

Annual Report

Maryland Cancer Registry

Health–General §18-204(b)(6)
Fiscal Year 2021

Larry Hogan
Governor

Boyd Rutherford
Lieutenant Governor

Dennis R. Schrader
Secretary

September 2021





DEPARTMENT OF HEALTH

Larry Hogan, Governor · Boyd K. Rutherford, Lt. Governor · Dennis R. Schrader, Secretary

October 19, 2021

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: Chapter 251 of the Acts of 2001 (HB 636) and Health-General Article §18-204(b)(6)
2021 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 respectfully submits this annual legislative report on the activities of the Maryland Cancer Registry.

If you have any questions about this report, please contact Heather Shek, Director of Governmental Affairs, at 410-767-5282.

Sincerely,

Dennis R. Schrader
Secretary

Cc: Jinlene Chan, Deputy Secretary, Public Health Services
Heather Shek, Director, Office of Governmental Affairs
Sarah Albert, Department of Legislative Services (5 copies) MSAR #5544

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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 US Centers for Disease Control and Prevention (CDC), National Program of Cancer Registries (NPCR).

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, 2020 through June 30, 2021 (Fiscal Year 2021). 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 later 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) 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 2021 ACTIVITIES

3.1 ADMINISTRATIVE ACTIVITIES

Myriddian provided quality assurance and data management throughout Fiscal Year 2021. The Myriddian team and MCR staff met at least monthly to discuss progress. Maryland exchanged data 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 (Agreement). As of June 30, 2021, 48 registries, including the District of Columbia, Guam, Puerto Rico, and Virgin Islands, were participants in the Agreement.

3.1.1 Cancer Registry Advisory Committee

The Cancer Registry Advisory Committee met three times during Fiscal Year 2021 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, 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 Department program planning. The Department also processes and fulfills data requests from the public, reporting facilities, local health departments, researchers, and the media. Administrative highlights during Fiscal Year 2021 included:

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

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 2021 United States Cancer Statistics report and other analytic data sets.

2. NAACCR Certification:

The MCR submitted 2018 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 continued 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 41 other registries in Fiscal Year 2021.

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 release of individual-level data on matched cases.

6. LexisNexis Accurint:

During Fiscal Year 2021, the MCR utilized the LexisNexis Accurint tool to look up certain missing patient information in order to improve the quality of data linkage for a research study. The MCR purchased a LexisNexis license in March 2021 for continued quality assurance purposes. This tool supports the program in correcting addresses that did not geocode, resolving duplicates, researching death dates, finding the proper spelling of patient names, and resolving cases with an unknown race.

7. 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 2006-2018 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 began using FLccSC as a training resource for MCR reporters. The website is hosted and paid for as part of the NPCR funding. Materials available on the website include NPCR training materials, NAACCR webinars, 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 were able to access the pre-recorded webinars at their facilities and were granted continuing education units upon completion of the webinars. The webinars were posted on FLccSC.

10. National Cancer Registrars Week (April 6-10, 2021):

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 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 16,678 searches in the MVA database in Fiscal Year 2021.

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 2021:

- Received and processed reports for the MCR (see Table 3.4.1).
- Utilized the Myriddian Quality Assessment Tool (MQAT) to identify and prevent the processing of duplicate and non-reportable cases from facilities.
- Completed de-duplication by Social Security number, first and last name, and date of birth for years 1996 to 2019.
- Utilized a ticketing system for tracking and managing reporter, facility, and information technology tasks and communications.
- Conducted SQL analysis of deleted/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.
- 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

All hospital facilities reporting to the MCR are audited at least once during a five-year cycle. Myriddian conducted seven facility audits between July 1, 2020 and June 30, 2021. 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 in order to perform audits during the COVID-19 pandemic.

For each audit, the selected facility submitted a list of potential reportable cancer cases to Myriddian, each of which was reviewed 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 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 Department's Vital Statistics Administration (VSA) records of deaths in order to identify those who are now deceased, the cause of death, 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 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 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. Myriddian also developed and utilized an automated, computerized process to enter cases once the quality assurance team reviewed the information.

3.2.3 Case Consolidation

Myriddian received 81,688 facility abstracts in Fiscal Year 2021 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 41 state/territory central cancer registries through the National Interstate Data Exchange. One of the exchange platforms, the National Interstate Data Exchange Application System (N-IDEAS), was upgraded and installed with edit sets designed to reduce the number of errors in the files.

3.2.5 Technical Assistance and Training

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.

3.3 ACTIVITIES TO IMPROVE MCR-QUALITY ASSURANCE/DATA MANAGEMENT

Department 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 V21 edit file in all Registry Plus products;
- Create and run multiple data extracts using Gen-Edits in preparation for 1996-2019 data submission to NPCR and NAACCR;
- Research the decrease in caseload reporting for non-hospital facilities;
- Migrate to updated data storage servers for increased efficiency;
- Monitor and work with reporters with a history of submission delays and assist facilities in developing a submission plan;
- Continue to communicate with facilities regularly to identify any challenges that could negatively impact data submission; and
- Continue to present virtual educational workshops for central registry Certified Tumor Registrar staff.

3.3.1 Data Quality and Completeness

Myriddian continued to provide presentations and virtual 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:

- NAACCR Annual Conference, via a virtual platform; and,
- NPCR Annual Conference, also via a virtual platform.

3.4 TUMOR ABSTRACTS RECEIVED DURING FISCAL YEAR 2021 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 2021 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 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, 2021. 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, 2021. As noted in the table footnote, as of June 30, 2021, reporting and processing of cases diagnosed in 2019 through 2021 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 2021 by Year of Diagnosis and State of Residence at Diagnosis, July 1, 2020 to June 30, 2021

Year of Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2021^	136	25	161
2020^	12,502	1,828	14,330
2019^	41,743	5,839	47,582
2018	15,244	1,923	17,167
2017	1,036	108	1,144
2016	608	113	721
2015	147	31	178
2014	105	22	127
2013	64	13	77
2012	39	14	53
2011	22	7	29
2010	13	2	15
2009	19	3	22
2008	13	1	14
2007	12	4	16
2006	7	3	10
2005	10	1	11
2004	5	0	5
2003	5	1	6
2002	5	0	5
2001	1	1	2
2000	1	0	1
1999	2	0	2
1998	0	0	0
1997	1	0	1
1996	0	0	0
1995	1	0	1
1994	1	0	1
1993	1	0	1
1992	0	0	0
1991	1	0	1
Before 1990	4	0	5
TOTAL:	71,748	9,939	81,688

Data Source: Myriddian using the MCR abstract database as of June 30, 2021.

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

^As of June 30, 2021, the MCR is still completing its data for submission for the 2019 incidence year; therefore, 2019-2021 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, 2021 by Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2021^	2	0
2020^	247	22
2019^	1,176	70
2018	1,101	71
2017	1,194	88
2016	1,044	77
2015	976	73
2014	933	76
2013	861	80
2012	883	77
2011	733	73
2010	896	71
2009	809	106
2008	740	77
2007	620	69
2006	550	57
2005	519	53
2004	494	50
2003	373	45
2002	301	24
2001	157	13
2000	29	3
Before 2000	631	71
TOTAL:	15,269	1,346

Data Source: Myriddian using the MCR consolidated database of finalized cases as of June 30, 2021.

*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, 2021, the MCR is still completing its data for submission for the 2019 incidence year; therefore, 2019-2021 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, 2021 by the Year of Diagnosis (Benign and Borderline)

Year of Diagnosis	Number of Cases
2021^	1
2020^	46
2019^	169
2018	261
2017	243
2016	235
2015	256
2014	253
2013	254
2012	239
2011	248
2010	224
2009	213
2008	201
2007	178
2006	135
2005	122
2004	111
2003	116
2002	125
2001	87
2000	23
1999	7
Before 1999	1
Total	3,748

Data Source: Myriddian using the MCR consolidated database as of June 30, 2021.

*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, 2021, the MCR is still completing its data for submission for the 2019 incidence year; therefore, 2019-2021 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 2021.

Table 3.5.1 Data Requests Requiring MCR Analysis, Received and Processed in Fiscal Year 2021

Type of Request	Number of Requests Pending as of July 1, 2020 (start of Fiscal Year 2021)	Number of Requests Received in Fiscal Year 2021	Number of Requests Processed by June 30, 2021 (End of Fiscal Year 2021)
Research/Special Studies	1	12	13
Reporting Facilities Requesting their own Information	0	1	1
Health Services Planning	0	6	6
Public Request for Information	1	3	4
Total	2	22	24

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 2021.

Table 3.5.2 Cancer Cluster Concerns by Jurisdiction, Type of Analysis, and Results in Fiscal Year 2021

Jurisdiction	Type of Analysis by MCR	Results
Harford	Minimal analysis	Ongoing
Cecil	Workplace report	Unknown

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
MQAT	Myriddian Quality Assessment Tool
MVA	Motor Vehicle Administration
N-IDEAS	National Interstate Data Exchange Application System
NAACCR	North American Association of Central Cancer Registries
NPCR	National Program of Cancer Registries
VPR-CLS	Virtual Pooled Registry Cancer Linkage System
VSA	Vital Statistics Administration