



Larry Hogan, Governor · Boyd K. Rutherford, Lt. Governor · Robert R. Neall, Secretary

December 7, 2020

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

The Honorable Bill Ferguson
President of the Senate
H-107 State House
Annapolis, MD 21401-1991

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

Re: Ch. 251 of the Acts of 2001 (HB 636) and HG §18-204(b)(6) 2020 Legislative Report of the Maryland Cancer Registry

Dear Governor Hogan, President Ferguson, 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 Webster Ye, Director of Governmental Affairs, at (410) 767-6481.

Sincerely,

Dennis R. Schrader
Acting Secretary

Annual Report

Maryland Cancer Registry

Health–General §18-204(b)(6)
Fiscal Year 2020

Larry Hogan
Governor

Boyd K. Rutherford
Lieutenant Governor

Robert R. Neall
Secretary

September 2020



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The Maryland Cancer Registry is supported by Maryland General Funds, the Maryland Cigarette Restitution Fund, and by Cooperative Agreement number NU58DP006333 from the Centers for Disease Control and Prevention, National Program of Cancer Registries.

1. INTRODUCTION

Health-General Article §18-204(b)(6), Annotated Code of Maryland, requires a report on the Maryland Cancer Registry (MCR) be submitted to the Governor and Maryland State legislature annually. This report covers the period from July 1, 2019 to June 30, 2020 (Fiscal Year 2020). The MCR is a cancer incidence data system maintained under the direction of the Maryland Department of Health (the Department). 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 further amended to require the reporting of benign brain and central nervous system tumors to the MCR beginning October 1, 2001.

The Department subcontracts MCR data collection, data management, and quality assurance activities to an outside entity, Myriddian, LLC (Myriddian). 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.

¹ Annotated Code of Maryland, Health-General Article §§ 18-203 and 18-204.

3. FISCAL YEAR 2020 ACTIVITIES

3.1 ADMINISTRATIVE ACTIVITIES

Myriddian provided quality assurance and data management throughout Fiscal Year 2020. The Myriddian team and MCR staff met twice per month to discuss progress. Data were exchanged twice with cancer registries in surrounding states and the District of Columbia. Maryland also sent and received data from other state and regional registries that are signatories to the National Interstate Data Exchange Agreement (Agreement). As of June 30, 2020, 47 registries, including the District of Columbia, Guam, Puerto Rico, and the Virgin Islands, were participants in the Agreement.

3.1.1 Cancer Registry Advisory Committee

The Cancer Registry Advisory Committee met twice during Fiscal Year 2020 to receive updates from MCR staff and provide feedback. Discussion topics at the meetings included MCR quality assurance and data management activities, data use and dissemination, data submission, data use policy and procedures, MCR regulations, 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. MCR also processes and fulfills data requests from the public, reporting facilities, local health departments, researchers, and the media. Administrative highlights during Fiscal Year 2020 included:

1. CDC NPCR National Data Completeness and Quality Standard:

The Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) recognized the MCR as meeting the publication standard that allows Maryland data to be included in the 2020 United States Cancer Statistics report and other analytic data sets.

2. NAACCR Certification:

The MCR submitted 2017 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.

3. 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 47 other registries in Fiscal Year 2020.

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. Virtual Pool Registry:

The MCR has agreed to participate in the Virtual Pooled Registry Cancer Linkage System (VPR-CLS). The VPR-CLS is a secure online service designed to:

- Efficiently connect researchers performing minimal risk linkage studies with multiple U.S. population-based cancer registries;
- Perform linkages utilizing a single cohort file, standard linkage software, and consistent matching algorithms;
- Provide initial aggregate match count results to researchers; and,
- Streamline the process of applying for release of individual-level data on matched cases.

Coordinated by NAACCR with funding from the National Cancer Institute, the VPR-CLS provides a single location to facilitate timely access to and use of high-quality cancer surveillance data for minimal risk linkage studies. Use of an automated, standard linkage methodology and streamlined application process will significantly reduce the level of effort researchers and registries must dedicate to the approval and linkage process.

6. Linkage with Breast and Cervical Cancer Program Database:

The MCR linked its database with the Department's Breast and Cervical Cancer Program database of cancer cases diagnosed from 2006-2017, 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.

7. NAACCR Conversion of the MCR database from Version 16 to 18d:

The MCR completed the software program conversion to NAACCR Version 18d, which began in Fiscal Year 2019. Because of multiple changes by cancer data standard setters, updates in the Registry Plus programs provided by CDC were delayed and could not be completed until Fiscal Year 2020.

8. 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.

9. Fundamental Learning Collaborative for the Cancer Surveillance Community:

The MCR began using the Fundamental Learning Collaborative for the Cancer Surveillance Community (FLccSC) as a training website for MCR reporters. The website

is hosted and paid for as part of the NPCR funding. Materials placed on the website include NPCR training materials, NAACCR webinars, and training developed by Myriddian and other central registries.

10. National Cancer Registrars Week (April 6-10, 2020):

During National Cancer Registrars Week, the MCR recognized the dedicated work of Maryland certified tumor registrars who submit quarterly data to the MCR. A letter was sent to each reporter to show appreciation for their dedicated efforts towards providing high quality data.

11. Motor Vehicle Administration Unknown Race Look-Up:

To identify the race of individuals reported as unknown race in the MCR, MCR staff searched 3,340 names in the Motor Vehicle Administration database to obtain the missing race information.

3.1.3 Quality Assurance and Data Management Activities

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, Myriddian completed the following activities during Fiscal Year 2020:

- Received and processed reports to the MCR (see Table 3.4.1)
- Ran de-duplication scripts to identify patients with duplicate patient IDs, reviewed those cases manually, and made corrections.
- Completed de-duplication by Social Security number, first and last name, and date of birth for years 1996 to 2018.
- Established a ticketing system for tracking and managing reporter, facility, and information technology tasks and communications.
- Updated SQL analysis of deleted/updated critical fields.
- 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 2018.
- 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.

3.2 ROUTINE DATA PROCESSING

3.2.1 MCR Facility Audits

Myriddian conducted seven facility audits between July 1, 2019 and June 30, 2020. 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. Final audit reports were prepared and delivered to the facilities after receipt of reconciliation notes.

3.2.2 Death Case Finding and Updating Death Information

The MCR matched individuals with cancer in the MCR database to death records held by the Department's Vital Statistics Administration in order to identify those who are now deceased, as well as the cause and date of death. Myriddian 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 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 followback survey was prepared for all non-matches and sent to the hospital, nursing home, or assisted living facility in addition to 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 was completed during Fiscal Year 2020.

3.2.3 Case Consolidation

Myriddian received 71,114 facility abstracts in Fiscal Year 2020 and processed them into consolidated, newly diagnosed tumor records (see Table 3.4.1).

3.2.4 Interstate Data Exchange

Myriddian completed interstate data exchange procedures with 49 state/territory central cancer registries through the National Interstate Data Exchange.

3.2.5 Technical Assistance and Training

Myriddian provided technical assistance and abstracting and coding expertise to Maryland cancer case abstractors and reporters through the MCR Technical Help Line (available via phone, fax, and e-mail) including:

- One-on-one instruction for new Web Plus (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.

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

3.3 ACTIVITIES TO IMPROVE MCR-QUALITY ASSURANCE/DATA MANAGEMENT

MDH plans for improving the MCR quality assurance and data management system include:

- Run NAACCR, Cancer in North America (CINA), and NPCR edits on the datasets;
- Install and test revisions to the V18 edit file in all Registry Plus products;
- Create and run multiple data extracts using Gen-Edits in preparation for 1996-2018 data submission to NPCR and NAACCR;
- Research the issue of non-hospitals not reporting or the reasons for decreases in caseload;
- Develop a quarterly virtual or onsite training for paper and Web Plus direct entry reporters to reduce errors and improve data accuracy;
- Migrate to updated data storage servers for increased efficiency;
- Maintain the exchange agreement with the Baltimore Veterans Affairs Medical Center to capture cancer cases of veterans treated at the facility;
- Monitor and work with reporters with a history of submission delays and assist facilities in developing a submission plan; and
- Continue to communicate with facilities regularly during the COVID-19 pandemic to identify and assist with staff furloughs and other challenges that could negatively impact data submission.

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:

- Tumor Registrars Association of Maryland Annual Meeting, Baltimore, MD;
- NAACCR Annual Conference, via a virtual platform; and
- CDC/NPCR 2019 Program Review Meeting, Atlanta, GA.

3.4 TUMOR ABSTRACTS RECEIVED DURING FISCAL YEAR 2020 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 2020 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 demonstrated in the table, abstracts may be reported to the MCR several years after the date of diagnosis.

Table 3.4.2 and Table 3.4.3, present data from the MCR by year of diagnosis on conditions 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, 2020. 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, 2020. As noted in the table footnote, as of June 30, 2020, reporting and processing of cases diagnosed in 2018 through 2020 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 2020 by Year of Diagnosis and State of Residence at Diagnosis, received July 1, 2019 to June 30, 2020

Year of Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2020^	81	5	86
2019^	6053	464	6517
2018^	37927	4391	42318
2017	16068	1611	17679
2016	1608	311	1919
2015	567	89	656
2014	389	65	454
2013	334	68	402
2012	258	28	286
2011	184	20	204
2010	131	12	143
2009	73	11	84
2008	57	16	73
2007	54	6	60
2006	31	5	36
2005	25	8	33
2004	27	6	33
2003	17	2	19
2002	13	5	18
2001	3	3	6
2000	6	1	7
1999	3	3	6
1998	3	2	5
1997	4	1	5
1996	3	0	3
1995	1	0	1
1994	2	1	3
1993	2	1	3
1992	5	0	5
1991	2	0	2
1990	3	0	3
Before 1990	69	6	75
TOTAL:	64,003	7,141	71,144

Source: Myriddian, LLC using the MCR abstract database as of June 30, 2020.

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

^As of June 30, 2020, the MCR is still completing its data for submission for the 2018 incidence; therefore, 2018-2020 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, 2020 by Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2020^	3	0
2019^	184	14
2018^	944	58
2017	1168	87
2016	1015	77
2015	967	73
2014	925	76
2013	857	80
2012	879	77
2011	732	73
2010	894	71
2009	806	106
2008	739	77
2007	619	69
2006	550	57
2005	520	53
2004	494	50
2003	372	46
2002	300	24
2001	157	13
2000	28	3
Before 2000	630	71
TOTAL:	13,783	1,255

Data Source: Myriddian, LLC using the MCR consolidated database of finalized cases as of June 30, 2020.

*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.

^As of June 30, 2020, the MCR is still completing its data for submission for the 2018 incidence; therefore, 2018-2020 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, 2020 by Year of Diagnosis (Benign and Borderline)

Year of Diagnosis	Number of Cases
2020^	N/A
2019^	14
2018^	175
2017	234
2016	229
2015	255
2014	252
2013	252
2012	239
2011	248
2010	224
2009	214
2008	201
2007	179
2006	135
2005	122
2004	111
2003	116
2002	124
2001	87
2000	23
1999	7
Before 1999	18
TOTAL:	3,459

Data Source: Myriddian, LLC using the MCR consolidated database as of June 30, 2020.

*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.)

^As of June 30, 2020, the MCR is still completing its data for submission for the 2018 incidence; therefore, 2018-2020 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 2020.

Table 3.5.1 Data Requests Requiring MCR Analysis, Received and Processed in Fiscal Year 2020

Type of Request	Number of Requests Pending as of July 1, 2019 (start of Fiscal Year 2020)	Number of Requests Received in Fiscal Year 2020	Number of Requests Processed by June 30, 2020 (End of Fiscal Year 2020)
Research/Special Studies	0	6	3
Reporting Facilities Requesting their own Information	0	2	2
Health Services Planning	2	15	15
Public Request for Information	0	1	1
TOTAL:	2	24	21

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 2020.

Table 3.5.2 Cancer Cluster Concerns by Jurisdiction, Type of Analysis, and Results in Fiscal Year 2020

Jurisdiction	Type of Analysis by MCR	Results
Worcester County	Minimal Analysis	No cluster found

4. CONCLUSION

The MCR is a valuable resource 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 better able to 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	Centers for Disease Control and Prevention
CINA	Cancer in North America
FLccSC	Fundamental Learning Collaborative for the Cancer Surveillance Community
ICD-O-3	International Classification of Diseases for Oncology -3 rd Edition
MCR	Maryland Cancer Registry
MDH	Maryland Department of Health
NAACCR	North American Association of Central Cancer Registries
NPCR	National Program of Cancer Registries
VPR-CLS	Virtual Pooled Registry Cancer Linkage System