|  |
| --- |
| **Delaware Cancer Consortium** **Delaware Cancer Registry Advisory Committee (DCRAC)** **Monday, July 10, 2023****APPROVED Minutes****HYBRID Meeting**Location: Edgehill Training Center 43 S. DuPont Hwy., Dover, DE 19901**Time: 10:00am – 11:00am**  |
|  |
| **Attendance** |
|  |  |

|  |  |
| --- | --- |
| **Members** |  |
| Did Not Attend | Rachel Gardner, Nanticoke Health Systems |
| Did Not Attend | Robert Hall-McBride, Christiana Care Health Systems |
| Did Not Attend | Stephanie Guarino, Nemours |
| Attended | James M. Monihan, MD, Allied Diagnostic Pathology Consultants, PA  |
| Did Not Attend | Roxann Nichols, Beebe Hospital, Tunnell Cancer Center |
| Attended | Nicholas Petrelli, MD, Helen F. Graham Cancer Center |
| Attended | Rishi Sawhney, MD, Bayhealth Medical Center |
| Attended | John D. Shevock, Bayhealth Medical Center |
| AttendedDid Not AttendDid Not Attend | James Spellman, MD– Beebe Healthcare - Tunnell Cancer CenterJessica Beckstrand, American Childhood Cancer OrganizationAubrey Reichard-Eline, American Childhood Cancer Organization |
|  |  |
| **Staff** |  |
| Attended | Wilhelmina Ross, Delaware Cancer Registry/Westat |
| Attended | Jason Lawson, Delaware Division of Public Health |
| AttendedAttended AttendedAttended | Sumitha Nagarajan, Delaware Division of Public HealthPaulette Robinson-Wilkerson, Delaware Division of Public HealthMaxwell Amoako, Delaware Division of Public HealthDavid Rockwell, Westat IT |

**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 April 2023 meeting as written.

**Member Participation**

Dr. Nicholas Petrelli, DCRAC Chairman, inquired about the participation status of three committee members: Aubrey Reichard-Eline; Roxann Nichols; and Stephanie Guarino. He asked Ms. Wilhelmina Ross, Project Manager, to follow up with these members to poll their continued interest in being on the committee. Aubrey Reichard-Eline has left her job at the American Childhood Cancer Organization (ACCO) and will no longer be participating in the Delaware Cancer Registry Advisory Committee (DCRAC). Stephanie Guarino is still interested in participating but has a conflict. She will plan to be at the next meeting. Delaware Cancer Registry (DCR) staff is awaiting a response from Roxann Nichols, Beebe Hospital, and will continue to follow up.

**DCR Information Technology Modernization Plan**

Mr. Jason Lawson, IT Manager, gave updates on the DCR IT Modernization Plan. EMaRC+, which is the Centers for Disease Control (CDC)’s software used to receive lab results electronically, is currently in North American Association of Central Cancer Registries (NAACCR) Version 22 (v22), awaiting the release of NAACCR Version 23 (v23). They are working on getting a patch and some specific software fixes applied that will resolve software-wide issues related to dates on cases from 2018 or later. WebPlus, the software through which providers can submit their cancer cases electronically, is also currently on NAACCR v22. Mr. Lawson and his colleagues will begin the WebPlus update to NAACCR v23 sometime this summer.

**Registry Updates – Feedback from the CDC Site Visit (June 5-6, 2023, Dover, DE)**

Ms. Wilhelmina Ross, Project Manager, gave updates on the CDC Site Visit. It went very well. Ms. Ross shared the feedback they received from the CDC. Topics covered during the Site Visit included: Data Modernization, Electronic Data Exchange, Cancer Surveillance, Data Completeness and Quality Activities, Quality Assurance, Westat and Delaware Department of Public Health (DPH) organizational structure, Data Use and Monitoring, Collaborations, and Evaluation.

Ms. Ross stated that one area of feedback was data completeness. The CDC has set a target of 90% completeness for 12-month data. This criterion will be set as a standard for the 2024 national data submission. In recent years the DCR has not reached the 90% completeness mark for the 12-month data, with current completeness estimates at 47% thus far. However, the DCR does routinely meet the 24-month data standards set by the CDC. Currently, the DCR data is at 94% completeness for 24-month data. Ms. Ross also mentioned there is a delay in reporting, and encouraged facilities to report cases in a timelier manner so that the estimated completeness percentages improve before data submission.

Dr. Nicholas Petrelli, DCRAC Chairman, reported timeliness issues with Christiana Care’s external registrar staffing company, Champion Registry Group. Dr. James Spellman, Beebe Healthcare, had concerns with the same group regarding their inclusion and exclusion criteria and how it is being applied. Dr. Petrelli asked Mr. John Shevock, Bayhealth, if his facility is using an external registrar staffing company and having issues. Mr. Shevock confirmed they use a mix of outsourced and in-house registrars but do not utilize Champion Registry Group. He was not aware of any issues with timeliness of reporting but did mention software updates to their electronic medical record (EMR) systems can change the efficiency of how it interfaces with their cancer registry software, and must be fixed when it occurs.

Mr. Shevock inquired about the DCR’s process for follow-up to facilities if cancer information is missing at the central registry. Ms. Ross explained that DCR is an incidence registry and thus does not usually track follow-up information. DCR does follow-up, however, in case finding instances or death clearance procedures. She explained that process to the committee.

Dr. Spellman brought up usability and accuracy issues with inputting Death Certificate data. The online electronic system will not accept specific causes of death that aren’t related to cancer. Dr. Petrelli asked if there was a contact they could speak to from Vital Statistics about these data quality concerns. By the time these minutes were prepared, Ms. Ross located a contact, Maridelle A. Dizon, within the Bureau of Health Statistics and Vital Statistics that maintains the Delaware Vital Events Registration System (DelVERS) that houses electronic death registration and forwarded this contact to Dr. Petrelli.

Another area of feedback was the Race Unknown (%) category. This percentage has slowly been increasing over the last five years. DCR is investigating this issue and has preliminarily found that this information is not being received from the reporting facilities. The DCR staff plan to reach out to reporters to further assess the barriers to reporting and will continue to utilize the Delaware Health Information Network (DHIN) to find the missing Race information.

Lastly, Ms. Ross reviewed Breslow Tumor Thickness in melanoma cases, diagnosed between 2018 and 2020, as the third area of feedback. The percentage of unknown values increased for this data item as well. After investigation, DCR found that registrars are not reporting this item to the DCR in several instances. DCR will re-educate and create different displays for dermatology facilities that routinely report melanoma. Dr. James Monihan, Allied Diagnostic Pathology Consultants, PA, pointed out that many dermatologists do not use Breslow Thickness anymore, instead utilizing Clark’s level staging.

In summary, DCR met the National Program of Cancer Registries (NPCR)’s 24-month standards for all five recent data submissions but should monitor the percentage of unknown race and Breslow Tumor Thickness. An excellent overall accuracy rate was found for major errors in the most recent data quality evaluation. DCR was overall found to have activities in place to ensure high data quality.

**Epidemiology Working Group**

Ms. Sumitha Nagarajan, Chronic Disease Epidemiologist, gave two updates regarding the Epidemiology Working Group. DCR data is in the process of being displayed on both the My Healthy Community website and the web tool that Westat is creating for Delaware DPH which is associated with the National Cancer Institute (NCI)/NAACCR Cancer Zone Project. One issue is that My Healthy Community has different reporting time periods than Delaware DPH, so they are working to figure out how to resolve this issue before rollout. Ms. Nagarajan will give an update on this progress at the next meeting. Westat has almost finished with their NCI/NAACCR Cancer Zone Project Web Tool and Ms. Nagarajan will also give an update on this at the next meeting.

**Data Modernization**

Ms. Ross and Mr. David Rockwell, Westat IT Analyst, gave updates on data modernization opportunities for DCR. Ms. Ross explained that the CDC NPCR program will be moving to a cloud-based reporting platform. This platform will have the capacity to reduce cancer reporting delays as well as bring more data modernization to the cancer surveillance field. DCR staff also is thinking to modernize processes at the central in anticipation of cloud-based cancer reporting as it will be necessary to process cases more efficiently and timely to reduce lag time in the availability of cancer registry data. There are opportunities to utilize Natural Language Processing (NLP), Optical Character Recognition (OCR), and Power BI for the automation of various processes such as security, hardcopy processing/formatting, auditing/tracking files, messaging, and quality assurance activities. Dashboards can also be created for data visualization, announcements, user information, secure file transfer, and more based on the specific user.

**Next Steps**

* Continue to monitor registry completeness numbers and areas of improvement identified by the CDC Site Visit.
* Locate contact from Vital Statistics/the Electronic Death Registration System to speak to about death certificate electronic system concerns.
* Update on My Healthy Community and Westat’s NCI/NAACCR Cancer Zone Project Web Tool at the next meeting.

**Future Meetings**

|  |  |
| --- | --- |
| **Next Meeting:****October 16, 2023** | **Upcoming Meetings:** **January 2024- Exact date TBD** |