September 11, 2018

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 Michael E. Busch
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) 2018 Legislative
Report of the Maryland Cancer Registry; COMAR 10.14.01.06 D**

Dear Governor Hogan, President Miller, and Speaker Busch:

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 Mr. Webster Ye, Deputy Chief of
Staff, Office of the Secretary, at 410-767-6480 or webster.ye@maryland.gov.

Sincerely,

Robert R. Neall
Secretary

Annual Report
Maryland Cancer Registry

Health–General §18-204(b)(6)
Fiscal Year 2018

Larry Hogan
Governor

Boyd Rutherford
Lieutenant Governor

Robert R. Neall
Secretary

September 2018

MARYLAND
Department of Health

(This Page Intentionally Left Blank)

Table of Contents

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, 2017 through June 30, 2018 (Fiscal Year 2018). 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. Westat, Incorporated (Westat), assumed responsibility for providing quality assurance and database management services for the MCR on February 1, 2008. Westat was selected through the State procurement process as the vendor for the MCR for the period of five years, July 1, 2013 through June 30, 2018.

During Fiscal Year 2018, the MCR began the process of selecting a new vendor for data collection, data management, and quality assurance activities.

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.

---

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

3. FISCAL YEAR 2018 ACTIVITIES

3.1 ADMINISTRATIVE ACTIVITIES

The MCR-Quality Assurance/Data Management team at Westat met with MCR staff at least monthly to discuss progress and plans. Westat continued its quality assurance and data management activities during Fiscal Year 2018. Data were exchanged twice with surrounding states and the District of Columbia cancer registries. Maryland began to send and receive data from other states and regional registries that are signatories to the National Interstate Data Exchange Agreement (Agreement). As of June 30, 2018, 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 once to receive updates from MCR staff and provide feedback. Discussion topics included MCR-Quality Assurance/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 2018 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 23 that achieved the designation for the most recent data submission. Meeting these standards allows Maryland's data to be included in the 2018 United States Cancer Statistics report and other analytic data sets.

---

[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/providers-professionals/meaningful-use-definition-objective)

2. National Interstate Data Exchange Agreement:
   The NAACCR developed a model 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 single agreement replaces multiple individual
   interstate data exchange agreements that currently exist.

3. NAACCR Certification:
   The MCR submitted 2015 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 2007-2015, 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 16 to 16D:
   The MCR began the software program conversion to NAACCR Version 16D. CDC used
   Westat as a testing facility to identify potential issues related to the conversion.

7. MCR Training Webinars:
   The MCR hosted a series of NAACCR-presented webinars at MDH headquarters 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 now access the pre-recorded webinar at their facility and are granted
   continuing education units upon completion of the webinars.

8. National Cancer Registrars Week (April 9-13, 2018):
   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 sent a
   letter of appreciation to each reporter.

9. MCR Electronic Update:
   The MCR published a quarterly electronic update, which was sent to all reporting
   facilities, and included information on coding issues, facility audits, lab-only follow-back
   questions and answers, tips for cancer data reporters, recognitions, upcoming NAACCR

webinars, updated information from the Tumor Registrars Association of Maryland, and updates from Westat.

10. Meaningful Use Stage 2 Update:

The MCR continued its collaboration with the MDH Meaningful Use Group, which supports the implementation of the Maryland Electronic Health Records Incentive Program. During Fiscal Year 2018, Westat received test files from eligible providers. If the test file with dummy data is received in the correct format, known as Clinical Document Architecture, the provider is placed in a queue in preparation for regular electronic reporting. During Fiscal Year 2018, 25 providers moved into full production by sending actual data to MCR.

Table 3.1 Cumulative Number of Eligible Providers by Testing and Registration Status as of June 30, 2018

Testing Status	Number of Eligible Providers by Registration Status				
	Actively Engaged	Excluded	Inactivated	Non-responsive	**Total**
Pending account information	0	0	0	0	**0**
Pending primary test file submission	3	126	29	23	**181**
Initiated primary validation testing	18	22	14	1	**55**
Primary testing error free, requested secondary test file	1	0	0	0	**1**
Pending secondary test file submission	1	0	6	0	**7**
Initiated secondary validation testing	7	1	0	0	**8**
Passed testing, not in production	1	0	1	0	**2**
Passed testing, in production	25	0	0	0	**25**
Total:	**56**	**149**	**50**	**24**	**279**

Data Source: Westat, using the Meaningful Use Database

11. Motor Vehicle Administration Unknown Race Look-Up:

To identify the race of individuals reported as unknown race in the Registry, MCR staff searched 3,268 names in the Motor Vehicle Administration database to obtain the missing race information.

3.1.3 Quality Assurance and Data Management Activities

Westat performed quality assurance and data management services for the MCR including: accepting cancer reports from facilities, case finding, and quality assurance and quality control of data submitted; and submission of data to NAACCR and NPCR. Specifically, Westat completed the following activities during Fiscal Year 2018:

- Received and processed reports to the MCR (see Table 3.4.1).
- Completed the upgrade of the MCR system to NAACCR.NET programming for the Registry Plus applications.
- 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 2016.
- 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

Westat conducted a total of 10 facility audits between July 2017 and June 2018. 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 Westat, 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, Westat re-abstracted a number of cases to determine if the coding provided by the facility was correct. Findings were presented as part of the reconciliation records prepared for reporting hospitals. In addition, final audit reports were prepared and delivered to the facilities.

3.2.2 Death Case Finding and Updating Death Information

Westat continued to improve the death case finding procedures and Westat staff reviewed all death certificates to confirm case reportability and to estimate the date of diagnosis. Westat staff matched apparently reportable, but missed, cases to the disease indices covering the period 2012 to 2016, to determine the best facility to be contacted for a follow-back survey for each decedent. Additionally, Westat staff reviewed death certificate data to confirm case reportability and estimate the date of diagnosis for tumors not reported by other sources. The MCR also continued to identify people with cancer reported to the MCR, and to match them to the MDH Vital Statistics Administration's records of deaths in order to identify cause of death and date of death; Westat then wrote the information to the MCR database.

3.2.3 Case Consolidation

Westat received 55,447 facility abstracts in Fiscal Year 2018 and processed them into consolidated, newly diagnosed tumor records (see Table 3.4.1).

3.2.4 Interstate Data Exchange

Westat completed interstate data exchange procedures with 32 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 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 to Westat) 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

Westat made recommendations to MDH for improving the MCR-Quality Assurance/Data Management system in the future. These recommendations include:
- Develop a system to identify and alert the data acquisition manager to gaps in the accession numbers as a tool to improve case completeness.[3] Hospital accession number lists should be exchanged between hospital and central registries, such as the MCR. By comparing the list, the two registries can identify cases that have been accessioned in the hospital registry but are missing from the central registry.
- Explore the application of an online tool for conducting death clearance and lab only follow-back activities.
- Migrate to updated data storage servers for increased efficiencies.
- Additional improvements specifically to improve Meaningful Use workflow, including:
  - Create an edits program to automatically correct data that are submitted, and use the program prior to the data being reviewed in Prep Plus (part of the suite of Registry Plus applications), in order to reduce manual editing.

---

[3]Accession numbers are created when a hospital begins to document a case of cancer. The numbers are continuous and never repeated, so each case has a unique identifier. Though some cases are voided by the hospital, large gaps in accession numbers suggest a missed submission by the hospital.

- Provide feedback to providers with quality issues after errors are identified in Prep Plus.
- Create an automated report that is sent to providers confirming that the MCR received their files.
- Perform ongoing analyses on non-matched files received via Meaningful Use to determine if additional reports were sent from other sources for the same patient, in order to determine the true number of cases that the Meaningful Use process yields.
- Explore collaborations with the Maryland Health Information Exchange and the Chesapeake Regional Information System for our Patients for linkage or access to cancer patient treatment information.
- Activities and recommendations related to Benign Brain and Central Nervous System Tumor report processing include:
  - Inform Maryland reporters about reportability requirements for benign brain and central nervous system tumors via the MCR e-newsletter and Tumor Registrars Association of Maryland meetings.
  - Develop algorithms to apply default values to abstracts that are submitted on benign brain and central nervous system tumors. Develop rules for the verification of the World Health Organization Grade, a grading system specific to central nervous system tumors.

3.3.1 Data Quality and Completeness

Westat 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 Westat staff attended the following conferences:
- National Cancer Registrars Association Annual Meeting, New Orleans, LA;
- Tumor Registrars Association of Maryland Annual Meeting, Rockville, MD and Baltimore, MD;
- NAACCR Annual Conference, Pittsburgh, PA;
- NAACCR 2017 Coordinated Call for Data Webinar; and
- Education and Training Coordinator Training, CDC NPCR, New Orleans, LA.

3.4 TUMOR ABSTRACTS RECEIVED DURING FISCAL YEAR 2018 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 2018 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 the condition of special interest: 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, 2018. 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, 2018. As noted in the table footnote, as of June 30, 2018, reporting and processing of cases diagnosed in 2016 and 2017 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 2018 by Year of Diagnosis and State of Residence at Diagnosis Received, July 1, 2017 to June 30, 2018

Year of Tumor Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2018	N/A	N/A	**N/A**
2017	22,301	2,664	**24,965**
2016	18,837	2,649	**21,486**
2015	5,475	243	**5,718**
2014	791	74	**865**
2013	526	52	**578**
2012	401	31	**432**
2011	335	27	**362**
2010	177	14	**191**
2009	111	15	**126**
2008	118	14	**132**
2007	101	13	**114**
2006	64	15	**79**
2005	65	3	**68**
2004	55	5	**60**
2003	31	2	**33**
2002	11	2	**13**
2001	42	10	**52**
2000	23	5	**28**
1999	17	0	**17**
1998	15	1	**16**
1997	14	0	**14**
1996	15	5	**20**
1995	10	0	**10**
1994	15	0	**15**
1993	12	0	**12**
1992	7	0	**7**
1991	2	7	**9**
1990	5	0	**5**
Before 1990	20	0	**20**
TOTAL:	**49,596**	**5,851**	**55,447**

Data Source: Westat, using the MCR abstract database as of June 30, 2018.

Note: Due to delays in receiving new requirements from the national data standard designators, MCR has not been able to receive or process cases diagnosed in 2018. Additionally, this table does not include voided abstracts that were duplicates or determined to be non-reportable conditions.

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, 2018 by Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2018>	N/A	N/A
2017^	314	31
2016^	820	62
2015	883	72
2014	850	74
2013	805	78
2012	839	76
2011	703	72
2010	869	71
2009	779	108
2008	717	77
2007	603	69
2006	539	56
2005	509	52
2004	482	50
2003	373	46
2002	300	24
2001	156	12
2000	28	3
Before 2000	620	71
Total	**11,189**	**1,104**

Data Source: Westat, using the MCR consolidated database of finalized cases as of June 30, 2018.

*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 designators, MCR has not been able to receive or process cases diagnosed in 2018.

^ As of June 30, 2018, the MCR is still completing its data for submission for the 2016 incidence year and has just begun processing cases diagnosed in 2017, therefore the 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, 2018 by the Year of Diagnosis (Benign and Borderline)

Year of Diagnosis	Number of Cases
2018>	N/A
2017^	56
2016^	172
2015	244
2014	237
2013	244
2012	231
2011	241
2010	221
2009	210
2008	200
2007	179
2006	130
2005	120
2004	111
2003	115
2002	123
2001	82
2000	21
1999	7
Before 1999	11
Total	**2,955**

Data Source: Westat, using the MCR consolidated database as of June 30, 2018.

*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 designators, MCR has not been able to receive or process cases diagnosed in 2018.

^ As of June 30, 2018, the MCR is still completing its data for submission for the 2016 incidence year and has just begun processing cases diagnosed in 2017, therefore the 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 2018.

Table 3.5.1 Data Requests Requiring MCR Analysis, Received and Processed in Fiscal Year 2018

Type of Request	Number of Requests Pending as of July 1, 2017 (start of Fiscal Year 2018)	Number of Requests Received in FY18	Number of Requests Processed by June 30, 2018 (end of Fiscal Year 2018)
Research/Special Studies	0	9	7
Reporting Facilities Requesting their own Information	0	2	2
Health Services Planning	0	12	12
Public Request for Information	1	9	10
Total	**1**	**32**	**31**

3.5.2 Cancer Cluster Concerns

Table 3.5.2 shows the cancer cluster concerns by jurisdiction, the type of analysis provided, and the results of the analysis for Fiscal Year 2018.

Table 3.5.2 Cancer Cluster Concerns by Jurisdiction, Type of Analysis, and Results in Fiscal Year 2018

Jurisdiction	Type of Analysis by MCR	Results
Baltimore City	Work place report	Unable to process further
Baltimore County	Minimal Analysis	No cluster found
Cecil County	Minimal Analysis	No cluster found
Montgomery 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, Maryland is able to better focus its cancer prevention and control efforts and evaluate its cancer programs and services. The MCR will continue collecting, analyzing, and disseminating data in its efforts 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