewed and approved the minutes from the January 2024 meeting as written.

National Data Quality Standards: Missing/Unknown Race and County: Update

Dr. Nicholas Petrelli, DCRAC Chair, brought up the previously discussed issue of percentage of missing race and county data meeting national data quality standards and improving the completeness of these fields. Ms. Wilhelmina Ross, Project Manager, stated that the registry is still working on assessing these items. Registry staff utilize the Delaware Health Information Network (DHIN) to supplement the data when possible. Ms. Ross has heard other states are experiencing difficulties with collecting race data as well. As for missing county data, geocoding more often and performing data linkages may help.

Leftover Funds from DCRA Meeting, Check Issues: Update

Dr. Petrelli brought up a previously discussed issue with a check of leftover funds from the National Cancer Registrar's Association (NCRA) conference Delaware state basket

and asked whether the issue had been resolved and the funds had been deposited. Ms. Ross will follow up with Ms. Maricarmen Traverso-Ortiz, the Education and Training Coordinator and will report back to the DCRAC members at the next meeting.

Challenges Associated with Address Data: Update

Dr. Petrelli also brought up the previously discussed issues with incomplete address data that Ms. Diane Ng, Data Analyst, presented on at a prior meeting. One possibility to improve completeness/quality of address data would be to link with the Department of Motor Vehicles (DMV). This was denied by the DPH Privacy Board since it would require releasing Protected Health Information (PHI) to the DMV. Another possibility to be investigated was finding out the costs associated with running batch linkages with Accurint. Ms. Jennifer Miles, Chairperson of the Department of Public Health (DPH) Privacy Board, added that there was another in-house database possibility available for linkage. Mr. Jason Lawson, IT Manager, stated that the system is called Master Client Index (MCI). MCI is a central repository for information on all clients that receive services through the DHSS. The IT team is looking into the feasibility of this linkage, but it is still in early stages and Mr. Lawson hopes to be able to provide an update at the next meeting.

DCR Information Technology Modernization Plan/ Overview of EMaRC+, WebPlus and Migration to CRS Plus

Mr. Lawson gave updates on the Delaware Cancer Registry's (DCR) Information Technology Modernization Plan. EMaRC Plus and WebPlus have new versions available, but the IT Team will wait until some time has passed for software bugs to be identified and fixed before implementing these versions. Mr. Lawson will also discuss with Ms. Ross to decide when to move forward with the upgrade. The registry is exploring switching from Rocky Mountain Cancer Data Management System (RMCDS) to CRS Plus, a CDC software, because the CDC is hoping to make its products cloud-based, which would be beneficial in multiple ways. This investigation is still in the exploratory phase. Mr. Lawson hopes to give an update on this at the next meeting.

Registry Updates

Ms. Ross provided updates on the operations of the DCR. Multiple staff recently returned from the North American Association of Central Cancer Registries (NAACCR) conference in Idaho. DCR received Gold Certification, the highest possible certification, from the National Program of Cancer Registries (NPCR) for their 2023 annual Call for Data submission. Data completeness for 2021 data was 101.6% complete. Since the registry performed so well on completeness, the expected number of cases for the registry was increased. Currently, the registry is at 81% completeness for 24-month data after adjustment using the newly expected caseload counts from the Data Evaluation Report (DER). Data collection is still underway.

Ms. Ross announced that the registry is working with the Department of Veteran's Affairs (VA) in Delaware to receive their cancer cases in the future. The VA stopped reporting to the DCR in 2018 due to budget constraints but are interested in resuming case reporting gain. DCR is working with them to finalize a Business Associate Agreement (BAA) and

Memorandum of Understanding (MOU). Once this is in place, the registry can start receiving VA cases again.

DPH Privacy Board Overview

Ms. Jennifer Miles, Chairperson of the DPH Privacy Board, gave a presentation summarizing the structure and function of the DPH Privacy Board. Ms. Miles gave an overview of the Privacy Board, guiding legislation, the definition of research, and the DPH data request process. Anyone wanting to request DPH data can do so at the DPH website. Ms. Ross will distribute these slides to the members of this committee. Dr. Petrelli noted that most investigators probably are not aware that the data request process can take over a month, so investigators need to allocate at least a month of time to allow for the request to process. Dr. Petrelli asked if there are any ways to streamline the request timeline, and Ms. Miles responded that if the investigator provides as much information as possible for their request, it will help.

Epidemiology Working Group Updates

Ms. Ross gave updates on the operations of the Epidemiology Working Group. Three articles were submitted to the Delaware Journal of Public Health. One is an update to a 2013 colorectal cancer paper authored by Dr. Stephen S. Grubbs, Christiana Care. The second is an analysis of Commission on Cancer (CoC) quality of care measures in Delaware using registry data from 2018-2019. The third paper details Delaware's participation in the National Cancer Institute (NCI)/NAACCR Zone Design Project. Ms. Ross will update the committee members when she has more information on which issue of the journal the articles will be published in.

The registry has also been looking into a study investigating the COVID-19 pandemic and cancer. A preliminary search has been conducted on existing literature on this topic. Internally, they would like to study cancer screening and late-stage disease rates in Delaware pre-, during, and post-COVID-19 pandemic. However, more time needs to be allowed before analyzing late-stage disease data. Ms. Ross anticipates they will need committee members' expertise during this process, specifically concerning the COVID-19 policies that impacted healthcare operations and delivery at their facilities. Ms. Ross asked committee members if they could search for this data and provide timelines. Dr. Petrelli asked Ms. Ross what the endpoint of the study would be. Ms. Ross replied that the concept is still in development, but that they're expecting to see a rise in late-stage disease and a decrease in screening rates during the pandemic, and they aim to compare these rates in Delaware to the national rates. Mr. John Shevock, Bayhealth, mentions that the CoC screening project may be helpful in obtaining screening data. An additional potential future project is to examine HPV vaccination and cervical cancer rates over time.

Data Request Process Presentation

Ms. Ross presented slides that were created at the committee's request that are meant to guide investigators through the DPH data request process and answer frequently asked questions. Ms. Ross asked for committee feedback on these slides since they would be posted on the DPH website as an instructional guide. Ms. Ross will distribute these slides to the committee members for review.

Committee Member Participation Updates

Dr. Petrelli asked Ms. Ross whether Ms. Jessica Beckstrand, American Childhood Cancer Organization, had been thanked for her service to the committee since the last meeting. Ms. Ross confirmed this has occurred. Ms. Ross will also extend an invitation to Ms. Rita Williams, Beebe Hospital, to join the committee, and cc Dr. Petrelli, as members agreed that she would be a great addition to the committee.

Brainstorming Ideas for Future Meetings

Dr. Petrelli led the brainstorming discussion for future meeting topics. He requested this agenda item be moved to the top of the agenda and discussed at length at the next meeting.

Death Certification Issues

Dr. James Spellman, Beebe Healthcare, requested an update on the ongoing Death Certification data issue with classifying primary cause of death. Dr. Petrelli shared that there has been no further guidance other than what was discussed on a previous call with CDC, and there is a guidebook that has been sent out that members may review for further guidance. Dr. Spellman asked if there had been a resolution on the computer issue that would only allow him to input a cancer diagnosis as the primary cause of death, flagging it as incorrect otherwise. Dr. Petrelli will follow up on this with Ms. Mirabel Dizon, Delaware Bureau of Health Statistics and Vital Statistics, to see if it has been resolved.

Next Steps:

- Ms. Ross will check with the DCRA about the leftover funds to find out if it has been deposited.
- Ms. Ross will send the data requests presentations to the committee members for review and feedback.
- Mr. Lawson will investigate the feasibility of linkage with MCI and provide an update at the next meeting.
- Mr. Lawson will provide an update at the next meeting on the investigation into switching to CRS Plus.
- Ms. Ross will distribute both Ms. Miles' presentation and her Data Request Process slides to the committee members after the meeting.
- Ms. Ross will follow up on recruiting the new member and extend an invitation to Ms. Rita Williams at Beebe Hospital to join the committee.
- Move Brainstorming agenda item to the top of the agenda for next meeting.
- Dr. Petrelli will follow up with Ms. Mirabel Dizon about the computer/systems issue with entering primary cause of death.

Future Meetings	
Next Meeting: October 14, 2024 - Hybrid	Upcoming Meetings: Dates - TBD January 2025 April 2025 July 2025 October 2025