STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

Larry Hogan, Governor - Boyd Rutherford, Lt. Governor - Van Mitchell, Secretary

September 14, 2015

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

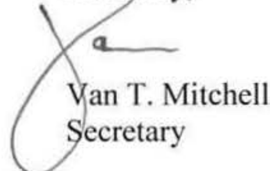
RE: Ch. 251 of the Acts of 2001 (HB 636) and HG § 18-204(b)(6)
2015 Legislative Report of the Maryland Cancer Registry

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
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Maryland Department of Health
and Mental Hygiene

ANNUAL REPORT
Maryland Cancer Registry

HG § 18-204 (b) (6)
Fiscal Year 2015

Larry Hogan
Governor

Boyd Rutherford
Lieutenant Governor

Van Mitchell
Secretary

SEPTEMBER 2015

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1. INTRODUCTION

Health-General Article § 18-204(b)(6) requires an annual report on the Maryland Cancer Registry. This report covers the period of July 1, 2014 through June 30, 2015 (FY15). The Maryland Cancer Registry (MCR) is a cancer incidence data system maintained under the direction of the Maryland 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 (CNS) 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 Maryland Cancer Registry 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. MCR MISSION STATEMENT

The Maryland Cancer Registry Advisory Committee (CRAC) 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 CNS 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.

[1] Md. Code Ann., Health-Gen., §§ 18-203 and 18-204 (1991).

3. FISCAL YEAR 2015 ACTIVITIES

3.1. ADMINISTRATIVE ACTIVITIES

The MCR-Quality Assurance/Data Management (QA/DM) team at Westat met with MCR staff at least monthly to discuss progress and plans. The MCR-QA/DM team 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 CRAC met twice to receive updates from MCR staff and provide feedback. Discussion topics included MCR-QA/DM activities, data use and dissemination, data submission, data use policy and procedures, MCR regulations and administrative activities, 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; 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 who report, local health departments, researchers, and the media. Administrative highlights during FY15 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, 2011.” This was the first 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 the MCR data has met the National Data Quality and Completeness Program standards, the highest standards set by this federal program.

3. *North American Association of Central Cancer Registries Certification:*
   The MCR submitted 2012 incidence data for evaluation and confidential feedback from the North American Association of Central Cancer Registries (NAACCR) and received “gold” certification, the highest certification set by this association. 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 the 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 (BCCP) database of cancer cases diagnosed from 2004-2011, resulting in a 100% case match across both files. The MCR links with the BCCP database annually to assist in case finding, and as a requirement of CDC funding for both programs.

6. *NAACCR Conversion of MCR Database from Version 14 to 15:*

   The MCR began conversion of its data and programs from NAACCR version 14 to version 15 beginning on May 8, 2015. Major changes from the conversion included changes in hematopoietic coding and new transgender codes.

7. *MCR Hosts 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 (CTRs) attending the sessions received Continuing Education Units.

8. *National Cancer Registrars Week (April 6–10, 2015):*

   During National Cancer Registrars Week, the MCR recognized the dedicated work of Maryland CTRs who submit quarterly data to the MCR. A Governor's Proclamation was issued recognizing CTRs and a letter was sent to each CTR expressing appreciation for their dedication.

9. *MCR Electronic Update:*

   The MCR continued the development of a quarterly electronic update that was sent to all reporting facilities and includes information on coding issues, facility audits, lab-only follow-back questions/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. In June 2013, DHMH began accepting registration for Stage 2 Meaningful Use for eligible providers, which includes physicians that diagnose and treat cancer. During FY15, Westat began receiving test files from eligible providers. If the test file was in the correct Clinical Document Architecture format (a special format for cancer registry programs), the provider was placed in a queue in preparation for regular electronic reporting. Ten physicians submitted test files; however, at this date none are ready to move into production.

11. Motor Vehicle Administration Unknown Race Look-Up:

To identify the race of individuals reported with unknown race in the registry, the MCR staff searched over 2,756 names in the Motor Vehicle Administration database for this missing race information.

3.1.3. Quality Assurance and Data Management Activities

Westat performed QA/DM 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 FY15:

- Data submissions to NAACCR and NPCR.
- Assured data quality:
  - Received and processed abstract cases reported to the MCR (see Table 3.4.1.).
  - Completed conversion of the MCR database from NAACCR version 14 to version 15.
  - Completed de-duplication by social security number, first and last name, and date of birth for years 2002-2012.
  - Continued to perform internal QA 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 edit set and the abstracts edit set.
  - Completed the latest derived NAACCR Hispanic and Asian/Pacific Islander Identification algorithm run and wrote back the results to the master file for incidence year 2012.
  - Completed Interstate Data Exchange procedures with 12 state and the District of Columbia central cancer registries with which MCR holds an interstate data exchange agreement.
- Developed the Follow-back Support System, a web-based software application that will support all follow-back operations including death clearance non-match cases follow-back, lab-only abstracts follow-back, and hospital disease index data management.
- Developed ComTrack, a tracking and decision support database that allows the MCR to identify and intervene to eliminate hospital reporting delinquency or deficiencies on a monthly basis.
- 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).

3.2. ROUTINE DATA PROCESSING

3.2.1. MCR Facility Audits

Westat conducted a total of six facility audits to determine the quality of data submitted by reporting facilities, and to direct the type of training the MCR provides facilities. For each audit, the selected facility was required to submit 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 was reported. In addition, Westat re-abstracted a number of cases to determine if the coding provided by the facility was correct. Findings were presented to the reporting facility as a component of the reconciliation records prepared for reporting hospitals.

3.2.2. Death Case Finding and Updating Death Information

Westat continued to improve the death case finding procedures and the Westat follow-back tracking tool. Westat continued to apply a SAS-based algorithm for conducting the tumor comparison step of the death case finding process. Westat staff also reviewed death certificate data to confirm case reportability and estimate the date of diagnosis for tumors not reported by other sources. Additionally, the MCR continued to identify people with cancer reported to the MCR and match them to the Vital Statistics Administration deaths in order to identify cause of death and date of death; once completed, Westat writes this information to the MCR database.

3.2.3. Case Consolidation

Westat received 62,822 facility abstracts in FY15 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 users with review of case finding and abstracting procedures;
- On-line Web Plus instruction; and
- Follow-up inquiries.

Westat also provided training during the Tumor Registrars Association of Maryland meetings held twice during FY15.

3.3. ACTIVITIES TO IMPROVE MCR-QA/DM

Westat made recommendations to DHMH for improving the MCR-QA/DM system in the future. These recommendations include:

- Install the updated eMaRC software application for processing physician reports resulting from Meaningful Use Stage 2.
- Develop new improved automated edits to verify the MCR database on a regular basis.
- Develop and automate the production of a report for Maryland cancer case reporters.
- Develop a system to identify and alert the data acquisition manager on gaps in the accession numbers as a tool to improve case completeness.
- Restructure hospital audits:
    - To implement blind re-abstracting by a Westat auditor using a copy of the medical record provided by the facility via access to electronic health records or a hard copy.
    - To ensure cases are randomly selected for re-abstracting rather than focusing on more common sites.
    - To focus re-abstraction on data items rather than a full case review.
- Undertake efforts to obtain cancer reports from federal facilities, in particular from those that support the American College of Surgeons Commission on Cancer accredited registries such as the National Cancer Institute Clinical Center, the Baltimore Veterans Administration Medical Center, and the Department of Defense Central Cancer Registry Program.

DHMH plans to continue discussions with Westat regarding the implementation of the above recommendations for improvement during FY16.

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 online software used to report cases of cancer to Westat. 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:

- American College of Surgeons Commission on Cancer conference;
- The NAACCR annual conference;
- The National Cancer Registrars Association annual conference; and
- CDC Reverse Site Visit and Technical Advisory meeting.

3.4. TUMOR ABSTRACTS RECEIVED DURING FY15 AND NUMBER OF BRAIN/CNS AND MYELODYSPLASIA CASES IN THE MCR

Table 3.4.1. displays the number of tumor abstracts received in FY15 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 conditions of special interest: benign and borderline malignant brain and CNS tumors, and malignant myelodysplastic syndrome tumors.

Table 3.4.2. presents the number of benign and borderline malignant brain and CNS tumors by year of diagnosis that were reported and entered into the MCR as of June 30, 2015. As noted in the table footnote, as of June 30, 2015, reporting and processing of cases diagnosed in 2013 and 2014 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, 2015. As noted in the table footnote, as of June 30, 2015, reporting and processing of cases diagnosed in 2013, 2014, and 2015 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 FY15 by the Year of Diagnosis and State of Residence at Diagnosis

Received between July 1, 2014 to June 30, 2015

Year of Tumor Diagnosis	State of Residence at Diagnosis		
	Maryland	Non-Maryland	Total
2015	46	2	**48**
2014	12,465	2,073	**14,538**
2013	29,521	4,608	**34,129**
2012	11,283	801	**12,084**
2011	587	62	**649**
2010	222	27	**249**
2009	670	12	**682**
2008	72	10	**82**
2007	125	6	**131**
2006	47	4	**51**
2005	34	0	**34**
2004	28	3	**31**
2003	9	2	**11**
2002	17	2	**19**
2001	14	1	**15**
2000	7	2	**9**
1999	7	0	**7**
1998	9	0	**9**
1997	6	0	**6**
1996	2	0	**2**
1995	1	1	**2**
1994	2	0	**2**
1993	4	2	**6**
1992	1	0	**1**
1991	3	0	**3**
1990	3	0	**3**
1989	4	0	**4**
1988	2	0	**2**
1987	1	0	**1**
1986	0	0	**0**
1985	1	0	**1**
Before 1985	11	0	**11**
TOTAL:	52,204	7,618	**62,822**

Data Source: Westat from the MCR abstract database as of June 30, 2015.
Table does not include voided abstracts not included in the MCR database because they were duplicates or were determined to be non-reportable conditions.

Table 3.4.2. Total Number of New Benign and Borderline Brain and Central Nervous System Tumors* in the Maryland Cancer Registry Residing in Maryland at Diagnosis as of June 30, 2015 by the Year of Diagnosis and by Tumor Behavior ICD-O-3 (Benign and Borderline)**

Year of Diagnosis	Behavior ICD-O-3	
	Benign	Borderline
2014^	282	36
2013^	582	55
2012	771	74
2011	662	72
2010	845	70
2009	750	108
2008	689	78
2007	591	68
2006	526	53
2005	502	50
2004	474	49
2003	374	46
2002	300	24
2001	157	13
2000	28	3
Before 2000	630	71
Total	**8,163**	**870**

*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, 2015.

^ As of June 30, 2015, the MCR is still completing its data for submission for the 2013 incidence year and has just begun gathering cases diagnosed in 2014, therefore the data are incomplete; see text on page 11.

Table 3.4.3. Total Number of Malignant Myelodysplastic Syndrome* Tumors in the Maryland Cancer Registry Diagnosed in Maryland Residents as of June 30, 2015 by the Year of Diagnosis **

Year of Diagnosis	Number of Cases
2015^	1
2014^	46
2013^	172
2012	214
2011	225
2010	214
2009	191
2008	190
2007	161
2006	119
2005	112
2004	100
2003	111
2002	118
2001	81
2000	18
1999	6
Before 1999	12
Total	**2,091**

**Data Source: Westat from the MCR consolidated database as of June 30, 2015.
*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-Mylodysplastic Syndrome with 5q deletion syndrome
9987-Therapy-related myelodysplastic syndrome, not otherwise specified
9989-Myleodysplastic syndrome, not otherwise specified
^ As of June 30, 2015, the MCR is still completing its data for submission for the 2013 incidence year and has just begun gathering cases diagnosed in 2014 and 2015, therefore the data are incomplete; see text on page 11.

3.5. DATA REQUESTS

Table 3.5. shows the number of requests for data that the MCR received and processed in FY15.

Table 3.5. Data Requests Requiring MCR Analysis, Received and Processed in FY15

Type of Request	Number of Requests Pending as of July 1, 2014 (start of FY15)	Number of Requests Received in FY15	Number of Requests Processed by June 30, 2015 (end of FY15)
Research/Special Studies	3	11	10
Reporting Facilities Requesting their own Information	0	1	1
Health Services Planning	1	10	9
Public Request for Information	1	3	3
DHMH Use	1	6	6
Total	6	31	29

4. CONCLUSION

The MCR is a valuable resource for the state of Maryland and permits tracking, evaluating, and comparing 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.

APPENDIX

Glossary of Key Abbreviations

BCCP	Breast and Cervical Cancer Program
CDC	Centers for Disease Control and Prevention
CNS	Central Nervous System
CRAC	Cancer Registry Advisory Committee
CTR	Certified Tumor Registrar
DHMH	Department of Health and Mental Hygiene
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
QA/DM	Quality Assurance/Data Management
SEER	Surveillance, Epidemiology and End Results