September 23, 2016

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
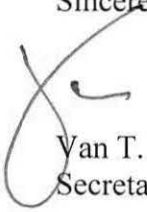Annapolis, MD 21401-1991

RE: Ch. 251 of the Acts of 2001 (HB 636) and Health - General § 18-204(b)(6)
       2016 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 and Mental Hygiene 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 Ms. Allison Taylor, Director of Governmental Affairs at 410-767-6481.

Sincerely,

Van T. Mitchell
Secretary

Enclosure

cc: Allison Taylor, M.P.P., J.D., Director, Office of Governmental Affairs
       Howard Haft, M.D., Deputy Secretary, Public Health Services
       Michelle Spencer, M.S., Director, Prevention and Health Promotion Administration
       Donna Gugel, M.H.S., Deputy Director, Prevention and Health Promotion Administration
       Sarah Albert, MSAR #5544

Maryland Department of Health
and Mental Hygiene

ANNUAL REPORT
Maryland Cancer Registry

HG §18-204 (b)(6)
Fiscal Year 2016

Larry Hogan
Governor

Boyd Rutherford
Lieutenant Governor

Van T. Mitchell
Secretary

SEPTEMBER 2016

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1. INTRODUCTION

Health-General § 18-204 (b)(6) requires an annual report on the Maryland Cancer Registry. This report covers the period July 1, 2015 through June 30, 2016 (FY16). The Maryland Cancer Registry (MCR) is a cancer incidence data system maintained under the direction of the Department of Health and Mental Hygiene (DHMH). 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.

DHMH subcontracts the database collection, data management, and quality assurance activities of the MCR to an outside entity. Westat, Incorporated (Westat), assumed responsibility for providing quality assurance and database management services to the MCR on February 1, 2008. Westat was selected through the state procurement process as the vendor for the MCR for the period of 5 years, July 1, 2013 through June 30, 2018, and continues to provide quality assurance and database management services to the MCR.

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

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

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

3.   FISCAL YEAR 2016 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. Data were exchanged twice with the 12 states and the District of Columbia cancer registries that have interstate data exchange agreements with the MCR.

3.1.1   Cancer Registry Advisory Committee

The Cancer Registry Advisory Committee met once to receive updates from MCR staff and provide feedback. Discussion topics included MCR-Quality Assurance/Data Management activities, data use and dissemination, data submission, data use policy and procedures, MCR regulations, Meaningful Use, nationwide Certified Tumor Registrar shortages, updates and cancer research, and surveillance activities.

The Maryland State Council on Cancer Control appointed a new chairperson for the Cancer Registry Advisory Committee during FY16: Kala Visvanathan, MD. Dr. Visvanathan is an Associate Professor in the Department of Epidemiology at Johns Hopkins Bloomberg School of Public Health and is also a member of the Maryland State Council on Cancer Control.

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, processes data requests, reviews research requests prior to Institutional Review Board submission, and analyzes data for DHMH program planning and for fulfilling data requests from the public, facilities that report, local health departments, researchers, and the media. Administrative highlights during FY16 included:

1. *MCR Data included in U.S. Survival Statistics*:
   The Centers for Disease Control and Prevention (CDC) selected MCR data for inclusion in "Invasive Cancer Incidence and Survival — United States, 2012." This is the second year that these statistics included states other than SEER (Surveillance, Epidemiology and End Results) states.

2. *National Program of Cancer Registries:*
   CDC's National Program of Cancer Registries (NPCR) has certified that MCR data has met the National Data Quality and Completeness Program standards, the highest standards set by this federal program. The MCR also moved its preliminary data submission to the CDC from January to November to be more aligned with NPCR requirements.

3. *North American Association of Central Cancer Registries Certification:*
   The MCR submitted 2013 incidence data for evaluation and confidential feedback from the North American Association of Central Cancer Registries (NAACCR) and received "gold" 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 and National Death Index Linkage:*
   The MCR linked Maryland data with the Social Security Death Index and the National Death Index to obtain more complete death information on cases in the MCR.

5. *Linkage with Breast and Cervical Cancer Program Database:*
   The MCR linked its database with the Maryland Breast and Cervical Cancer Program database of cancer cases diagnosed from 2004-2012, resulting in a 100% case match across both files. The MCR links with the Breast and Cervical Cancer Program database annually to assist in case finding and as a requirement of CDC funding for the MCR and the Breast and Cervical Cancer Program.

6. *NAACCR Conversion of MCR Database from Version 15 to 16:*
   The MCR began conversion of its data and programs from NAACCR version 15 to version 16.

7. *MCR Hosted Training Webinars*:
   The MCR hosted a series of NAACCR-presented online seminars (webinars) at DHMH 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 11-15, 2016):*
   During National Cancer Registrars Week, the MCR recognized the dedicated work of Maryland Certified Tumor Registrars who submit quarterly data to the Registry. A Governor's Proclamation was issued recognizing Certified Tumor Registrars and a letter was sent to each registrar expressing appreciation for their dedication.

9. *MCR Electronic Update:*
   The MCR published a quarterly electronic update that 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, and updates from the Central Registry (Westat).

10. *Meaningful Use Stage 2 Update*:

> The MCR worked with the DHMH Meaningful Use Group, which supports the implementation of the Maryland Electronic Health Records Incentive Program. The MCR provides aid for Meaningful Use reporting to providers that diagnose cancer cases so that their Electronic Health Record (EHR) data can also be entered into the MCR database, increasing the collection of Maryland cancer data from across the State and leading to greater cancer surveillance. During FY16, 138 eligible providers signed up for Meaningful Use and three providers moved into full production, submitting actual data. Eligible providers are required to sign up electronically through the DHMH 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. 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 EHR 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 7/1/2016

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	40	106	6	37	**189**
Initiated primary validation testing	25	19	2	5	**51**
Primary testing error free, requested secondary test file	1	0	0	0	**1**
Pending secondary test file submission	7	0	0	0	**7**
Initiated secondary validation testing	3	0	0	0	**3**
Passed testing, not in production	7	0	0	0	**7**
Passed testing, in production	3	0	0	0	**3**
Total	**86**	**125**	**8**	**42**	**261**

Data Source: Westat from the Meaning Use Database.

Please see section 3.3 for suggestions to improve providers' compliance with Meaningful Use.

11. Department of Motor Vehicle Unknown Race Look-Up:
To identify the race of individuals reported with unknown race in the registry, the MCR staff searched over 2,162 names in the Motor Vehicle Administration database for this missing race information.

3.1.3 Quality Assurance and Data Management Activities

Westat performed quality assurance and data management activities for the MCR including: accepting cancer reports from facilities; case finding and quality assurance/quality control of data submitted; and submission of data to NAACCR and NPCR.

Westat completed the following during FY16:
- Data submissions to NAACCR and NPCR.
- Assured data quality:
    - Received and processed abstract cases reported to the MCR (see Table 3.4.1).
    - Began conversion of the MCR database from NAACCR version 15 to version 16.
    - Completed de-duplication by social security number, first and last name, and date of birth for years 1996 to 2015.
    - Continued to perform internal quality assurance 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.
    - 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.
    - Ran the latest derived NAACCR Hispanic and Asian/Pacific Islander Identification algorithm and wrote back the results to master file for the entire database through the year 2014.
    - Completed Interstate Data Exchange procedures with 12 states and the District of Columbia central cancer registries with which the MCR holds an interstate data exchange agreement.
    - Produced and distributed an annual facility report to hospital reporters consisting of three sections:
        - The disease index match proportion (a measure of completeness);
        - The observed vs. expected abstracts ratio (a second measure of completeness); and
        - The proportion of abstracts reported at six months and nine months from diagnosis (a measure of timeliness).
    - Conducted validation testing for providers who are onboarding for Meaningful Use Stage 2 cancer reporting.
    - Communicated with providers, EHR vendors, and the CDC as part of the onboarding process for Meaningful Use.
    - Participated in Meaningful Use webinars and workgroup meetings including vendor-specific calls, Electronic Mapping, Reporting, and Coding (eMaRC) software physician reporting workgroup meetings, and CDC-NPCR Meaningful Use Collaboration workgroup meetings.

- o Developed and maintained the Meaningful Use Access database to track statuses, relevant events, and other pertinent information associated with providers registered for Meaningful Use cancer reporting.

3.2 ROUTINE DATA PROCESSING

3.2.1 MCR Facility Audits

Westat conducted a total of ten facility audits between July 2015 and June 2016. 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. Westat presented findings to the reporting facility as part of the reconciliation records prepared for reporting hospitals, and final 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 2015 to 2016 to determine the best facility to be contacted for a follow-back survey for each decedent. Additionally, Westat staff reviewed death certificate data to confirm case reportability and estimate the date of diagnosis for tumors not reported by other sources. The MCR also continued to identify people with cancer reported to the MCR and to match them to the Vital Statistics Administration's records of deaths in order to identify cause and date of death; Westat then wrote the information in the MCR database.

3.2.3 Case Consolidation

Westat received 46,091 facility abstracts in FY16 and processed them into consolidated, newly diagnosed tumor records (see Table 3.4.1).

3.2.4 Interstate Data Exchange

The MCR has active reciprocal reporting agreements with central registries in the District of Columbia and 12 state cancer registries: Alabama, Delaware, Florida, Georgia, New Jersey, New York, North Carolina, Pennsylvania, South Carolina, Texas, Virginia, and West Virginia. Westat completed interstate data exchange with all 12 states and the District of Columbia.

3.2.5 Technical Assistance and Training

Westat provided technical help and abstracting/coding expertise to Maryland cancer case abstractors and reporters via the MCR Technical Help Line (phone/fax/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,
- On-line 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 DHMH for improving the MCR Quality Assurance/Data Management system in the future. These recommendations include:

- Develop a system to identify and alert the data acquisition manager to gaps in the accession numbers as a tool to improve hospital case completeness. Hospital Accession Number lists should be exchanged between 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.
- Re-structure the hospital audits to:
  - Focus on blind re-abstracting using a copy of the medical record (either the EHR or a printed copy);
  - Randomly select cases based on information available in the abstracts submitted to the MCR; and
  - Verify the validity of answers the facility returned as part of the Disease Index Comparison Reconciliation.
- Make case-finding audits based on disease indices a routine procedure for all facilities licensed by the DHMH Office of Health Care Quality not designated as 'Psychiatric' or '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 adds a new tumor to the database), or contain quality stage and treatment data.
- Improve Meaningful Use Workflow:
  - Develop a screening system that identifies whether the EHR that a provider registers with 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 Certified Tumor Registrars of reportability requirements for benign brain and central nervous system tumors through use of the electronic newsletter and present reportability requirements during the MCR update at a Tumor Registrars Association of Maryland meeting.
- Develop algorithms to apply default values to empty fields in abstracts and edits submitted on benign brain and central nervous system tumors.

DHMH plans to continue discussions with Westat regarding the implementation of the above recommendations for improvement during FY17.

3.3.1 Data Quality and Completeness

Westat staff 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:
- Tumor Registrars Association of Maryland Annual Meetings, fall (Hagerstown, MD) and spring (Rockville, MD) (meeting hosted by Westat);
- NAACCR Annual Conference, St. Louis, MO;
- NAACCR 2015 Coordinated Call for Data Webinar;
- Education and Training Coordinator Training, CDC NPCR, Las Vegas, NV; and
- National Cancer Registrars Association Annual Meeting, Las Vegas, NV.

3.4 TUMOR ABSTRACTS RECEIVED DURING FY16 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 FY16 from all reporting facilities by year of tumor diagnosis and state of residence at diagnosis. Tumor abstracts are reported quarterly to the MCR within 6 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.

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, 2016. As noted in the table footnote, as of June 30, 2016, reporting and processing of cases diagnosed in 2014 and 2015 has not been finalized, so total numbers are lower than the finalized case numbers diagnosed in prior years.

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, 2016. As noted in the table footnote, as of June 30, 2016, reporting and processing of cases diagnosed in 2014, 2015, and 2016 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 Tumor Abstracts Received in FY16 by the Year of Diagnosis and State of Residence at Diagnosis

Received between July 1, 2015 to June 30, 2016

Year of Tumor Diagnosis	State of Residence at Diagnosis		
	Maryland	**Non-Maryland**	**Total**
2016	1	0	**1**
2015	21,911	2,951	**24,862**
2014	11,490	1,230	**12,720**
2013	6,250	147	**6,397**
2012	643	33	**676**
2011	330	25	**355**
2010	363	24	**387**
2009	197	11	**208**
2008	114	4	**118**
2007	67	6	**73**
2006	56	8	**64**
2005	47	3	**50**
2004	28	3	**31**
2003	22	1	**23**
2002	18	2	**20**
2001	11	1	**12**
2000	8	2	**10**
1999	12	1	**13**
1998	8	1	**9**
1997	6	2	**8**
1996	4	0	**4**
1995	11	1	**12**
1994	3	0	**3**
1993	5	0	**5**
1992	4	0	**4**
1991	2	0	**2**
1990	6	0	**6**
1989	7	0	**7**
1988	1	0	**1**
1987	1	0	**1**
1986	0	0	**0**
1985	1	0	**1**
Before 1985	8	0	**8**
TOTAL:	41,635	4,456	**46,091**

Data Source: Westat from the MCR abstract database as of June 30, 2016.
Table does not include voided abstracts in the MCR database because these abstracts were duplicates or were 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 Residing in Maryland at Diagnosis as of June 30, 2016** by the Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)

Year of Diagnosis	Behavior ICD-O-3	
	Benign	**Borderline**
2016^	0	0
2015^	337	32
2014^	765	66
2013	771	77
2012	810	76
2011	680	72
2010	854	71
2009	762	108
2008	694	77
2007	592	68
2006	533	53
2005	504	51
2004	475	50
2003	374	46
2002	300	24
2001	156	12
2000	28	3
Before 2000	621	71
Total	**9,256**	**957**

*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).

**Data Source: Westat from the MCR consolidated database of finalized cases as of June 30, 2016.

^ As of June 30, 2016, the MCR is still completing its data for submission for the 2014 incidence year and has just begun gathering cases diagnosed in 2015 and 2016, 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, 2016 by the Year of Diagnosis (Benign and Borderline)**

Year of Diagnosis	Number of Cases
2016^	0
2015^	90
2014^	176
2013	219
2012	219
2011	237
2010	216
2009	200
2008	198
2007	176
2006	129
2005	116
2004	108
2003	114
2002	122
2001	81
2000	19
1999	6
Before 1999	11
Total	**2,437**

**Data Source: Westat from the MCR consolidated database as of June 30, 2016.

*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, 2016, the MCR is still completing its data for submission for the 2014 incidence year and has just begun gathering cases diagnosed in 2015 and 2016, therefore the data are incomplete.

3.5 DATA REQUESTS

Table 3.5 shows the number of requests for data that the MCR received and processed in FY16.

Table 3.5 Data Requests, Requiring MCR Analysis, Received and Processed in FY16

Type of Request	Number of Requests Pending as of July 1, 2015 (start of FY16)	Number of Requests Received in FY 16	Number of Requests Processed by June 30, 2016 (end of FY16)
Research/Special Studies	3	6	7
Reporting Facilities Requesting their own Information	1	2	3
Health Services Planning	0	11	10
Public Request for Information	0	3	3
DHMH Use	0	4	4
Total	4	26	27

4. CONCLUSION

The MCR is a valuable resource for the state of Maryland and permits tracking, evaluation, and comparison of cancer statistics and rates with other states. Through the collection and analysis of MCR data, Maryland can 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.

Glossary of Key Abbreviations

CDC	Centers for Disease Control and Prevention
DHMH	Department of Health and Mental Hygiene
EHR	Electronic Health Record
eMaRC	Electronic Mapping, Recording, and Coding
FY	Fiscal Year
ICD-O-3	International Classification of Diseases for Oncology -3rd Edition
MCR	Maryland Cancer Registry
NAACCR	North American Association of Central Cancer Registries
NPCR	National Program of Cancer Registries
SEER	Surveillance, Epidemiology, and End Results