# SECTION ONE – INTRODUCTION

## Preface

The Maine Cancer Registry (MCR) is a statewide population-based cancer surveillance system. Our specific objectives are to collect information on all cancers diagnosed or treated in Maine, accurately determine patterns of cancer incidence in the state, contribute to epidemiological research and provide data for the planning and evaluation of cancer interventions. The general goal of the MCR is to help reduce the incidence of, and mortality from, cancer.

To accomplish these ends, the MCR was created by legislative mandate MRSA 22 § 1401-1407 (Appendix A) and began collecting data January 1, 1983. Since then, the MCR has undergone a number of changes to improve the utility of the database:

- In 1986, patient's usual occupation and industry became reportable data items.
- In 1989, AJCC stage, social security number, and patient's mailing address were made reportable.
- Cooperative case exchange agreements exist with Massachusetts, New Hampshire, New York, Vermont, Connecticut, Rhode Island, Florida, Arizona, Colorado, Nevada, Utah, and Wyoming in order to improve case ascertainment among Maine residents diagnosed out of state.
- In 1994, the MCR was awarded a grant from the Centers for Disease Control and Prevention through the National Program of Cancer Registries (NPCR), enabling the MCR to expand both the data set of collected items and the existing reporting requirements to include physicians.

The MCR strives to maintain compliance with the standards for abstracting and coding practices promoted by the national groups, including NPCR, the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, the North American Association of Central Cancer Registries (NAACCR), the American Joint Committee on Cancer (AJCC), and the American College of Surgeons (ACoS), including the Commission on Cancer (COC). These standards facilitate data exchange and allow for a "big picture" analysis of cancer in the United States.

Data are submitted annually to NAACCR for Registry Certification and publication in *Cancer in North America (CINA)*, to NPCR for assessment of standards and publication in *United States Cancer Statistics*, and to the Central Brain Tumor Registry for the United States (CBTRUS). Registries whose data meet NAACCR's established criteria for timeliness, quality, and completeness are recognized annually as Silver Certified or Gold Certified registries. MCR was recognized as a Gold Certified registry in 2004 and retained that status in 2005.

The purpose of this manual is to provide data standards for abstracting, coding and reporting cancer data to the MCR. Standard reporting is necessary for producing reliable and high quality information on cancer in Maine. Due to the ever-changing nature of the cancer registry world, this manual is designed to be a working document that can be modified to reflect changes in abstracting, coding, and reporting standards. As changes are made, replacement pages will be sent to all hospitals to be incorporated into the manual.

MCR staff is available to answer registry-related questions and to provide educational workshops. We thank you for your continued cooperation, and we look forward to working with you to attain our common goal of reducing the burden of cancer in the state of Maine. For more information, refer to the MCR website www.mainepublichealth.gov click on Cancer Registry located in the PH Program Index.

## Confidentiality

The MCR follows strict requirements of federal and state law to keep all personal information confidential. Any information that could identify a person is kept in locked files or secured computer accounts. Strict policies are in place regarding the release of data. In addition, MCR employees are required to sign confidentiality agreements and follow confidentiality procedures set forth in the Maine Cancer Registry Rules and Regulations (Appendix B).

HIPAA allows for the reporting of identifiable cancer data to public health authorities. The MCR falls under the definition of a public health authority. HIPAA allows facilities to report cancer incidence data to MCR in compliance with state statutes (MRSA 22 § 1401-1407). Written informed consent from each cancer patient reported to the MCR is not required by HIPAA nor is a Business Associated Agreement required. Facilities must simply document that reporting has occurred and will not be held liable for reporting.

## Audits

The MCR will periodically conduct case-finding and re-abstracting audits as required by NPCR. The purpose of these audits is to assess the quality and completeness of reporting to the MCR. Audit results will be summarized and shared with hospital registrars and reporters.

## Summary of Maine Cancer Registry Reporting Requirements

This is a general summary of the MCR reporting requirements. For detailed instructions for determining case reportability, see Section Two of this manual.

1. **Who is required to report to the Maine Cancer Registry?**
   As of 1995, all facilities that diagnose or treat patients with a reportable neoplasm are required to report. Physicians are required to report a case when the patient is not to be referred to a reporting hospital. Hospitals must report all reportable neoplasms seen at their facility, either as an inpatient or an outpatient. This includes patients seen for the diagnosis and evaluation of a reportable neoplasm and/ or for treatment or for treatment planning. This also includes patients who died at the reporting hospital even if no evaluation or treatment was performed at the reporting hospital.

2. **What cases are reportable?**
   a. All primary malignant neoplasms diagnosed on or after January 1, 1995. These include both in situ and invasive tumors.

      ***Exception 1****:* Beginning with cases diagnosed January 1, 2004, the MCR no longer requires facilities to report carcinoma in situ of the cervix.
      ***Exception 2****:* Juvenille astrocytoma, listed as 9421/1 in ICD-O-3, is required and should be recorded as 9421/3 in the registry.

   b. Basal and squamous cell skin cancers of the genital area.
   c. Malignant melanoma.

d. Non-malignant tumors of the brain, central nervous system and other intracranial sites.
**e. Intraepithelial neoplasia, grade III (VIN III, VAIN III and AIN III).**
f. All analytic and non-analytic cases (See page 9 for CoC Class of Case definitions) are reportable. These include inpatients, outpatients, patients who died at the reporting hospital with cancer present even if no evaluation or treatment was performed at the reporting facility, patients diagnosed at autopsy, and consult-only/pathology-only cases; however, for non-analytic cases, only data available in the medical record is required.
g. Both Maine residents and non-residents diagnosed or treated in Maine facilities. Reporting of out-of-state residents allows MCR to honor data exchange agreements with other states.

**3. What cases are not reportable?**

d. Cases diagnosed prior to January 1, 1995
e. Non-genital basal and squamous carcinomas of skin including tumors invading underlying tissue.
f. Benign tumors or tumors of uncertain behavior unless of the brain, central nervous system, or other intracranial sites.
g. Recurrences or secondary (metastatic) tumors from previously reported primary tumors.
h. Carcinoma in situ of the cervix, effective for cases diagnosed on or after January 1, 2004.

**4. What is the deadline for reporting cases to the MCR?**

Cases are to be reported within six months of diagnosis, discharge or date of first contact at the reporting hospital. Please use the following deadlines for reporting.

| Dates of Diagnosis, Discharge, or First Contact | Due Date at MCR |
|---|---|
| January 1st through March 31st | Last day in September of the same year |
| April 1st through June 30th | Last day in December of the same year |
| July 1st through September 30th | Last day in March of the following year |
| October 1st through December 31st | Last day in June of the following year |

**5. What data items are required to be reported to the MCR?**

The MCR must collect all data items required by the NPCR. In addition, the MCR may collect data items not required by NPCR, but necessary for complete reporting and analysis. Please see Section Three of this manual for the list of required data items.

**6. What is the recommended method for submitting new cases to the MCR?**

Facilities that do not have cancer registry software can report using the most recent paper abstract located on MCR's website. All other facilities must report electronically using the most current version of the NAACCR Record Layout. Data may be submitted on a floppy disk (3.5 inch, formatted) or a CD and should not be sent via email. In order to protect patient confidentiality, MCR recommends applying a password to all electronic submissions that are sent through the mail.

**7. What is the recommended method for resubmitting cases to the MCR?**

Hospitals resubmitting cases with changes should print out the electronic abstract, highlight the changes, and mail it to the MCR.

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