|  |  |
| --- | --- |
| **Delaware Cancer Consortium**  **Delaware Cancer Registry Advisory Committee (DCRAC)**  **Monday, January 8th, 2024**  **DCRA Combined Meeting**  **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 |
| Attended | Stephanie Guarino, Nemours |
| Attended | James M. Monihan, MD, Allied Diagnostic Pathology Consultants, PA |
| Attended | Nicholas Petrelli, MD, Helen F. Graham Cancer Center |
| Attended | Rishi Sawhney, MD, Bayhealth Medical Center |
| Attended | John D. Shevock, Bayhealth Medical Center |
| Did Not Attend  Did Not Attend | James Spellman, MD– Beebe Healthcare - Tunnell Cancer Center  Jessica Beckstrand, American Childhood Cancer Organization |
|  |  |
| **Staff** |  |
| Attended | Wilhelmina Ross, Delaware Cancer Registry/Westat |
| Attended | Jason Lawson, Delaware Division of Public Health |
| Attended  Attended | Sumitha Nagarajan, Delaware Division of Public Health  Diane Ng, Delaware Cancer Registry/Westat |

**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 October 2023 meeting as written.

**DCR Information Technology Modernization Plan**

Mr. Jason Lawson, IT Manager, gave updates on the Delaware Cancer Registry’s (DCR) Information Technology Modernization Plan. At the last meeting he mentioned that EMaRC had a minor patch that needed to be tested, but this was put aside to prioritize for the annual Call for Data Submission. Then the new version of EMaRC+, Version 23 (v23) was released. The plan is to finish testing the patch and then upgrade. In 1-2 months, EMaRC+ will be upgraded. In WebPlus, there is a minor issue that is being fixed. Dr. Nicholas Petrelli, DCRAC Chairman, requested at the next meeting if Mr. Lawson could give a brief overview of both EMaRC+ and WebPlus for the new committee members and Mr. Lawson agreed.

**Registry Updates/2022 Data Submission Results**

Ms. Wilhelmina Ross, Project Manager, gave updates on the latest activities of the DCR. They recently finished the submission for the Annual 2023 Call for Data. There were additional 2020 cases submitted to the registry that increased the total number of 2020 cases by approximately 600. This trend was observed at other registries as well. DCR is waiting to see if the Centers for Disease Control (CDC) will issue a correction/adjustment for completeness numbers. The Death Certificate Only (DCO) percentage is anticipated to be around 1.19% per DCR calculations.

Ms. Ross then shared a presentation displaying results from 2022’s Call for Data submission which was submitted in November 2022. DCR received Gold Certification for the quality of their data submission for 2020 data. The diagnosis years contained within the submission file were 1995-2021. The file met National Data Quality Standards for diagnosis years 2003-2020. There was a 0% duplicate rate, and the file was 100% error free for those years as well. DCR did receive feedback from CDC that the percentage of missing/unknown race and county was one area of potential improvement. For the 24-month data which comprised of diagnosis year 2020, completeness was at 96.2%. For 12-month data, the completeness was 60.6%. At that time there were not any guidelines on 12-month data, but this year there will be a target of 90% completeness for 12-month data. Facilities should be prepared to send their 12-month data earlier than usual to meet this goal.

**DCRA Updates**

Ms. Colleen Grosso, Delaware Cancer Registrar’s Association (DCRA) President, gave updates on behalf of DCRA. Each year at the National Cancer Registrar’s Association (NCRA) conference, there is an opportunity for each state to participate in putting together a basket for a registrar to win. For 2023, Delaware put together a basket which was sent to the winner. After the conference, the association collects all funds that were sent for the basket prize and raffles and distributes these leftover funds to the state. The leftover amount is sent on a check and is normally donated to a cancer center in Delaware. This year Ms. Grosso is having trouble depositing the check so she can donate it, since it is written out to DCRA, and the association no longer has a bank account. She is waiting to hear back from NCRA about the issue and hopes to have the check reissued to the State of Delaware and she would like to know the process to do so. Another option is to have to check rewritten directly to the cancer centers receiving the donations, or the check could be directly donated back to NCRA’s Educational Foundation.

The DCRA will be holding their first meeting of the year today followed by an educational webinar. They will meet again in April or May of this year for an educational conference and again in the fall around September or October. The DCRA has recently had an influx of new members joining and are planning more interactive activities for members.

Mr. Hall-McBride also reminded the group that the national Certified Tumor Registrar (CTR) credential has been renamed to Oncology Data Specialist (ODS).

**Death Certification Updates**

Dr. Petrelli gave an update on his ongoing discussion with Dr. James Spellman, Beebe Healthcare, Dr. Rishi Sawhney, Bayhealth, and John Shevock, Bayhealth, regarding death certificates and cancer. There is a concern that incorrectly reporting primary cause of death could be skewing the cancer rate in the state. There was a meeting with the CDC about this issue and some additional help from the State of Delaware as well. Dr. Robert Anderson, Chief of the Mortality Statistics Branch at the CDC, sent out some information about the proper process for filling out death certificates. Dr. Anderson was invited to speak with Delawarean physicians about this process with an emphasis on cancer and will be speaking on January 17th. They are in the process of trying to make the presentation virtual as well as in-person. Dr. Petrelli will distribute the virtual meeting link as soon as it is available.

**Address Data for Cancer Reporting and Analysis**

Ms. Diane Ng, Registry Research Associate, gave a presentation regarding address data and cancer analysis. DCR expects to receive address data at the time of diagnosis, but if this is not available the registry will seek the address from other sources. These addresses are then geocoded to determine the coordinates of areas associated with this address such as county and census tract. This data is then used for geospatial analysis and reporting. Challenges associated with address data include quality, accuracy, and precision. Ms. Ross brought up that other states link with their Department of Motor Vehicles (DMV) databases to complete their address data and improve data quality. She asked the group whether that would be feasible for Delaware. Ms. Ng is also going to investigate costs associated with running a batch linkage through the Accurint service.

**Epidemiology Working Group/My Healthy Community and NCI/NAACCR Cancer Zone Project Web Tool Updates**

Ms. Sumitha Nagarajan, Chronic Disease Epidemiologist, gave updates on the National Cancer Institute (NCI)/North American Association of Central Cancer Registries (NAACCR) Zone Project and the Epidemiology Working Group. Current data up until 2018 is displayed on the My Healthy Community website with supplemental data updates from 2015-2019 and 2016-2020 available to add. However, funding for My Healthy Community is limited, so the data will become updated when funding becomes available.

Users are now able to input their address in the NCI/NAACCR Zone Tool to see 5-year or 10-year trends, as well as other data such as demographics, income, and poverty level by geographic area. Next steps for the project include adding 2016-2020 data, providing cancer incidence rates by county, and incorporating data on cancer mortality.

**Data Request Tutorial Presentation**

Ms. Nagarajan discussed the Data Request Process for DCR. Data requests have been declining and DCR hopes to increase the public’s use of their data. The data request process is online. All requests must go through a Department of Public Health (DPH) Privacy Board Review. Next steps are to add a formal data dictionary of DCR data utilizing NAACCR guidelines. Ms. Nagarajan will create a PowerPoint to publicly share about the process and will send to DCRAC members to review. Dr. Sawhney reiterated that DCR also needs to investigate the process and see if any of it could be streamlined to make requesting data more efficient and accessible. Ms. Nagarajan will reach out to Ms. Jennifer Miles, Chairperson of the DPH Privacy Board, and invite her to a future meeting.

**Committee Membership**

Dr. Petrelli noted that some members have been absent from meetings. He also noted that the committee is lacking a representative from Nanticoke since Ms. Rachel Gardner, Nanticoke, is no longer on the committee. Ms. Roxann Nichols, Beebe Hospital, is also no longer an active member. Ms. Jessica Beckstrand, American Childhood Cancer Organization, has not attended any meetings and will be thanked for her participation and dismissed.

**Next Steps:**

* At next meeting, Mr. Lawson will give an overview of EMaRC+ and WebPlus.
* Distribute virtual meeting link to Dr. Anderson’s presentation.
* Investigate DMV database linkage and Accurint batch costs.
* Invite Ms. Jennifer Miles from the DPH Privacy Board to attend a future meeting and prepare Data Request statistics and PowerPoint.

**Future Meetings**

|  |  |
| --- | --- |
| **Next Meeting:**  **April 9, 2024 – Retreat – In- Person** | **Upcoming Meetings:**  **July 8, 2024- Hybrid**  **October 14, 2024 - Hybrid** |