December 19, 2019

The Honorable Larry Hogan
Governor
State of Maryland
Annapolis, MD 21401-1991

The Honorable Thomas V. Mike Miller, Jr.
President of the Senate
State House, H-107
Annapolis, MD 21401-1991

The Honorable Adrienne A. Jones
Speaker of the House of Delegates
State House, H-101
Annapolis, MD 21401-1991

RE: **Ch. 251 of the Acts of 2001 (HB 636) and HG §18-204(b)(6) 2019 Legislative Report of the Maryland Cancer Registry**

Dear Governor Hogan, President Miller, and Speaker Jones:

Pursuant to Health-General Article, §18-204(b)(6), Annotated Code of Maryland, the Maryland Department of Health is directed to submit this annual legislative report on the activities of the Maryland Cancer Registry.

If you have any questions about this report, please contact me or my Chief of Staff Tom Andrews at 410-767-0136 or Thomas.andrews@maryland.gov.

Sincerely,

Robert R. Neall
Secretary

Annual Report
Maryland Cancer Registry

Health–General §18-204(b)(6)
Fiscal Year 2019

Robert R. Neall
Secretary

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1. INTRODUCTION

Health-General Article, §18-204(b)(6), Annotated Code of Maryland requires an annual report on the Maryland Cancer Registry (MCR). This report covers the period from July 1, 2018 through June 30, 2019 (Fiscal Year 2019). The MCR is a cancer incidence data system maintained under the direction of the Maryland Department of Health (MDH). Data in the MCR are used to monitor trends in cancer incidence; identify differences in cancer incidence by age, sex, race, and geographic location; plan and evaluate cancer prevention and control programs in the State; and provide a valuable resource for cancer research.

The Maryland Cancer Reporting law, enacted in 1992, requires the electronic submission of all new cases of cancer diagnosed or treated in Maryland to the MCR by hospitals, radiation therapy centers, laboratories, and freestanding ambulatory care facilities.[1] The reporting law was amended in 1996 to require reporting by physicians whose non-hospitalized cancer patients are not otherwise reported. The law was later amended to require the reporting of benign brain and central nervous system tumors to the MCR beginning October 1, 2001.

MDH subcontracts MCR data collection, data management, and quality assurance activities to an outside entity. For the first six months of Fiscal Year 2019 (July 1, 2018 – December 31, 2018), Westat, Incorporated (Westat), provided quality assurance and database management services for the MCR. Myriddian, LLC (Myriddian) assumed responsibility for providing quality assurance and database management services for the MCR on January 1, 2019. Myriddian was selected through the State procurement process as the vendor for the MCR for a five-year contract period from January 1, 2019 through June 30, 2023.

2. MARYLAND CANCER REGISTRY MISSION STATEMENT

The Maryland Cancer Registry Advisory Committee adopted the following mission statements for the MCR:

1. Oversight of activities that implement Health-General Article, §18-203 and §18-204, Annotated Code of Maryland, and COMAR 10.14.01 - Cancer Registry;

2. Timely, cost-effective, complete, and accurate ascertainment of new cases of cancer and benign central nervous system tumors among Maryland residents;

3. Computerization of cancer reports to facilitate ready availability, accessibility, and analysis; and

4. Preparation and dissemination of reports on the incidence and stage of cancer at diagnosis, which provide information on the cancer site, county of residence, and date of diagnosis.

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[1] Md. Ann. Code Health-General Art., §§ 18-203 and 18-204.

3. FISCAL YEAR 2019 ACTIVITIES

3.1 ADMINISTRATIVE ACTIVITIES

The MCR-Quality Assurance/Data Management team at Westat provided quality assurance and data management activities for the first six months of Fiscal Year 2019 and met with MCR staff at least monthly to discuss progress and plans for the transition to a new contractor. Myriddian began providing quality assurance and data management for the MCR beginning on January 1, 2019. The Myriddian team and MCR staff met weekly through April 2019 and then once every two weeks thereafter. Data were exchanged twice with surrounding states and the District of Columbia cancer registries. Maryland also sends and receives data from other states and regional registries that are signatories to the National Interstate Data Exchange Agreement (Agreement). As of June 30, 2019, 50 registries, including District of Columbia, Guam, Puerto Rico, and Virgin Islands, are participants in the Agreement.

3.1.1 Cancer Registry Advisory Committee

The Cancer Registry Advisory Committee met three times during Fiscal Year 2019 to receive updates from MCR staff and provide feedback. Elizabeth Platz, MPH, ScD, was introduced as the new Chairperson at the October 4, 2018 meeting. Dr. Platz is a cancer epidemiologist who serves as a professor at the Johns Hopkins Bloomberg School of Public Health. Discussion topics for meetings included MCR quality assurance and data management activities, data use and dissemination, data submission, data use policy and procedures, MCR regulations, Meaningful Use,[2] availability of Maryland data, North American Association of Central Cancer Registries (NAACCR) conversion updates, and cancer research and surveillance activities.

3.1.2 Administrative Activities – MCR Headquarters

The MCR is charged with administrative and custodial oversight of all MCR operations and data. The MCR monitors reporting compliance, reviews research requests prior to Institutional Review Board submission, and analyzes data for MDH program planning. MDH also processes and fulfills data requests from the public, reporting facilities, local health departments, researchers, and the media. Administrative highlights during Fiscal Year 2019 included:

1. CDC NPCR National Data Completeness and Quality Standard:
    The US Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) recognized the MCR as a "Registry of Distinction." This achievement indicated that the MCR met the CDC NPCR National Data Completeness and Quality Standard. Of the 50 cancer registries supported by CDC, the MCR was one of 22 that achieved the designation for the most recent data submission. Meeting these standards

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[2] Meaningful Use is using certified electronic health record technology to: improve quality, safety, efficiency, and reduce health disparities; engage patients and family; improve care coordination, and population and public health; and maintain privacy and security of patient health information. (https://www.healthit.gov/topic/meaningful-use-and-macra/meaningful-use-and-macra)

allows Maryland's data to be included in the 2019 United States Cancer Statistics report and other analytic data sets.

2. National Interstate Data Exchange Agreement:
   The MCR continues to participate in the National Interstate Data Exchange Agreement to address issues related to patients diagnosed and/or treated for cancer in a location that is different from their state of residence. The MCR exchanged cancer data with 29 other states in Fiscal Year 2019.

3. NAACCR Certification:
   The MCR submitted 2016 incidence data for evaluation and confidential feedback from the NAACCR and received "gold" certification, which is the highest level of certification. The certification includes review of the following areas: completeness of case ascertainment, completeness of information recorded, percentage of "death certificate only" cases, duplicate primary cases, passing edits for specific coding requirements, and timeliness.

4. Social Security Death Index:
   The MCR linked Maryland data with the Social Security Death Index to obtain more complete death information on cases in the MCR.

5. Linkage with Breast and Cervical Cancer Program Database:
   The MCR linked its database with the MDH Breast and Cervical Cancer Program database of cancer cases diagnosed from 2008-2016, resulting in a 100 percent case match across both files. This annual exercise assists in case finding and is a requirement of federal grant funding for both the MCR and the Breast and Cervical Cancer Program.

6. NAACCR Conversion of the MCR database from Version 16D to 18C:
   The MCR began its software program conversion to NAACCR Version 18C in Fiscal Year 2019. Because of recent changes made by cancer data standard setters, updates in the Registry Plus programs provided by CDC have been delayed. The MCR expects to complete the conversion when all of the Registry Plus programs are released in Fiscal Year 2020.

7. MCR Training Webinars:
   The MCR hosted a series of NAACCR-presented webinars on topics that included abstracting cancer incidence and treatment data by hospital tumor registrars, and cancer surveillance data collection by central cancer registries. Certified tumor registrars may access the pre-recorded webinars at their facilities and are granted continuing education units upon completion of the webinars.

8. National Cancer Registrars Week (April 8-12, 2019):
   During National Cancer Registrars Week, the MCR recognized the dedicated work of Maryland certified tumor registrars who submit quarterly data to the MCR. The Maryland

Governor's Office issued a Proclamation recognizing certified tumor registrars and the MCR sent a letter of appreciation to each reporter.

9. Motor Vehicle Administration Unknown Race Look-Up:
    To identify the race of individuals reported as "unknown race" in the MCR, MCR staff searched 4,254 names in the Motor Vehicle Administration database to obtain the missing race information.

3.1.3 Quality Assurance and Data Management Activities

Westat and Myriddian performed quality assurance and data management services for the MCR including: accepting cancer reports from facilities; case finding; quality assurance and quality control of data submitted; and submission of data to NAACCR and NPCR. Specifically, Westat and Myriddian completed the following activities during Fiscal Year 2019:

- Received and processed reports to the MCR (see Table 3.4.1).
- Transitioned MCR databases from Westat to Myriddian.
- Established data backup and recovery procedures for MCR production hosts (Database, RDS, and WebPlus).
- Established a ticketing system for tracking and managing reporter, facility, and information technology tasks and communications.
- Completed de-duplication by Social Security number, first and last name, and date of birth for years 1996 to 2017.
- Ran the latest derived Hispanic and Asian/Pacific Islander ethnicity algorithm and wrote back the results to the master file for the entire database through the year 2017.
- Continued to perform internal quality assurance activities including: peer-to-peer oversight; director supervision; and the production of monthly, quarterly, and annual management reports to review trends and identify anomalies in data.
- Developed, installed, and maintained the MCR edits metafile, which consists of the consolidated tumor edits set, the incoming abstracts edits set, the radiation therapy/physician office edits set, and the ambulatory surgery/labs edits set.

3.2 ROUTINE DATA PROCESSING

3.2.1 MCR Facility Audits

Myriddian conducted five facility audits between January and June 2019. These audits are used to determine the quality of data submitted by reporting facilities and to direct the type of training the MCR provides to facilities. For each audit, the selected facility submitted a list of potential reportable cancer cases to Myriddian, who then performed a review of each case to determine: 1) if the cancer case should have been reported, and if so, 2) whether the case had actually been reported. In addition, Myriddian re-abstracted a number of cases to determine if the coding provided by the facility was correct. Findings will be presented as part of the reconciliation records prepared for reporting hospitals later this year.

3.2.2 Death Case Finding and Updating Death Information

The MCR matched individuals with cancer in the MCR database to the MDH Vital Statistics Administration's records of deaths in order to identify those who are now deceased, and the cause and date of death. Westat then wrote the information to the MCR database to be included in the most recent data submission.

The MCR also obtained a list of cancer deaths from the MDH Vital Statistics Administration. Myriddian staff matched the list of deaths from cancer to the MCR database. Individuals who were not found in the MCR database but who had a death certificate listing cancer as a cause of death were identified as non-matches; a follow-back survey was prepared for all non-matches and sent to the hospital, nursing home, or assisted living facility and the physician who signed the death certificate. Data from returned surveys were entered into the database. Additionally, Myriddian staff reviewed death certificate data to confirm case reportability and estimate the date of diagnosis for tumors not reported by other sources. This case finding activity will be completed in Fiscal Year 2020.

3.2.3 Case Consolidation

Westat and Myriddian collectively received 22,683 facility abstracts in Fiscal Year 2019 and processed them into consolidated, newly diagnosed tumor records (see Table 3.4.1). Due to delays in receiving new requirements from the national cancer data standard setters, the MCR has not been able to receive or process some cases diagnosed in 2017, and all cases diagnosed in 2018 and 2019. The MCR expects the 2017 cases to be processed and submitted prior to the November 2019 NPCR submission deadline.

3.2.4 Interstate Data Exchange

Westat and Myriddian completed interstate data exchange procedures with 34 state central cancer registries through the National Interstate Data Exchange. This exchange replaces the multiple formal interstate exchange agreements that the MCR had with 12 other states.

3.2.5 Technical Assistance and Training

Westat and Myriddian provided technical assistance and abstracting and coding expertise to Maryland cancer case abstractors and reporters via the MCR Technical Help Line (by phone, fax, and e-mail) including:
- One-on-one instruction for new Web Plus (the online software used to report cases of cancer) users with review of case finding and abstracting procedures;
- Online Web Plus instruction; and
- Responses to follow-up inquiries.

Westat also provided training during the Tumor Registrars Association of Maryland meetings.

3.3 ACTIVITIES TO IMPROVE MCR-QUALITY ASSURANCE/DATA MANAGEMENT

MDH's plans for improving the MCR-Quality Assurance/Data Management system include:
- Complete the Version 18 Registry Plus upgrade and training so that 2017 cases can be submitted and consolidated.
- Develop a quarterly virtual or onsite training for paper and WebPlus direct entry reporters to reduce errors and improve data accuracy.
- Ask reporting facilities to delay major software upgrades until all current cases are submitted to the MCR.
- Migrate to updated data storage servers for increased efficiency.
- Establish an exchange agreement with the Baltimore Veterans Affairs Medical Center to capture cancer cases of veterans treated at the facility.
- Test the use of the *Chesapeake Regional Information System for our Patients* to check for additional information on laboratory-only cases and cases not found in the MCR that are identified through death certificates.
- Set up Quest Diagnostic Laboratory for automatic case reporting to the MCR.
- Communicate rules for benign brain staging to facilities in order to improve adherence to staging standards.

3.3.1 Data Quality and Completeness

Myriddian continued to provide presentations and one-on-one training to new users of Web Plus. The trainings included instructions on identifying reportable cancer cases, abstracting case records, using Web Plus, and handling follow-up inquiries. One-on-one instruction was required to improve the quality of data submitted.

3.3.2 Other Activities

The MCR Program Manager, MCR staff, and key Myriddian staff attended the following conferences:
- National Cancer Registrars Association Annual Meeting in Denver, CO;
- Tumor Registrars Association of Maryland Annual Meeting in Baltimore, MD;
- NAACCR Annual Conference in Vancouver, Canada;
- CDC NPCR Program Review Meeting in Atlanta, GA; and
- CDC NPCR Education and Training Coordinator Training in Denver, CO.

3.4 TUMOR ABSTRACTS RECEIVED DURING FISCAL YEAR 2019 AND NUMBER OF BRAIN/CENTRAL NERVOUS SYSTEM AND MYELODYSPLASIA CASES IN THE MCR

Table 3.4.1 displays the number of tumor abstracts received in Fiscal Year 2019 from all reporting facilities by year of the diagnosis of the tumor and state of residence of the patient at

diagnosis. Tumor abstracts are reported quarterly to the MCR ideally within six months of the date of diagnoses. However, as shown in the table, abstracts may be reported to the MCR several years after the date of diagnosis.

Two tables, Table 3.4.2 and Table 3.4.3, present data from the MCR, by year of diagnosis, on benign and borderline malignant brain and central nervous system tumors, and malignant myelodysplastic syndrome tumors.

Table 3.4.2 presents the number of benign and borderline malignant brain and central nervous system tumors by year of diagnosis that were reported and entered into the MCR as of June 30, 2019. As noted in the table footnote, the table does not include voided abstracts that were duplicates or determined to be non-reportable conditions.

Table 3.4.3 presents the number of malignant myelodysplastic syndrome tumors that have been reported in Maryland residents by year of diagnosis and entered into the MCR as of June 30, 2019. As noted in the table footnote, as of June 30, 2019, reporting and processing of cases diagnosed in 2017 and 2018 has not been finalized, so the total numbers are lower than the finalized case numbers of tumors diagnosed in prior years.

Table 3.4.1 Number of Cancer Abstracts Received in Fiscal Year 2019 by Year of Diagnosis and State of Residence at Diagnosis Received, July 1, 2018 to June 30, 2019

Year of Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	**Total**
2019>	1	0	**1**
2018>	4	0	**4**
2017^3	12,434	2,034	**14,468**
2016	6,149	522	**6,671**
2015	452	99	**551**
2014	169	31	**200**
2013	126	24	**150**
2012	87	17	**104**
2011	166	28	**194**
2010	52	10	**62**
2009	45	15	**60**
2008	34	9	**43**
2007	21	6	**27**
2006	25	9	**34**
2005	19	4	**23**
2004	14	2	**16**
2003	6	3	**9**
2002	12	3	**15**
2001	10	2	**12**
2000	7	2	**9**
1999	6	0	**6**
1998	2	1	**3**
1997	1	1	**2**
1996	3	2	**5**
1995	2	0	**2**
1994	1	0	**1**
1993	0	0	**0**
1992	1	0	**1**
1991	1	0	**1**
1990	3	1	**4**
Before 1990	5	0	**5**
Total	**19,858**	**2,825**	**22,683**

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[3] Table 3.4.1 provides the year of diagnosis for cancer abstracts received during Fiscal Year 2019\. The majority of abstracts received during this time period were for cancers that were diagnosed in 2017. Although the Maryland Cancer Registry (MCR) continues to receive abstracts for cancers from prior years, we would expect the majority of cases being reported to be more recent. Cases from 2018 and 2019, however, were limited due to delays in receiving new requirements from the national data standard setters which prevented the MCR from receiving and processing cases diagnosed in 2018 and 2019.

Data Source: Myriddian, using the MCR abstract database as of June 30, 2019.

Note: This table does not include voided abstracts that were duplicates or determined to be non-reportable conditions.

> Due to delays in receiving new requirements from the national data standard setters, the MCR has not been able to receive or process cases diagnosed in 2018 and 2019. The MCR is expecting the 2018 cases to be processed and submitted prior to the November 2020 NPCR submission deadline.

^ As of June 30, 2019, the MCR is still completing its 2017 incidence data for submission to NPCR and NAACCR; therefore, the 2017 data are incomplete.

Table 3.4.2 Total Number of Benign and Borderline Brain and Central Nervous System Tumors* in the Maryland Cancer Registry Diagnosed in Maryland Residents as of June 30, 2019 by Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2019>	N/A	N/A
2018>	N/A	N/A
2017^	698	61
2016	947	76
2015	919	72
2014	875	76
2013	822	78
2012	860	77
2011	719	73
2010	878	71
2009	792	107
2008	724	77
2007	607	69
2006	546	57
2005	514	52
2004	484	50
2003	373	46
2002	300	24
2001	157	13
2000	28	3
Before 2000	634	71
Total	**11,877**	**1,153**

Data Source: Myriddian, using the MCR consolidated database of finalized cases as of June 30, 2019.

*Brain and Central Nervous System Tumors defined by the ICD-O-3 primary site (C70.0-C70.9, C71.0-C71.9, C72.0-C72.9, C75.1-C75.3) with behavior codes of 0 or 1.

> Due to delays in receiving new requirements from the national data standard setters, the MCR has not been able to receive or process cases diagnosed in 2018 and 2019. The MCR expects 2018 cases to be processed and submitted prior to the November 2020 NPCR submission deadline.

^ As of June 30, 2019, the MCR is still completing its data for submission for the 2017 incidence year; therefore, the 2017 data are incomplete.

Table 3.4.3 Total Number of Malignant Myelodysplastic Syndrome Tumors* in the Maryland Cancer Registry Diagnosed in Maryland Residents as of June 30, 2019 by the Year of Diagnosis (Benign and Borderline)

Year of Diagnosis	Number of Cases
2019>	N/A
2018>	N/A
2017^	144
2016	219
2015	247
2014	247
2013	247
2012	237
2011	247
2010	223
2009	210
2008	200
2007	179
2006	133
2005	121
2004	111
2003	116
2002	124
2001	87
2000	21
1999	7
Before 1999	11
Total	**3,131**

Data Source: Myriddian, using the MCR consolidated database as of June 30, 2019.

*The following ICD-O-3 diagnosis codes with malignant behavior were included:

9980-Refractory anemia
9982-Refractory anemia with ringed sideroblasts
9983-Refractory anemia with excess blasts
9984-Refractory anemia with excess blasts in transformation
9985-Refractory cytopenia with multilineage dysplasia
9986-Myelodysplastic Syndrome with 5q deletion syndrome
9987-Therapy-related myelodysplastic syndrome, not otherwise specified
9989-Myelodysplastic syndrome, not otherwise specified
9991-Refractory neutropenia (This code is effective for cases diagnosed 2010 and later.)
9992-Refractory thrombocytopenia (This code is effective for cases diagnosed 2010 and later.)

[>] Due to delays in receiving new requirements from the national data standard setters, the MCR has not been able to receive or process cases diagnosed in 2018 and 2019. The MCR expects 2018 cases to be processed and submitted prior to the November 2020 NPCR submission deadline.

^ As of June 30, 2019, the MCR is still completing its data for submission for the 2017 incidence year; therefore, 2017 data are incomplete.

3.5 DATA USE

3.5.1 Data Requests

Table 3.5.1 shows the number of requests for data that the MCR received and processed in Fiscal Year 2019.

Table 3.5.1 Data Requests Requiring MCR Analysis, Received and Processed in Fiscal Year 2019

Type of Request	Number of Requests Pending as of July 1, 2018 (start of Fiscal Year 2019)	Number of Requests Received in Fiscal Year 2019	Number of Requests Processed by June 30, 2019 (End of Fiscal Year 2019)
Research/Special Studies	2	5	7
Reporting Facilities Requesting their own Information	0	4	4
Health Services Planning	0	17	17
Public Request for Information	0	7	7
Total	**2**	**33**	**35**

3.5.2 Cancer Cluster Concerns

Table 3.5.2 shows cancer cluster concerns by jurisdiction, the type of analysis provided, and the results of the analysis for Fiscal Year 2019.

Table 3.5.2 Cancer Cluster Concerns by Jurisdiction, Type of Analysis, and Results in Fiscal Year 2019

Jurisdiction	Type of Analysis by MCR	Results
Worcester County	Minimal Analysis	No cluster found
St. Mary's County	Minimal Analysis	No cluster found
Harford County	Moderate Analysis	No cluster found

4. CONCLUSION

The MCR is a valuable resource for Maryland that facilitates tracking, evaluation, and comparison of cancer statistics and rates with other states. Through the collection and analysis of MCR data, the State of Maryland is able to better focus cancer prevention and control efforts and evaluate cancer programs and services. The MCR will continue collecting, analyzing, and disseminating data to further the goal of a healthier Maryland.

APPENDIX

Glossary of Key Abbreviations

CDC   US Centers for Disease Control and Prevention
ICD-O-3 International Classification of Diseases for Oncology -3rd Edition
MCR   Maryland Cancer Registry
MDH   Maryland Department of Health
NAACCR North American Association of Central Cancer Registries
NPCR   National Program of Cancer Registries