



MARYLAND Department of Health

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

October 24, 2017

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 Health - General §18-204(b)(6)
2017 Legislative Report of the Maryland Cancer Registry

Dear Governor Hogan, President Miller, and Speaker Busch:

Pursuant to Health-General Article, § 18-204(b)(6), Annotated Code of Maryland, the 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,

A handwritten signature in black ink, appearing to read "Dennis R. Schrader".

Dennis R. Schrader
Secretary

Enclosure

cc: Webster Ye, J.D., Deputy Chief of Staff, Office of the Secretary
Jinlene Chan, M.D., M.P.H., F.A.A.P., Acting Deputy Secretary, Public Health Services
Donna Gugel, M.H.S., Director, Prevention and Health Promotion Administration
Anna McCreary, M.P.H., Director, Cancer and Chronic Disease Bureau
Ken Lin Tai, M.D., M.P.H., Director, Center for Cancer Prevention and Control
Sarah Albert, MSAR #5544

Annual Report

Maryland Cancer Registry

Health – General §18-204(b)(6)
Fiscal Year 2017

Larry Hogan
Governor

Boyd Rutherford
Lieutenant Governor

Dennis Schrader
Secretary

OCTOBER 2017



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The Maryland Cancer Registry is supported by Maryland General Funds, the Maryland Cigarette Restitution Fund, and by contract number U55/CCU321894 from the Centers for Disease Control and Prevention, National Program of Central Registries.

1. INTRODUCTION

Health - General §18-204(b)(6) requires an annual report on the Maryland Cancer Registry (MCR). This report covers the period from July 1, 2016 through June 30, 2017 (FY17). The MCR is a cancer incidence data system maintained under the direction of the Maryland Department of Health (MDH). Data in the registry 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 database 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 a period of five years, July 1, 2013 through June 30, 2018, and continues to provide quality assurance and database management services to the MCR.

During FY17, the MCR began preparations for the solicitation of a new vendor to provide quality assurance and database management services beginning on July 1, 2018.

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 reporting status and regulations);
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

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

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

3. FISCAL YEAR 2017 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. The MCR-Quality Assurance/Data Management contractor continued its quality assurance and data management activities during the fiscal year. Maryland also signed the National Interstate Data Exchange Agreement (NIDEA) during FY17. Data were exchanged twice with surrounding states and the District of Columbia cancer registries. Maryland has begun sending and receiving data from other states that are signatories to the NIDEA.

3.1.1 Cancer Registry Advisory Committee

The Cancer Registry Advisory Committee met twice 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 FY17 included:

1. *CDC NPCR National Data Completeness and Quality Standard:*

The U.S. 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 48 cancer registries supported by CDC, less than half achieve this designation. Meeting these standards allows Maryland’s data to be included in the 2017 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-objectives>)

2. *National Interstate Data Exchange Agreement:*

The NAACCR developed a model national interstate data exchange agreement to address the 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. Maryland was among 43 states and territories in the country to sign the agreement.
3. *NAACCR Certification:*

The MCR submitted its 2014 incidence data for evaluation and confidential feedback from the NAACCR and received “gold” certification, which represents 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, 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 the 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 2006-2014, 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 15 to 16:*

The MCR continued the conversion of its data and programs from NAACCR version 15 to version 16. CDC used Westat as a testing facility to identify potential issues related to the conversion.
7. *MCR Hosted 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 attending the sessions received continuing education units.
8. *National Cancer Registrars Week (April 10-14, 2017):*

During National Cancer Registrars Week, the MCR recognized the dedicated work of Maryland certified tumor registrars who submit quarterly data to the Registry. The Maryland Governor’s Office issues 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 FY17, 14 eligible providers signed up for Meaningful Use and a total of 15 providers moved into full production, submitting actual data (including providers who signed up for Meaningful Use in FY16). Eligible providers are required to sign up through the MDH website. Westat then provides account information to begin primary testing with dummy data. When the dummy data is received without errors, eligible providers send a secondary test file with actual data. When that file passes testing, the eligible provider can begin submitting Meaningful Use electronic data to the MCR automatically. *[Note: Eligible providers can request an exclusion from the cancer reporting objective of Meaningful Use Stage 2 if they do not diagnose or treat cancer patients or if their electronic health record is not certified to submit cancer data. An eligible provider can also become inactivated or non-responsive by not following the validation process or answering emails within a specified period of time.]*

Table 3.1 Cumulative Number of Eligible Providers by Testing and Registration Status as of June 30, 2017

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	9	127	24	20	180
Initiated primary validation testing	22	20	13	3	58
Primary testing error free, requested secondary test file	2	0	0	0	2
Pending secondary test file submission	1	0	5	1	7
Initiated secondary validation testing	5	1	0	0	6
Passed testing, not in production	7	0	0	0	7
Passed testing, in production	15	0	0	0	15
Total	61	148	42	24	275

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 in the registry, MCR staff searched over 3,100 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/quality control of data submitted; and submission of data to the NAACCR and NPCR. Specifically, Westat completed the following activities during FY17:

- Data submissions to the NAACCR and NPCR.
- Assured data quality:
 - Received and processed reports to the MCR (see Table 3.4.1).
 - Completed de-duplication by social security number, first and last name, and date of birth for the years 1996 to 2016.
 - Ran the latest derived Hispanic and Asian/Pacific Islander Identification algorithm and wrote back the results to the master file for the entire database through the year 2015.
 - 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.
 - Completed 10 facility audits of hospital reporting facilities with accompanying feedback reports.

3.2 ROUTINE DATA PROCESSING

3.2.1 MCR Facility Audits

Westat conducted a total of 10 facility audits between July 2016 and June 2017. 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 death case finding procedures. 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 of 2012 to 2015 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 45,047 facility abstracts in FY17 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 29 state central cancer registries through the NIDEA. The NIDEA 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 help 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 numbers³ as a tool to improve hospital case completeness. Hospital accession number lists should be exchanged between the hospital and central registries. 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.
- Make case finding audits based on disease indices a routine procedure for all facilities licensed by the MDH Office of Health Care Quality not designated as "Psychiatric" or

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.

“Rehabilitation.” Case finding audits based on disease indices should be completed at the hospital level and extended to the radiation therapy centers level.

- Develop a system to automatically assess whether cancer abstracts are complete, which therefore adds a new tumor to the database, or to contain quality stage and treatment data.
- Complete the upgrade of the MCR database to NAACCR version 16 of the Registry Plus applications.
- Improve Meaningful Use Workflow:
 - Develop a screening system that identifies whether the electronic health record with which the provider registers is certified for cancer reporting under Meaningful Use.
 - Develop a method for providers to indicate that they want to be excluded from the cancer reporting objective at the time of registration for Meaningful Use if there is not already a means for them to do so.
- Remind Maryland reporters on reportability requirements for benign brain and central nervous system tumors through use of electronic newsletter and present reportability requirements during the MCR update at Tumor Registrars Association of Maryland meeting.
- Develop algorithms to apply default values to abstracts and edits submitted on benign brain and central nervous system tumors, and develop rules for verification of the World Health Organization Grade, a grading system used specifically for central nervous system tumors.

MDH plans to continue discussions with Westat regarding the implementation of the above recommendations for improvement during FY18.

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, utilizing 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, Gaylord National Harbor, MD;
- Tumor Registrars Association of Maryland Annual Meeting, Harbor Hospital, Baltimore, MD;
- NAACCR Annual Conference, Albuquerque, NM;
- NAACCR 2016 Coordinated Call for Data Webinar; and
- Education and Training Coordinator Training, CDC NPCR, Gaylord National Harbor, MD.

3.4. TUMOR ABSTRACTS RECEIVED DURING FY17 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 FY17 from all reporting facilities by year of tumor diagnosis and state of residence at diagnosis. Tumor abstracts are reported quarterly to the MCR within six months of the date of diagnoses.

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, 2017. 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, 2017. As noted in the table footnote, as of June 30, 2017, 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 diagnosed in prior years.

Table 3.4.1 Number of Cancer Abstracts Received in FY17 by Year of Diagnosis and State of Residence at Diagnosis Received, July 1, 2016 to June 30, 2017

Year of Tumor Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2017	9	0	9
2016	19,981	2,782	22,763
2015	12,095	2,116	14,211
2014	2,870	464	3,334
2013	743	290	1,033
2012	971	300	1,271
2011	476	130	606
2010	221	33	254
2009	193	43	236
2008	127	23	150
2007	145	28	173
2006	118	24	142
2005	115	11	126
2004	94	9	103
2003	75	4	79
2002	65	5	70
2001	90	6	96
2000	58	8	66
1999	68	4	72
1998	58	0	58
1997	50	1	51
1996	34	2	36
1995	35	2	37
1994	11	0	11
1993	5	4	9
1992	2	1	3
1991	4	4	8
1990	4	0	4
1989	3	0	3
1988	5	1	6
1987	6	1	7
1986	1	0	1
1985	4	0	4
Before 1985	12	3	15
TOTAL	38,748	6,299	45,047

Data Source: Westat, using the MCR abstract database as of June 30, 2017

Note: MCR requirements allow for a six month delay in reporting of cases to allow for completion of the first course of treatment. Therefore, few cases diagnosed in 2017 would be received by June 30, 2017. 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, 2017 by Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2017^	0	0
2016^	208	18
2015^	720	62
2014	825	72
2013	789	78
2012	823	76
2011	691	72
2010	861	70
2009	770	108
2008	706	78
2007	599	69
2006	538	56
2005	507	52
2004	478	50
2003	373	46
2002	300	24
2001	156	12
2000	28	3
Before 2000	620	71
Total	9,992	1,017

* 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, and C75.1-C75.3)

Data Source: Westat from the MCR consolidated database of finalized cases as of June 30, 2017

^ As of June 30, 2017, the MCR is still completing its data for submission for the 2015 incidence year and has just begun gathering cases diagnosed in 2016 and 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, 2017 by the Year of Diagnosis (Benign and Borderline)

Year of Diagnosis	Number of Cases
2017[^]	49
2016[^]	196
2015[^]	225
2014	231
2013	226
2012	240
2011	217
2010	203
2009	198
2008	176
2007	130
2006	120
2005	110
2004	114
2003	122
2002	81
2001	19
2000	6
1999	49
Before 1999	11
Total	2,723

Data Source: Westat, using the MCR consolidated database as of June 30, 2017

*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

[^] As of June 30, 2017, the MCR is still completing its data for submission for the 2015 incidence year and has just begun gathering cases diagnosed in 2016 and 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 FY17.

Table 3.5.1 Data Requests Requiring MCR Analysis, Received and Processed in FY17

Type of Request	Number of Requests Pending as of July 1, 2017 (start of FY18)	Number of Requests Received in FY17	Number of Requests Processed by June 30, 2017 (end of FY17)
Research/Special Studies	1	10	11
Reporting Facilities Requesting their own Information	0	2	2
Health Services Planning	0	2	2
Public Request for Information	0	6	5
MDH Use	0	2	2
Total	1	22	22

3.5.2 Cancer Cluster Concerns

Table 3.5.2 shows the cancer cluster concerns by county, the type of analysis provided, and the results of the analysis for FY17.

Table 3.5.2 Cancer Cluster Concerns by County, Type of Analysis and Results in FY17

County	Type of Analysis by the MCR	Results
Baltimore County	Minimal Analysis to date	Not yet completed
Cecil County	Minimal Analysis	No cluster found
Howard County	Minimal Analysis	No cluster found
Montgomery County	Minimal Analysis to date	Not yet completed
Prince George's County	Minimal Analysis	No cluster found
Prince George's County	Analysis could not be performed as cluster concern was based on a common worksite	Not applicable

4. CONCLUSION

The MCR is a valuable resource for the State of Maryland, which 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	Centers for Disease Control and Prevention
FY	Fiscal Year
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
NIDEA	National Interstate Data Exchange Agreement
NPCR	National Program of Cancer Registries