DATA COLLECTION MANUAL

MASSACHUSETTS CANCER REGISTRY

Abstracting and Coding Manual For Hospitals

Fifth Edition

December 2003
includes revisions through July 2007

corresponding to NAACCR Data Exchange Record Layout
Version 11.1 for diagnoses made in 2007

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The manual is posted electronically at http://www.mass.gov/dph/mcr .

Permissions

The information in the manual is largely compiled from previously published materials. It is not possible to provide specific citations within this manual each time a piece of information is derived from another source, so the MCR cites its main sources here.

Extensive material appearing in this manual comes from the *AJCC Cancer Staging Manual, Sixth Edition*. The MCR has received permission from the publisher and the AJCC to use this material -- provided, in part, that the following credit is prominently displayed at the front of this manual: **Used with the permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original source for this material is the *AJCC Cancer Staging Manual, Sixth Edition* (2002) published by Springer-Verlag New York, www.springer-ny.com.**

Extensive material is also used from the *Facility Oncology Registry Data Standards*, published in 2002 by the American College of Surgeons, Commission on Cancer ("*FORDS* Manual"), now updated as the *FORDS: Revised for 2007* Manual. The MCR has permission from the COC/AJCC Education and Training program to use *FORDS* Manual material with this citation. Jerri Linn Phillips, Andrew K. Stewart and Pat Tary were the original *FORDS* editors, and Mr. Stewart and Ms. Phillips were the editors of the 2004 version. The *FORDS* Manual was also updated during 2005, 2006 and 2007.

The National Institutes of Health, National Cancer Institute, Survival, Epidemiology and End Results program's *SEER Program Code Manual, Third Edition*, published in 1998 and updated several times since, is also a source of extensive material appearing in this manual. Its editors were April Fritz and Lynn Ries. Several other SEER publications and documents are also the source of important material -- see the **Other References** section on pages 4-7. The *SEER Program Coding and Staging Manual 2004, Fourth Edition*, published in September 2004 and edited by Carol Hahn Johnson, and its *Revision 1* published March 2006, and the *SEER Program Coding and Staging Manual 2007* published May 2007 and edited by Carol Hahn Johnson and Margaret Adamo, are also sources.

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Abbreviations Repeated in this Manual

ACoS	American College of Surgeons
AJCC	American Joint Committee on Cancer
aka	also known as
CDC	Centers for Disease Control and Prevention
CNS	Central Nervous System
COC	Commission on Cancer
CS	Collaborative Staging
DAM	COC's *Data Acquisition Manual*
DPH	Massachusetts Department of Public Health
Ed.	Edition
EOD	Extent of Disease (SEER coding system for stage)
FIN	Facility Identification Number
FORDS	COC's *Facility Oncology Registry Data Standards* Manual
ICD-O-2	World Health Organization's *International Classification of Diseases for Oncology, Second Edition*
ICD-O-3	World Health Organization's *International Classification of Diseases for Oncology, Third Edition*
MCR	Massachusetts Cancer Registry
MP/H	multiple primary/histology
NAACCR	North American Association of Central Cancer Registries
NOS	not otherwise specified
NPCR	National Program of Cancer Registries
NPI	National Provider Identifier
p., pp.	page, pages
ROADS	COC's *Registry Operations and Data Standards* Manual
SSF	(Collaborative Staging) Site-Specific Factor
SEER	National Cancer Institute's Surveillance, Epidemiology and End Results program
TNM	staging system of the American Joint Committee on Cancer's *Cancer Staging Manual, Sixth Edition*
WHO	World Health Organization

PREFACE TO THE FIFTH EDITION

This edition of the Massachusetts Cancer Registry *Abstracting and Coding Manual for Hospitals* has had the title *Data Collection Manual* added to it. This is a revision of the Fourth Edition (published in 2001). It applies to cases diagnosed beginning in 2003 and corresponds, whenever possible, to the data standards for the North American Association of Central Cancer Registries' Data Exchange Record Layout Version 11.1. NAACCR field names and columns in this manual correspond to Layout Version 11.1 even when marked "Version 10".

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The Massachusetts Cancer Registry (MCR) strives for compatibility with coding and abstracting practices of the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program, the Centers for Disease Control and Prevention's National Program of Cancer Registries (CDC/NPCR), the North American Association of Central Cancer Registries (NAACCR) and the American College of Surgeons (ACoS), including the Commission on Cancer (COC) and American Joint Committee on Cancer (AJCC). Compatibility with these groups assures consistent coding and allows Massachusetts hospitals and the MCR to compare data with other states and the nation.

The codes in this edition are to be used for cases diagnosed beginning January 1, 2003. When abstracting and coding a case diagnosed before 2003, certain data fields will need to be coded as they would have been at the time of diagnosis (for example, some surgery codes). This manual cannot contain all the codes necessary from previous manuals, so please retain abstracting, coding and staging manuals from earlier diagnosis years for such cases.

If the Date of Diagnosis of a particular case is completely unknown, the year of diagnosis should be estimated and the case coded accordingly with the data standards of the estimated diagnosis year; if even the approximate year of diagnosis cannot be estimated, the case should be coded in accordance with the coding standards in place for the Date of First Contact. (For example, if your facility's first contact with a cancer patient is in September 2005 *and you cannot estimate the year of diagnosis* for the case, code the case as if the diagnosis occurred during 2005, i.e., with ICD-O-3 codes, Collaborative Staging and *FORDS* Manual treatment codes.)

The manual is formatted for use in a three-ring binder. As changes are made, updated replacement pages will be sent to all hospitals so that each copy of the manual will remain consistent with current abstracting and coding procedures. The manual posted on the MCR's website (www.mass.gov/dph/mcr) will be kept updated.

The following is a summary of the **data fields that have been deleted, changed or added** since the previous edition of this manual:

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Table I

Fields Deleted Since the Fourth Edition

These data fields are no longer collected by the MCR:

- Managing Physician Name
- Number of Regional Lymph Nodes Removed--At This Facility
- Number of Regional Lymph Nodes Removed--Summary
- Pediatric Stage
- Pediatric Staging System
- Radiation--At This Facility
- Radiation--Summary
- Reconstruction--First Course
- Type of Reporting Source
- Year First Seen for This Primary

Appendices B (paired sites, moved elsewhere) and H (pediatric stage, eliminated) are also deleted.

Fields Changed Since the Fourth Edition

Data Field	Comments
Facility Name (p. 37)	a few **name and code changes**
Facility Code (p. 37, Appendix G)	ACoS/COC **shortened codes**; some additions; code changes
Sequence Number -- Hospital (p. 39)	**new coding scheme**; code ranges extended
Primary Payer at Diagnosis (p. 45)	some **code and category changes**
Date of First Contact (p. 46)	**rule** for Class 7 cases added
Birthplace, Place of Death (Appendix A)	a **new code** for a Canadian territory
Patient Name -- Suffix and Alias (p. 48, 50)	now **optional**
Address at Diagnosis (pp. 54-59)	street address **field lengthened** to conform with US Postal Service standards; new abbreviation for Newfoundland; **new code** for Canada, NOS; **change in** meaning of **codes** US, ZZ
Spanish/Hispanic Origin (pp. 68-72)	a **new code** for Dominican Republic origin added 2005
Primary Site Code (pp. 77-81D)	new **terms** for breast and bladder subsites
Grade/Differentiation/ Immunophenotype (p. 100)	**new codes** for nuclear grades; new data **priority rules**; **COC rule** for coding Gleason 7 adopted; new **terms** for some codes
Class of Case (p. 111)	designation for **Class 7** cases added
Institution Referred From, Institution Referred To (pp. 114, 115)	ACoS/COC **codes shortened**; some new codes
EOD -- Tumor Size (p. 116)	**new rules** conforming to COC standards; for 2003 diagnoses

Table I (cont.)

Data Field	Comments
TNM fields (pp. 123-143)	**new timing rule and codes** from AJCC Sixth Edition staging; for 2003 diagnoses; new codes for pN for breast cancers
Regional Nodes Examined, Regional Nodes Positive (pp. 152-154)	**new rules** conforming to COC rules and to Collaborative Staging rules; RN Positive **code changes**
Surgical Diagnostic and Staging Procedures (pp. 153-155)	**new name** for the fields that were called "diagnostic/ staging/palliative"; palliative bypasses moved into new field
Surgery of Primary Site, Scope of Regional Lymph Node Surgery, Surgery of Other Sites (Appendix D, pp. 177-186)	changes to some site-specific primary site surgery schemes and some **new codes**; RLN and Other Sites surgery **no longer site-specific**
Reason For No Primary Site Surgery (p. 181)	**name and rule changes**; a **new code**; now refers to only primary site surgery
Surgery of Primary Site, Scope of Regional Lymph Node Surgery, Surgery of Other Sites, 1998-2002 (pp. 187-188)	**new names** for *ROADS* surgery code fields, for diagnoses made before 2003
Chemotherapy, Hormone Therapy, Immunotherapy (pp. 195-204)	modality **fields lengthened**; **code changes**; **new date code** when treatment has not yet begun; dates **no longer edited**; transplants and endocrine surgery/radiation in new field
Appendix C (abbreviations)	more entries from NAACCR, AJCC, medical dictionaries
Fields Added Since the Fourth Edition	
NPI--Reporting Facility (p. 37); NPI--Registry ID (p. 39); and NPI--Physician--Follow-Up (p. 47)	**new** coded fields; **required beginning in 2008**
Following Physician Name (p. 47)	**replaces** Managing Physician Name
Name -- Spouse/Parent (p. 76)	new **optional** item for the MCR to help distinguish patients and research addresses
Patient System ID--Hosp (p. 76)	new **optional** item to help distinguish and link patient info
Address at Diagnosis--Supplemental (p. 56)	new NAACCR item from US Postal Service standards
Current Address (p. 59)	**optional** and **not edited**
ICD-O-2 Conversion Flag (p. 99)	new administrative item for the MCR to help identify when ICD-O-2 codes were converted from ICD-O-3 codes
NPI--Inst Referred From and To (p. 114)	**new** coded fields; **required beginning in 2008**

Table I (cont.)

Data Field	Comments
TNM Clinical/Pathologic Descriptors (pp. 127, 134)	new items for MCR for better interpretation of AJCC codes; for 2003 diagnoses
Collaborative Staging fields (pp. 162-168E)	for diagnoses made beginning in 2004
Date of 1st Positive Bx (p. 177)	date of a first positive incisional biopsy; optional field for diagnoses made beginning in 2004
Surgery of Primary Site, Scope of Regional Lymph Node Surgery, Surgery of Other Sites (pp. 178-181, Appendix D)	items for the *FORDS* surgery codes, for diagnoses made beginning in 2003
Date of Most Definitive Resection (p. 181)	date of most important primary site surgery
Radiation -- Regional Modality (p. 190)	partially replaces Radiation -- Summary and -- At This Facility
Systemic Treatment -- Date Started (p. 194)	new *FORDS* item covering overall start of systemic treatments
Hematologic Transplants & Endocrine Procedures (p. 205)	for procedures formerly recorded as Hormone Therapy and Immunotherapy
Palliative Care (pp. 210, 211)	new items; include some bypasses formerly coded as surgical diagnostic/staging/palliative procedures
Systemic/Surgery Sequence (p. 212)	chronological sequence of the first surgery and systemic treatment
First Recurrence -- Type and Date (p. 213)	new optional items to help identify those recurrences that must be counted as new primaries by central registries; not edited
Record Type, NAACCR Record Version (p. 218)	metadata fields to ensure that the MCR can verify the type of record received and its layout
Current Treatment Coding System, Original and Current COC Coding System, Original and Current Morphology Coding System (pp. 218-219)	administrative fields to ensure that the MCR can interpret codes received

The purpose of this manual is to establish common data standards governing the collection of cancer data by the MCR to ensure uniform statewide reporting of cancer information. This manual is designed to be a working document that will change to reflect changes in collection, coding and data standards.

SECTION I - INTRODUCTION

Introductory Note

The Massachusetts Cancer Registry (MCR) was established by legislation -- Massachusetts General Law Chapter 111, Section 111B -- in July 1980. This bill authorized the Commissioner of Public Health to establish a statewide cancer incidence registry and mandatory reporting system. After a planning and approval period of approximately two years, the MCR began operations on January 1, 1982. Effective July 1 , 2003, the law was amended to define a "malignant disease and benign brain-related tumor registry".

The purpose of the MCR is twofold: first, the Registry is designed to provide public information and statistical analyses of cancer incidence in Massachusetts; second, it is designed to serve as a resource for epidemiologic investigations of cancer in Massachusetts. The design and structure of the registry were developed based upon the experience of several other population-based registries in North America and Europe.

In the fall of 1994, the MCR was awarded a grant from the CDC under the National Cancer Registries Amendment Act to expand both the data set collected and the existing reporting requirements to include not only hospitals, but all health care facilities and practitioners. As a result, the regulations governing cancer reporting in Massachusetts (105 CMR 301.000) were amended on March 24, 1995 to expand the collected data set. These regulations were then further revised to expand the definition of those required to report cancer cases to include non-hospital reporting sources on October 6, 1995. On April 23, 2004 the regulations were amended to include language from the Benign Brain Tumor Cancer Registries Amendment Act that enabled CDC to collect non-malignant cancers of brain and related sites. For links to the law and regulations, see http://www.mass.gov/dph/mcr; www.mass.gov/legis/laws/mgl/111-111b.htm; www.mass.gov/Eeohhs2/docs/dph/regs/105cmr301.pdf .

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The MCR *Data Collection Manual* (*Abstracting and Coding Manual for Hospitals*) is designed to provide hospitals with abstracting and coding procedures pertaining to those data items collected by the MCR. In no way does this manual imply any restriction on the type or scope of information collected at the hospital level. Many hospitals, particularly those with ACoS-approved cancer programs, will collect a much larger data set. Facilities may choose to accession cases that are not reportable to the MCR.

Confidentiality

As stated previously, Chapter 111, Section 111B of the Massachusetts General Laws establishes the Cancer Registry within the MA Dept. of Public Health to record cases of malignant disease and benign brain-related tumors in Massachusetts residents. The Cancer Registry Regulations (at 105 CMR 301.040) stipulate that the identity of individual patients whose cases are reported to the MCR are to be held in the strictest confidence. Information concerning a particular individual, and any other information maintained by the MCR which, because of name, identifying number, mark, or description, can be readily associated with a particular individual shall not be released to or discussed with anyone other than authorized personnel at the reporting facility, unless prior informed consent is received from the patient or his/her guardian or legal representative.

Massachusetts General Law does provide [at 105 CMR 301.040(E)] for the release of MCR data by the Commissioner of Public Health, for research and statistical purposes, to the authorized representative of a study or research project sanctioned by the Commissioner under strict conditions guaranteed to maintain confidentiality. The Cancer Registry Regulations specifically prohibit the release of Social Security Number. The MCR also maintains confidentiality policies and procedures to protect information that could be used to identify data concerning a specific facility or physician. For detailed MCR-related HIPAA information, see http://www.mass.gov/dph/comm/hipaa/faq_mcr.htm .

Casefinding

Casefinding is the process of identifying reportable cases. It involves careful monitoring of records maintained by the departments that usually deal with cancer patients at your facility. Primary sources for case identification include these records:

- pathology reports (histology, cytology, hematology, bone marrow, autopsy findings)
- disease indexes
- daily discharges
- outpatient records
- radiation therapy records
- oncology clinic records

At a minimum, the following should also be considered as additional sources for casefinding:

- surgery reports
- nuclear medicine logs and radiology logs (including logs of scans)

General Reporting Requirements

Hospitals must report all cancer cases diagnosed on or after January 1, 1982, whether first seen at your facility with evidence of cancer or for cancer treatment or palliative care. Cases first diagnosed at autopsy should also be reported. A report is required regardless of whether or not the patient was previously diagnosed elsewhere. A report is not required if the patient was first seen at the reporting facility for a cancer case prior to 1982 and is later admitted again for that cancer. Do not report recurrences except as specified by the MCR. Massachusetts residents and non-residents (including foreign countries) are to be reported.

Analytic cases (Class 0, 1 and 2) are reportable for all diagnosis years beginning in 1982. Nonanalytic cases of Class 3, 4 and 9 *diagnosed during 1995 and thereafter* should be reported. Cases of Class 3, 4 and 9 *diagnosed before 1995* should not be reported so that MCR tumor counts can remain consistent with changes in reporting requirements necessitated by our becoming a CDC/NPCR registry. [Nonanalytic cases of Class 5 (autopsy-only cases) are reportable for any diagnosis year 1982 and later.] Reporting cases of Class 6 and 7 is optional; if a Class 6 case was *diagnosed before 1996*, it should not be reported; Class 7 cases *diagnosed before 2003* need not be reported. (Classes 6 and 7 were not clearly defined before 1996 and 2003, respectively.) Physician office and pathology-only cases not reported by hospitals are requested directly from their primary sources.

Cases must be reported to the MCR within 180 days (six months) of the Date of Diagnosis for cases of Class 0, 1, 5 and 7. Cases of Class 2, 3, 4, 6 and 9 must be reported to the MCR within 180 days of your facility's Date of First Contact with the patient. [For example, if a patient was diagnosed October 1, 2002 but *your* facility had no contact with the patient until January 1, 2004 and the case is of Class 3 to you, then you are required to report the case to the MCR by July 1, 2004.] This is in keeping with ACoS/COC rules for analytic case reporting (*FORDS* Manual p. 83). MCR timely reporting requirements may be relaxed during national periods of conversion to record layouts and codes. The MCR communicates any deviations from the 180-day requirements to data reporters and software vendors at such times. The 180-day requirement is in effect unless otherwise specified by the MCR.

Please see the **REPORTABILITY** section for extensive details of reporting requirements.

Reporting Methods: Media and Formats

Cases should be reported to the MCR on floppy diskette (3.5-inch, IBM-formatted) or compact diskette in NAACCR Data Exchange Record Layout Version 11.1. Paper submissions to the MCR must be printed legibly or typed. The MCR provides a free reporting system upon request. The MCR has received approval for electronic transmission (for example via secure electronic mail) of confidential public health data and detailed instructions for reporting electronically will be provided in the near future.

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For facilities employing the services of a software vendor for reporting cases, it is the *hospital's* responsibility to work with that vendor to ensure that the proper cases and data fields are received at the MCR in the proper format. The MCR does not have contracts with software vendors and therefore cannot be involved in arrangements with them. This is the hospital's responsibility.

Changes to Previously Submitted Cases

With the passage of time, a patient's medical record becomes more complete with regard to information initially missing or uncertain. It is therefore established practice to accept the thinking and information about the case at the time of the latest submission, or the most complete or detailed information. Thus, there may be changes in the coding of primary site, histology, stage (at diagnosis), etc., as the information becomes more certain. The patient's birthdate, Social Security Number, or the spelling of his/her name might also be changed on your data system. The MCR must be made aware of such changes.

There may also be cases reported which later information indicates never were reportable diagnoses. The MCR must be notified so that these cases can be deleted from our system.

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You may call the MCR (Judy Raymond or Pat Drew at 617-624-5680 or 617-624-5653) and report a change/delete confidentially over the telephone. Have the patient's identifiers ready. Be sure to speak directly to a registrar or leave a message that you'd like to be called back. Do not leave patient information on the MCR voice-mail system. The MCR cannot yet process electronic change forms ("M"-type records) except for identifying reportable recurrences, but we plan to develop a procedure for handling routine electronic change forms in the near future.

Other Reference Manuals and Materials

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In addition to this manual, a hospital registry should have access to the following references. Asterisks (*) mark materials used for diagnoses made in 2007 and after. Most of these materials are sources of the information contained in this MCR manual.

* *International Classification of Diseases for Oncology, Third Ed.* (World Health Organization, 2000; errata published May 2001 and May 2003, http://seer.cancer.gov/icd-o-3/errata.d05222001.pdf, http://seer.cancer.gov/icd-o-3/errata.d05062003.pdf) -- The "ICD-O-3" (purple) manual contains internationally recognized codes for different types of cancer and sites in the body where they occur. This edition is used for cases diagnosed beginning in 2001. The softcover version (subtitled *US Interim Version 2000*) differs slightly from the hardcover. Be sure that your copy is kept updated.

- *International Classification of Diseases for Oncology, Second Ed.* (World Health Organization, 1990) -- The "ICD-O-2" (green) manual is for cases diagnosed between 1992 and 2000. After its publication, a few histology codes (see *SEER Program Code Manual, 3rd Ed.*, pp. 98-99) and a grade/cell origin code (8) were added, and a topography code (C14.1) was deleted. Be sure that your copy was kept updated. (The MCR began accepting ICD-O-2 codes early -- for 1991 diagnoses -- because hospitals had already switched to ICD-O-2 by the time 1991 cases were being reported to us.)

- *International Classification of Diseases for Oncology, First Ed.* (World Health Organization, 1976) -- "ICD-O" or "ICD-O-1" is for cases diagnosed before 1992. (Field trial editions of ICD-O-2 published 1986 - 1988 may be used for diagnoses between these years and 1991.)

* *Clarifications for Abstracting and Coding Hematopoietic Diseases* (SEER Program, National Cancer Institute, 2001) -- These brief notes provide guidance for handling ICD-O-3 hematopoietic diseases and some other ICD-O-3 rules and issues. They are at http://seer.cancer.gov/icd-o-3/hematopoietic_clarifications.d05222001.pdf .

* *Abstracting and Coding Guide for the Hematopoietic Diseases* (SEER Program, National Cancer Institute, 2002) -- This orange booklet helps with identifying and abstracting the "new" ICD-O-3 blood and bone marrow diseases. It's available from the MCR or SEER (Publication # 02-5146). For updates see errata at http://seer.cancer.gov/manuals/errata_hemediseases_%2010012005.pdf and http://seer.cancer.gov/manuals/errata2_hemediseases_10012006.pdf .

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* *Collaborative Staging Manual and Coding Instructions, Version 01.03.00*, Collaborative Staging *Task* Force of the American Joint Committee on Cancer [published by AJCC (Chicago)/US Dept. of Health and Human Services, 2003] -- This manual for understanding and coding in the Collaborative Staging system is available in two parts at http://www.cancerstaging.org/cstage/manuals.html . It applies to diagnoses made beginning in 2004. Updates to the original version 1 for Part II (version 1.01 in August 2004, version 1.02 in April 2005 and August 2005, version 1.03 in September 2006) and Part I (October 2005 and December 2006) continue to be released.

- *AJCC Cancer Staging Manual, Sixth Ed.* (American Joint Committee on Cancer/Springer-Verlag, 2002) - This manual (portions also published in smaller format as *AJCC* Cancer *Staging Handbook*) contains information for assigning TNM stages to cases diagnosed beginning in 2003. Clarifications originally issued in April 2003 are available (dated July 16, 2003) at http://www.cancerstaging.net/ under "Coding Updates and Clarifications". Springer-Verlag provided a few replacement pages for the Manual and Handbook in June 2003. [The Fifth Ed. should be used to stage cases diagnosed 1998-2002. The Fourth Ed. (called *Manual for Staging of Cancer*) is for cases diagnosed 1993-1997; the Third Ed. is for cases *diagnosed* 1989-1992; the Second Ed. is for cases diagnosed 1984-1988; the First Ed. is for 1978-1983.] The publisher and AJCC wish the current publication to be cited as "Greene F.L., Page D.L., Fleming I.D., et al. *AJCC Cancer Staging Manual, Sixth Edition*. New York: Springer-Verlag, 2002". MCR no longer collects TNM stages as of 2004 diagnoses.

- *SEER Summary Staging Manual 2000: Codes and Coding Instructions* (National Cancer Institute, 2001) -- This (red) book defines Summary Stages and codes for diagnoses made beginning in 2001; see http://seer.cancer.gov/tools/ssm/ ; electronic versions posted before 6/18/2001 differ slightly from the final version; errata published June 2001, May 2002, August 2002 (August includes May revisions) are in the same SEER web area. MCR no longer collects Summary Stage as of 2004 diagnoses.

- *Summary Staging Guide for the Cancer Surveillance, Epidemiology and End Results Reporting (SEER) Program* (National Institutes of Health, 1977, last Revision 7/86) -- This staging guide defines Summary Stages for diagnoses made 1977-2000 (same material in SEER *Self Instructional Manual for Tumor Registrars: Book 6*); also known as "SEER Summary Staging Guide 1977". Changes in SEER Extent of Disease coding caused changes in Summary Stage results over the years, but the published version of the book was not updated after 1986.

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* SEER*Rx Interactive Antineoplastic Drug Database -- This electronic resource for cancer drug categorization replaces *SEER Book 8* (below) for diagnoses made starting in 2005. SEER*Rx can be downloaded after a password has been requested and issued through email. See http://seer.cancer.gov/tools/seerrx/ . Note that some drugs from *SEER Book 8* (or its additions) have changed treatment category in SEER*Rx; but *Book 8* codes assigned to pre-2005 diagnoses do not have to be changed. SEER*Rx Version 1.0 was posted July 2005. Version 1.1.0 was posted August 2006 and Version 1.1.1 was posted September 2006.

- *Self Instructional Manual for Tumor Registrars, Book 8, Antineoplastic Drugs, Third Ed.* (SEER Program, National Institutes of Health, 1993) -- *Book 8* was the standard for coding cancer drugs for pre-2005 diagnoses. Changes/additions were made May 2000 and May 2002 (updated June 2003). See http://seer.cancer.gov/tools/SEER.Book8.Addenda.pdf.

* *Multiple Primary and Histology Coding Rules January 01, 2007* (SEER Program, National Cancer Institute, 2006) - This manual has rules for determining single-vs.-multiple primaries and for assigning the best histologic type code to each primary for tumors diagnosed beginning in 2007. This manual was first posted during summer 2006 (335 pages) and was replaced/updated November 2006 (349 pages). Further updates are expected. The whole manual is at http://seer.cancer.gov/tools/mphrules/mphrules_manual_01012007.pdf . Individual sections are at http://seer.cancer.gov/tools/mphrules/download.html .

The following references can be very helpful when abstracting and coding cases.

- *TNM Atlas: Illustrated Guide to the TNM Classification of Malignant Tumours, Fifth Ed.* (International Union Against Cancer/John Wiley & Sons, 2005) -- This book and earlier editions show pictures of extent of disease spread in the AJCC staging system for selected cancers. The Fifth Ed. Atlas corresponds to Sixth Ed. TNM staging.

- *AJCC Cancer Staging Atlas* (American Joint Committee on Cancer/Springer Science + Business Media, 2006) -- This book complements AJCC Sixth Edition staging by providing anatomic illustrations of TNM classifications and stage groupings for major cancer types.

* Registry Plus™ Online Help - This downloadable system includes several electronic reference manuals, including the *FORDS*, Collaborative Staging Manual and ICD-O-3. It needs to be replaced on your computer whenever its content is updated. It self-installs using an .exe program found at http://www.cdc.gov/cancer/npcr/tools/registryplus/rpoh.htm .

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* *Facility Oncology Registry Data Standards* and *Facility Oncology Registry Data Standards: Revised for 2007 (FORDS)*. (American College of Surgeons, 2002) Many revisions were issued August 2002-March 2003, and again in December 2003, April 2004, September 2004, October 2005, September 2006 and June 2007. *FORDS* contains field definitions and codes for hospitals with ACoS approved cancer programs. See http://www.facs.org/cancer/coc/fordsmanual.html . Its Appendix C summarizes all revisions. *FORDS* originally applied to 2003 diagnoses and this Revision is for diagnoses made beginning in 2007. Try to keep your copy updated.

- *Standards of the Commission on Cancer Volume II: Registry Operations and Data Standards (ROADS).* (American College of Surgeons, 1996, *Supplement* issued 1997; revised January 1998, March and August 2000, January 2002) -- Precursor to the *FORDS* and successor to the *Data Acquisition Manual* (DAM, 1988-1996), *ROADS* applied to cases diagnosed 1997-2002.

* *Standards for Cancer Registries, Volume II: Data Standards and Data Dictionary* (North American Association of Central Cancer Registries) -- This data dictionary series describes the fields and codes accepted in NAACCR data exchange records. Layout Versions 10 (for 2003), 10.1 (2004), 10.2 (2005), 11 (2006), 11.1 (2007) and 11.2 (2008) were published 2002-2007. These are useful for understanding which fields are required by which groups, how codes have changed, and on which data items standard-setters have disagreed. Watch for revisions to these books after their initial releases. http://www.naaccr.org/index.asp?Col_SectionKey=7&Col_ContentID=133 .

* *The SEER Program Coding and Staging Manual 2007* (SEER Program, National Institutes of Health, 2007) -- This book provides data standards for SEER registries when reporting to the National Cancer Institute, starting with 2007 diagnoses. It includes the Collaborative Staging and MP/H Manuals. It was posted May 2007 at http://seer.cancer.gov/tools/codingmanuals/ .

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- *The SEER Program Coding and Staging Manual 2004, Fourth Ed.* and *Revision 1* (SEER Program, 2004, 2006) -- This resulted from a significant re-writing of the long-used Third Edition of the SEER Manual and incorporated the Collaborative Staging Manual in a site-specific appendix. It applied to diagnoses made 2004-2006. This and earlier versions of the SEER Manual are available from SEER on CD-ROM, or see http://seer.cancer.gov/tools/codingmanuals/historical.html .

- *The SEER Program Code Manual, Third Ed.* (SEER Program, 1998) -- Precursor to the Fourth Ed. (above), this was for diagnoses made 1988-2003. It was updated many times, notably in January 2003 (Revision 1). It's available on CD-ROM, or see http://seer.cancer.gov/tools/codingmanuals/historical.html .

- *SEER Extent of Disease - 1988, Codes and Coding Instructions, Third Ed.* (SEER Program, 1998; several updates issued). This has codes and instructions for coding staging data in the SEER EOD system through 2003 diagnoses. See http://seer.cancer.gov/tools/codingmanuals/historical.html (also available on CD-ROM).

- *Self Instructional Manuals for Tumor Registrars* (SEER Program, National Institutes of Health) (entire series now available from SEER on a single CD-ROM)
  Book 1. *Objectives and Functions of a Tumor Registry* (1999)
  Book 2. *Cancer Characteristics and Selection of Cases* (1991)
  Book 3. *Tumor Registrar Vocabulary - The Composition of Medical Terms* (1992)
  Book 4. *Human Anatomy as Related to Tumor Function* (1995)
  Book 5. *Abstracting a Medical Record: Patient Identification, History & Exams* (1993)
  Book 6. *Classification for Extent of Disease (Summary Staging Guide)* (1977)
  Book 7. *Statistics and Epidemiology for Cancer Registries* (1994)
  Book 8. *Antineoplastic Drugs* (1993) -- described above

- *NAACCR Implementation Guidelines* (North American Assn. of Central Cancer Registries) - These describe code conversions, data collection practices and software changes needed by hospital and central registries and vendors when changing to some NAACCR Layouts. Watch for revisions to these important documents after their initial releases. http://www.naaccr.org/index.asp?Col_SectionKey=7&Col_ContentID=431 .

- SEER and CDC/NPCR have training modules available. See http://seer.cancer.gov/training/ and http://www.cdc.gov/cancer/npcr/training/ .

* *Data Collection of Primary Central Nervous System Tumors* (National Program of Cancer Registries "Training Materials" series, CDC, 2004) -- Disseminated in 2005, this book has specialized information on CNS and other intracranial tumors. See http://www.cdc.gov/cancer/npcr/training/pdfs/braintumorguide.pdf .

* "Recording Tumor Markers in Collaborative Staging System Site-Specific Factors" (April Fritz, CS Task Force, 2005) -- This document provides information to help identify laboratory results for Collaborative Stage coding.
  http://www.cancerstaging.org/cstage/tumormarkers.pdf

* "Coding Regional Lymph Nodes for Breast" (CS Task Force, 2006) -- This document helps explain how to code information related to lymph nodes for the Collaborative Staging breast scheme. http://www.cancerstaging.org/cstage/BreastNodesExplanation.doc

* "Table of Unknown and Not Applicable Values for Collaborative Staging Data" (CS Steering Committee, 2006) -- This table shows the default codes for unknown/not applicable categories for the CS input fields for all schemas. Though created for CS version 1.02, it should also apply to 1.03.
  http://www.cancerstaging.org/cstage/defaultunknownCSvalues.xls

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- "Coding Complex Morphologic Diagnoses" (SEER Program, National Cancer Institute, last revised August 2002) -- This document was superseded by corresponding rules in the 2004 and 2007 *SEER Program Coding and Staging Manuals* and the MP/H Manual. It provided rules and guidance for assigning the best code for multiple histologies in a single tumor. There was some guidance for combining multiple tumors into one primary. Do not use this document for diagnoses made since 2003.

If you are missing and unable to locate important reference manuals or their revisions, the MCR will try to assist you (Mary Mroszczyk, 617-624-5659, mary.mroszczyk@state.ma.us).

Abstracting Requirements for Nonanalytic Cases & Reportable Recurrences

Nonanalytic Cases

Although the ACoS does not require hospitals to abstract nonanalytic cases, population-based cancer registries like the MCR must record all cases regardless of place of diagnosis or Class of Case. The MCR therefore requires that nonanalytic cases (of Classes 3, 4, 5 and 9) be submitted. Reporting cases of Class 7 (also nonanalytic) and Class 6 (*now* nonanalytic) is optional; *if* your facility collects Class 6 or 7 cases, you should report them to us.

Reporting requirements for cases in Classes 3, 4, 6, 7 and 9 are less stringent than those for other cases. The reporting hospital's medical record often does not contain all the required data, or contains only second-hand data. Report any information included in the medical record. It is not necessary to obtain *missing* information although you may choose to do so. It is not necessary to obtain any information on First Course of Treatment or stage at diagnosis.

Although a complete abstract with narratives is not required, certain data items must be specified in order for the case to be processed:

Reporting Facility Code
Medical Record Number or Accession Number
Patient Name (Last, First, Middle)
Address (preferably at the time of diagnosis; otherwise, for the current admission)
Birth Date
Age at Diagnosis
Social Security Number
Sex
Race Codes
Primary Site Code
Laterality
Histology/Behavior/Grade Codes (not Grade for MCR-reportable recurrences)
Date of Diagnosis
Sequence Number--Hospital
Date of Last Contact

Please try to provide good information for the data fields listed above. Even though information for many collected fields might not be available, all of the coded fields must be filled in (i.e., not left empty except as noted in this manual). When necessary, as for Collaborative Staging fields, use the (default) entries and codes for UNKNOWN, NONE, NOT DONE or NOT APPLICABLE or let your data system generate these default codes. No text fields are strictly required for nonanalytic cases, but MCR screening edits check that Primary Site and Histology/Behavior/Grade narratives appear for all cases. Unusual combinations of site and histology should always be backed up with text.

Reportable Recurrences

For tumors diagnosed beginning in 2007, use the Multiple Primary/Histology rules in the MP/H Manual to determine which new tumors are new primaries and need to be abstracted as such. Both central registries and hospital registries will follow the same MP/H Manual rules beginning with 2007-diagnosed tumors. Under the new rules there will no longer be situations where the central registry must count a case as a new primary when the hospital does not. Complete an abstract for each case that is determined to be a new primary based on the rules in the MP/H Manual. This will include some cases that in the past would have been counted as recurrences (not new primaries) by the hospital or MCR.

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For tumors diagnosed before 2007, the following rules were used:

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Central population-based registries like the MCR are required to count certain recurrences as new primaries -- whenever an *in-situ* tumor diagnosed since 1995 recurs invasively after more than two months. Previously the MCR has required separate case reports for the original diagnosis and the recurrence. The COC, NPCR and other groups have worked together to try to make it easier for hospitals to report these recurrences to their central registries (for example, the COC changed its recurrence codes). No other kinds of recurrence are reportable to the MCR until 2007. We know of NO exceptions to the *in situ*-followed-by-invasive rule; for example, if diagnosed after two months, an invasive recurrence of a non-invasive transitional cell carcinoma of the bladder is MCR-reportable, as is invasive prostate carcinoma after PIN or invasive cervical carcinoma after cervical carcinoma *in situ*.

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Users of CIMS-Satellite must submit abstracts for the original *in-situ* case AND the MCR-reportable invasive recurrence. They cannot at this time retrieve an already completed case and simply fill in the First Recurrence fields. Satellite users must report both cases separately, regardless of how quickly (after the two-month time period) the invasive recurrence occurs.

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Pre-2007 rules continued:

All other reporting facilities (those not using CIMS-Satellite) now have two options for reporting these recurrences to us. Choose only one of these reporting methods:

Option 1:

Continue to report both the original case and recurrence as separate primaries just as you have done before. (If your facility had no contact with the patient until the recurrence, you need only report the recurrence to us. If we have received no report from anyone about the original case, we may contact you for further information.)

Use the date on which the recurrence was diagnosed as the Date of Diagnosis. This then determines the time for all other at-diagnosis information (like age, address, etc.).

Use the original Primary Site where the *in-situ* case occurred with the recurrence's invasive (/3) morphology. The recurrence's Grade/Differentiation is not applicable.

Please report what you know about the recurrent case. You are not required to try and find information that is missing from your data system and medical records. Rely on the appropriate default entries for unknown/not applicable/none in the staging fields, treatment fields and other fields that you cannot specify. As a guide, refer to the list of specified fields needed for nonanalytic cases (page 8). The MCR will contact you if we need further clarification about the patient, the original case, or the recurrence.

Option 2:

Use the First Type of Recurrence fields (Type of First Recurrence and Date of First Recurrence, page 213).

Abstract the original *in-situ* case, and fill in the two First Type of Recurrence fields.

If the original *in-situ* case has been sent to the MCR when you fill in the Recurrence fields, be sure that your system recognizes that it needs to re-send us that record. (It may send it flagged as a "M"-type NAACCR record.) We will relate that record to the *in-situ* tumor on our system and change it into a new primary. We may need further information.

If the disease recurred quickly enough after the two-month period, you may not yet have reported the original *in-situ* case to us. Probably, when the *in-situ* case is exported for us, we'll find the Recurrence fields filled in. We will then create an abstract for a new primary at the MCR. Again, we may need more information.

If the *in-situ* case was diagnosed and treated at Facility A (in Massachusetts) and your hospital had no patient contact until the recurrence, please abstract the original case as best you can so that the Recurrence fields can be filled under Option 2. In fact the case may appear Class 3 to your facility and you may not know that the original case was *in situ*. If the *in-situ* case has been reported to us by Facility A, we will need just enough information to link your record to the original. If the original case has not been sent to us, we will need to determine if it was reportable to us at diagnosis; if it was not, then only the recurrence needs to be counted by the MCR. The MCR will have to determine when certain Class 3 reports are actually MCR-reportable recurrences.

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Pre-2007 rules continued:

Examples:

A patient has an *in-situ* breast cancer diagnosed and excised in April at your facility. She is then clinically free of disease. In October she is diagnosed at your facility with an invasive cancer in the same breast that has the same histology as the *in-situ* case. The physician calls this a recurrence rather than new disease. You may send the MCR two case abstracts (if you've chosen Option 1) or fill in the correct codes in the Recurrence fields in the *in-situ* case record (if you're using Option 2) and re-transmit it if it's already been sent to us.

A patient is diagnosed at your facility with an invasive cervical cancer in 2003. The medical record indicates that this is a recurrence (not just progression) of CIN III or an *in-situ* cervical cancer from two years earlier. CIN III and CIS of the cervix are not reportable to the MCR for diagnoses made in 2001, but the 2003 recurrence is reportable to us. Send an abstract record for just the recurrence (Option 1) or abstract the non-invasive 2001 case and fill in the two Recurrence fields (Option 2). (If your facility collects CIN III or CIS of the cervix on its own, you should just need to fill in the Recurrence codes for Option 2; but your software will need to recognize that a normally non-reportable case needs to be exported for the MCR because of the Recurrence codes.)

A patient is diagnosed with non-invasive transitional cell carcinoma of the bladder and this is reported to the MCR. A year later he is diagnosed with recurrent TCC of the bladder that is now invasive. There is no "bladder exception" for central registries following the NPCR recurrence rules, so both of these cases are MCR-reportable. Send a second record as if the recurrence were a new primary (Option 1), or fill in the Recurrence fields on the non-invasive record so that it can be re-sent to us (Option 2).

As has been repeated many times the MCR may need further information from you when you report a recurrence to us. The more information you can send us in narratives, the less we will have to bother you later. The MCR surveyed facilities to determine your plans for recurrence reporting so that we know what to expect. We need to be kept informed (617-624-5622) if you want to switch recurrence reporting Options.

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