Preface for 2009

Revisions have been made to ***The Maine Cancer Registry Data Collection Manual for Hospitals, Fourth Edition - 2005*** in order to provide all necessary documentation to support changes in case reporting for 2009 diagnoses and for clarification of some of the existing reporting requirements:

In **SECTION ONE – INTRODUCTION**, Summary of Maine Cancer Registry Reporting Requirements, page 2, typographical errors have been corrected in the first paragraph. There have been no changes to content.

In **SECTION THREE – CODING INSTRUCTIONS**, there are clarifications and revised coding instructions for five data items:

- ***Name – First***: Hyphens are not allowed in this field.
- ***Laterality***: The instructions for codes 4 and 9 have been clarified.
- ***Date of Initial Diagnosis***: The instructions have been revised for this data item when the date of diagnosis is unknown and cannot be estimated.
- ***Date of First Positive Biopsy***: The source of this data item is now NAACCR, not the CoC.
- ***NPI- Reporting Facility***: The definition for NPI codes has been expanded.

In utero diagnoses: Beginning in 2009, the dates of diagnosis and treatment for tumors developed while in utero should reflect the dates on which they occur. In the past, these dates were assigned to the date the baby was born. This change is reflected in revised edits rather than revised coding instructions. For example, the edit "***Age, Primary Site, Morph ICDO3--Pediatric (NPCR***)" has been revised. Over-ride codes 2 (Reviewed: Case was diagnosed in utero) and 3 (Reviewed: Conditions 1 and 2 above apply) have been added.

Maine Cancer Registry Edits for Hospitals: MCR has adopted an edit set for incoming records. Starting in 2009, MCR staff will run edits on incoming data submissions, and the resultant Edit Error Reports will be returned to the reporting hospital for resolution. To reduce the number of errors, reporting hospitals are encouraged to run edits on their data prior to submission to MCR. MCR Edits for Hospitals is a subset of the NAACCR_v11_3A metafile and includes the edit sets Central: Vs11 State Ex-Incoming Abstracts, Hosp: Vs11 CoC Required All and Text Edits. We have compiled and distributed an edits dictionary which also includes instructions for interpreting the Edit Error Message.

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 has since maintained that status.

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

By law all hospitals that diagnose and/or treat cancer patients must report to the Maine Cancer Registry. Below is a general summary of the MCR reporting requirements. For detailed instructions on determining case reportability, see Section Two of this manual.

Which cases are reportable to the Maine Cancer Registry?

1. Patients seen at your hospital for the diagnosis, evaluation, treatment and/or treatment planning of a reportable neoplasm. This includes:
    a. A new diagnosis or a recurrence
    b. Inpatient and/or outpatient encounters
2. Patients who died at your hospital with a reportable neoplasm even if no evaluation or treatment was performed at your hospital.

What is a reportable neoplasm?

1. 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*:* Pilocytic (Juvenile) astrocytoma, listed as 9421/1 in ICD-O-3, is required and should be recorded as 9421/3 in the registry.

2. Basal and squamous cell skin cancers of the genital area.
3. Malignant melanoma.

NAME – FIRST	Item Length: 14 NAACCR Item #2240 Source of Standard: NAACCR (Revised 01/09) Dx Yr Req by MCR: All

Description: *Identifies the first name of the patient.*

Instructions for Coding (See *FORDS Revised for 2004* p. 40)

- Record the first name of the patient. Truncate the name if more than 14 letters long. Do not use punctuation **including hyphens**.

If the patient's name consists of a first initial followed by a middle name, record only the first initial in this field

> ***Example:*** If the patient's name is listed as A. Robert, record only the A in this field. Robert should be recorded in the *Name – Middle* field

LATERALITY	Item Length: 1 NAACCR Item #410 Source of Standard: SEER/CoC (Revised 01/09) Dx Yr Req by MCR: All

Description: *Identifies the side of a paired organ or the side of the body on which the reportable tumor originated. This applies to the primary site only.*

Instructions for Coding (See *FORDS Revised for 2007* pp. 92)

- Code laterality for all paired sites. (See *FORDS Revised for 2004* pp. 11-12 for a list of paired organ sites.)
- Code all nonpaired sites 0.
- Record laterality for unknown primary site (C80.9) as 0 (not a paired site).
- Do not code metastatic sites as bilateral involvement.
- Code midline lesions 9.

Code	Definition
0	Organ is not considered to be a paired site.
1	Origin of primary is right.
2	Origin of primary is left.
3	Only one side involved, right or left origin not specified.
4	Bilateral involvement, lateral origin unknown, stated to be a single primary; both ovaries simultaneously, single histology; bilateral retinoblastomas; bilateral Wilms' tumors
9	Paired site, but no information concerning laterality; midline tumor.

DATE OF INITIAL DIAGNOSIS	Item Length: 8 NAACCR Item #390 Source of Standard: SEER/CoC (Revised 01/09) Dx Yr Req by MCR: All

Description: *Records the date of initial diagnosis by a physician for the tumor being reported. The date of initial diagnosis is the month, day, and year that this primary cancer was first diagnosed by a recognized medical practitioner. The first two digits are the month, the third and fourth digits are the day, and the last four digits are the year. Note: If the exact date on which the diagnosis was made is not available, then record an approximate date.*

Instructions for Coding (See *FORDS Revised for 2004* pp. 89-90)

- Use the first date of diagnosis whether clinically or histologically confirmed.
- Refer to the list of "Ambiguous Terms" in Section Two of this manual for language that represents a diagnosis of cancer.
- If the physician states that in retrospect the patient had cancer at an earlier date, then use the earlier date as the date of diagnosis.
- Use the date therapy was started as the date of diagnosis if the patient receives a first course of treatment before a definitive diagnosis.
- The date of death is the date of diagnosis for a Class of Case 5 (autopsy only case)
- Use the Date of Birth as the Date of Initial Diagnosis for an in-utero diagnosis.
- If exact date of initial diagnosis is not known, record an approximate date.

> If the month and year is known but not the day, code day to "15".
>
> If the date of diagnosis is unknown and cannot be estimated, then use one day before the date of first contact at your facility and document it in the "Remarks" text field. This will most often apply to recurrent cases (Class of Case 3).
>
> ***Note:*** Whenever using an estimated date, please document in a text field.

If information is limited to a descriptive term use the following:

Descriptive Term Used	Date Code
"Spring"	April
"The middle of the year"	July
"Fall/autumn"	October
"Winter"	Try to determine if this means the beginning or the end of the year. Code January or December as indicated.

DATE OF FIRST POSITIVE BIOPSY	Item Length: 8 NAACCR Item #1080 Source of Standard: NAACCR (Revised 01/09) Dx Yr Req by MCR: 2005+

Description: *Records the date first positive tissue biopsy/histology.*

Instructions for Coding (See *ROADS p. 177)**

- Record the date on which the first positive incisional or excisional biopsy (positive histology) was performed at this or any facility.
  - The biopsy may be taken from the primary or a secondary site.
  - The first positive biopsy may be at any time during the disease course.
  - It may be noncancer-directed or cancer-directed surgery.

> If *Diagnostic Confirmation* is anything other than "1", then Date of First Positive Biopsy must be blank.

- If exact date of the first positive biopsy is not known, record an approximate date.

> If the month and year is known but not the day, code day to "15".
>
> ***Note:*** Whenever using an estimated date, please document in a text field.

  - If information is limited to a descriptive term use the following:

Descriptive Term Used	**Date Code**
"Spring"	April
"The middle of the year"	July
"Fall/autumn"	October
"Winter"	Try to determine if this means the beginning or the end of the year. Code January or December as indicated.

**Note: As of January 1, 2003, this date is no longer supported by CoC.*

NPI – REPORTING FACILITY	Item Length: 10 NAACCR Item #545 Source of Standard: CMS (Revised 01/09) Dx Yr Req by MCR: 2007+

Description: *The NPI (National Provider Identifier) identifies the facility submitting the data in the record.*

NPI, a unique identification number for health care providers, is scheduled for 2007-2008 implementation by the Centers for Medicare & Medicaid Services (CMS) as part of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Instructions for Coding (See *FORDS Revised for 2007 p 208A)*

- NPI should be recorded as available for cases diagnosed during 2007, and is required to be recorded for all cases diagnosed January 1, 2008, and later.
- NPI may be blank for cases diagnosed on or before December 31, 2006.

Code	Definitions
(fill spaces)	Only valid NPI assigned 10-digit numeric codes (9-digit numbers plus 1 check digit*) for the reporting facility
(leave blank)	NPI for the reporting facility is unknown or not available.

* The check digit algorithm is available at
https://nppes.cms.hhs.gov/NPPES/NPIRegistryHome.do