



## **Annual Report Maryland Cancer Registry**

Health-General §18-204(b)(6)

Fiscal Year 2022

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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, 2021, through June 30, 2022 (Fiscal Year 2022). 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.<sup>1</sup> 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.

The MDH subcontracts MCR data collection, data management, and quality assurance activities to an outside entity. Myriddian, LLC was selected through the State procurement process as the vendor to provide data management and quality assurance activities 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.

## **3. FISCAL YEAR 2022 ACTIVITIES**

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

### **3.1 ADMINISTRATIVE ACTIVITIES**

Myriddian provided quality assurance and data management throughout Fiscal Year 2022. The Myriddian team and MCR staff met at least monthly to discuss progress. Data were exchanged twice with cancer registries in surrounding states, including 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 (the Agreement). As of June 30, 2022, 48 registries, including the District of Columbia, Guam, Puerto Rico, and the U.S. Virgin Islands, were participants in the Agreement.

Fiscal Year 2022 continued to be a challenging time due to the ongoing effects of the COVID-19 pandemic. During the fiscal year, MCR maintained efforts to evaluate the effects of the pandemic on various registry operations and overall data collection. These effects include hospital registry staff being pulled from their positions to assist in other areas and physicians closing practices, which resulted in a decrease in data submission.

Fiscal Year 2022 was also marked by an MDH network disruption due to a ransomware attack in December 2021. No MCR data was lost or compromised as a result of the network disruption, and the MCR vendor, Myriddian, continued to process data without any interruptions. MCR staff maintained continuity of all activities without any major interruptions. MCR sustained a schedule of virtual meetings for regular staff meetings, and with Myriddian on a monthly basis.

#### **3.1.1 Cancer Registry Advisory Committee**

The Cancer Registry Advisory Committee met twice during Fiscal Year 2022 to receive updates from MCR staff and provide feedback. The meetings were held virtually. Discussion topics at the meetings included MCR quality assurance and data management activities, data use and dissemination, data submission, data use policy and procedures, data completeness, 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. MDH also processes and fulfills data requests from the public, reporting facilities, local health departments, researchers, and the media. Administrative highlights during Fiscal Year 2022 included:

1. Centers for Disease Control and Prevention (CDC) NPCR National Data Completeness and Quality Standard/Data Evaluation Report:

The CDC NPCR recognized the MCR as a Registry of Distinction for meeting the National Data Quality Standard and the Publication Standard that allows Maryland data to be included in the 2022 United States Cancer Statistics report and other analytic data sets.

2. NAACCR Certification:  
The MCR submitted 2019 incidence data for evaluation from the NAACCR and received “Gold” certification, which is the highest level of certification. The certification includes a 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 (N-IDEAS):  
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 28 other registries in Fiscal Year 2022.
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 continues 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 the release of individual-level data on matched cases.
6. LexisNexis Accurint:  
During Fiscal Year 2022, the MCR continued to utilize the LexisNexis Accurint to perform linkages for the NAACCR Virtual Pooled Registry system. LexisNexis was used to perform nine linkage studies during the fiscal year. LexisNexis also aided the MCR in quality control processes including correcting names, social security numbers, dates of birth, dates of death, and addresses. Additionally, it was used for geocoding, resolving duplicates, and resolving race unknowns. The national agencies require the MCR to meet requirements for these processes.
7. 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 2006-2020 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.
8. Fundamental Learning Collaborative for the Cancer Surveillance Community (FLccSC):

The MCR uses the Fundamental Learning Collaborative for the Cancer Surveillance Community (FLccSC) as a training resource 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, related trainings from other cancer registries, and training developed by Myriddian and other central registries.

9. 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. The webinars are posted on FLccSC.

10. National Cancer Registrars Week (April 4-8, 2022):

During National Cancer Registrars Week, the MCR recognized the dedicated work of Maryland-certified tumor registrars who submit quarterly data to the MCR. National Cancer Registrars Week was established by the National Cancer Registrars Association (NCRA) as an annual celebration to promote the work of cancer registry professionals. The MCR sent a letter to each reporter to show appreciation for their dedicated efforts to providing high-quality data.

11. Motor Vehicle Administration Look-Up:

The Motor Vehicle Administration (MVA) database was used to obtain the missing race information, addresses, death dates, birth dates, and name spellings for individuals in the MCR. The MCR completed 3,481 searches in the MVA database in Fiscal Year 2022.

### **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 2022:

- Received and processed reports to the MCR (see Table 3.4.1);
- Utilized and upgraded the Myriddian Quality Assessment Tool (MQAT) to identify and prevent the processing of duplicate and non-reportable cases from facilities as well as make it compatible with V21 and V22 XML;
- Completed deduplication by Social Security number, first and last name, and date of birth for years 1996 to 2020;
- Completed the Death Clearance Only earlier in the year to improve the submission process;
- Performed quality review on consolidated cases;
- Updated the deduplication process to find duplicate patient identities;
- Identified facilities on the verge of reporting delays and provided needed assistance to prevent data submission delays;
- Identified high-volume facilities and established digital and timely reporting of cases;
- Updated and backed-up SQL analysis of deleted or updated critical fields;

- Ran the latest NAACCR-derived Hispanic and Asian/Pacific Islander ethnicity algorithm and wrote back the results to the master file for the entire database through the year 2019; and
- 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, 2021, and June 30, 2022. 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. Myriddian worked with hospitals to establish remote access to their electronic medical record systems to perform audits.

For each audit, the selected facility submitted a list of potential reportable cancer cases to Myriddian, each of which was then reviewed to determine: 1) if the cancer case should have been reported, and if so, 2) whether the case was 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 their reconciliation notes.

### **3.2.2 Death Case Finding and Updating Death Information**

In addition to LexisNexis searches, the MCR matched individuals with cancer in the MCR database to the MDH Vital Statistics Administration (VSA) records of deaths to identify those who are now deceased, the cause of death, and the 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 VSA. 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 developed and utilized a robotic process to enter cases once the quality assurance team reviewed the information, which allows for the review and editing of cases with race, ethnicity, sex, vital status, date of death, and cause of death. Staff also reviewed death certificate data to confirm case reportability and estimate the date of diagnosis for tumors not reported by other sources.

Myriddian also utilized the Chesapeake Regional Information System for our Patients database to identify additional information on the Death Certificate Only cases.

### **3.2.3 Case Consolidation**

Myriddian received abstracts from 91 facilities in Fiscal Year 2022 and processed them into consolidated, newly diagnosed tumor records (see Table 3.4.1). Other activities included:

- Upgrades and revisions to the Registry Plus suite of applications to accommodate the changes and reduce errors; and
- Review and revision of consolidation rules to improve data quality and minimize errors.

### **3.2.4 Interstate Data Exchange**

Myriddian completed interstate data exchange procedures with 28 state/territory central cancer registries through the National Interstate Data Exchange. Other activities included:

- The new N-IDEAS upgrade and the N-IDEAS edit set. This was placed in the exchange to reduce the number of errors in the files; and
- Re-importing the interstate files to WebPlus to make use of the MQAT capabilities to identify duplicates and to limit processing to only unreported cases.

### **3.2.5 Technical Assistance and Training**

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

- Reporter technical one-on-one instruction for case finding and abstracting procedures;
- Responses to follow-up inquiries and a dedicated email address provided to all reporters; and
- Assistance and tutorials are provided using teleconferences and videoconferences.

## **3.3 ACTIVITIES TO IMPROVE MCR-QUALITY ASSURANCE/DATA MANAGEMENT**

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

- Updating and deploying Power BI to track files submitted, as well as file processing and accountability;
- Running NAACCR, Cancer in North America (CINA), and NPCR edits on the datasets;
- Creating and providing a V21 metafile to vendors for testing and release to the facilities;
- Updating display types to complement new data fields and edit requirements;
- Updating display types in Web Plus to accommodate changes with V21 for physician offices, laboratories, and hospital reporters;
- Continuing to communicate with facilities regularly to identify any challenges that could negatively impact data submission; and
- Continuing to present virtual educational workshops for central registry Certified Tumor Registrar staff and data submitters.

### **3.3.1 Data Quality and Completeness**

Myriddian continued to provide one-on-one instruction to reporting facilities to improve the quality of data submitted. Other activities included:

- Creation of multiple data extracts to run through the Gen-Edits process in preparation for 1996-2019 data submission to NPCR and NAACCR;
- Deduplication of cases from Link Plus generated lists;
- Submission of 1996-2019 incident cases to NAACCR and NPCR timely without errors; and
- Submitting 2020 incident cases to NAACCR and NPCR following deduplication and edit corrections in January 2022.

### **3.3.2 Other Activities**

The MCR Program Manager, MCR staff, and key Myriddian staff participated in the following activities:

- Attendance at the NAACCR Annual Conference via a virtual platform. This included an accepted poster entitled “Improving Central Registry Data Processing and Quality Assurance Through Innovation: Myriddian Quality Assessment Tool (MQAT)” and a presentation entitled “Improving Cancer Registry Processes: Workflow, Monitoring and Accountability Using Power BI”;
- Attendance at the NPCR Annual Conference via a virtual platform; and
- Addition of a reporters’ log feature to the MQAT enhancement to enable storage, updates, and creation of email mailing lists as needed from the database.

### **3.4 TUMOR ABSTRACTS RECEIVED DURING FISCAL YEAR 2022 AND THE 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 2022 from all reporting facilities by year of the diagnosis of the tumor and the state of residence of the patient at diagnosis. Tumor abstracts are reported quarterly to the MCR ideally within six months of the date of diagnosis. However, as shown 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 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, 2022. 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 that were entered into the MCR as of June 30, 2022. As noted in the table footnote, as of June 30, 2022, the reporting and processing of cases diagnosed in 2020 through 2022 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 2022 by Year of Diagnosis and State of Residence at Diagnosis Received, July 1, 2021 to June 30, 2022**

Year of Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2022^	76	15	91
2021^	21,743	2,196	23,939
2020^	28,845	3,405	32,250
2019	8,360	589	8,949
2018	1,541	126	1,667
2017	631	43	674
2016	335	122	457
2015	115	10	125
2014	77	10	87
2013	47	7	54
2012	52	5	57
2011	24	2	26
2010	31	8	39
2009	24	1	25
2008	16	2	18
2007	11	0	11
2006	16	1	17
2005	7	0	7
2004	3	1	4
2003	8	0	8
2002	8	0	8
2001	3	0	3
2000	13	0	13
Before 2000	23	0	23
<b>TOTAL:</b>	<b>62,009</b>	<b>6,543</b>	<b>68,552</b>

Data Source: Myriddian using the MCR abstract database as of June 30, 2022.

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

^As of June 30, 2022, the MCR is still completing its data for submission for the 2020 incidence; therefore, 2020-2022 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, 2022, by Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)**

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2022^	1	0
2021^	400	25
2020^	892	70
2019	1,332	86
2018	1,135	71
2017	1,209	88
2016	1,100	78
2015	979	73
2014	939	76
2013	871	80
2012	885	77
2011	735	73
2010	897	71
2009	811	106
2008	740	77
2007	620	69
2006	550	57
2005	520	53
2004	495	50
2003	373	45
2002	301	24
2001	157	13
2000	29	3
Before 2000	630	71
<b>TOTAL:</b>	<b>16,601</b>	<b>1,436</b>

Data Source: Myriddian using the MCR consolidated database of finalized cases as of June 30, 2022.

\*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, 2022, the MCR is still completing its data for submission for the 2020 incidence; therefore, 2020-2022 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, 2022, by the Year of Diagnosis (Benign and Borderline)**

Year of Diagnosis	Number of Cases
2022^	0
2021^	105
2020^	252
2019	245
2018	276
2017	251
2016	237
2015	256
2014	251
2013	254
2012	240
2011	247
2010	224
2009	214
2008	201
2007	178
2006	135
2005	123
Before 2005	480
<b>Total</b>	<b>4,169</b>

Data Source: Myriddian, LLC using the MCR consolidated database as of June 30, 2022.

\*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 in 2010 and later)
- 9992-Refractory thrombocytopenia (this code is effective for cases diagnosed in 2010 and later.)

^As of June 30, 2022, the MCR is still completing its data for submission for the 2020 incidence; therefore, 2020-2022 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 2022.

**Table 3.5.1 Data Requests Requiring MCR Analysis, Received and Processed in Fiscal Year 2022**

Type of Request	Number of Requests Pending as of July 1, 2021 (start of Fiscal Year 2022)	Number of Requests Received in Fiscal Year 2022	Number of Requests Processed by June 30, 2022 (End of Fiscal Year 2022)
Research/Special Studies	1	15	14
Reporting Facilities Requesting their own Information	0	0	0
Health Services Planning	0	8	8
Public Request for Information	0	1	1
<b>Total</b>	<b>1</b>	<b>24</b>	<b>23</b>

#### 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 2022.

**Table 3.5.2 Cancer Cluster Concerns by Jurisdiction, Type of Analysis, and Results in Fiscal Year 2022**

Jurisdiction	Type of Analysis by MCR	Results
Baltimore	Minimal analysis	Complete
Howard	Minimal analysis	Ongoing
Montgomery	Minimal analysis	Complete
Baltimore City	Minimal analysis	Complete
Baltimore City	Minimal analysis	Ongoing

## 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 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**

<b>CDC</b>	Centers for Disease Control and Prevention
<b>FLccSC</b>	Fundamental Learning Collaborative for the Cancer Surveillance Community
<b>ICD-O-3</b>	International Classification of Diseases for Oncology - 3 <sup>rd</sup> Edition
<b>MCR</b>	Maryland Cancer Registry
<b>MDH</b>	Maryland Department of Health
<b>NAACCR</b>	North American Association of Central Cancer Registries
<b>NPCR</b>	National Program of Cancer Registries
<b>VPR-CLS</b>	Virtual Pooled Registry Cancer Linkage System