

MECC Manual of Coding and Staging Version 5.1 July 2009

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To be used with cases diagnosed January 1, 2007 forward.

These coding standards were originally developed via contract from the Middle East Cancer Consortium to the Rollins School of Public Health in the Department of Epidemiology of Emory University, Atlanta, Georgia, USA.

The First Edition was disseminated, reviewed, and revised at the Second Semi-Annual Meeting of the MECC Joint Cancer Registration Project Steering Committee, December 1998

The Second Edition contained minor changes and was widely distributed among the MECC registries

The Third Edition documented the change to ICD-O-3 and Summary Stage 2000 and was disseminated at the January 2002 MECC Steering Committee Meeting

The Fourth Edition was released in March 2005 and expanded instructions on the coding of primary site, histology, and grade.

This Fifth Edition was adopted at the November 2008 Steering Committee Meeting in Larnaca, Cyprus and incorporates the new multiple primary rules of the International Association of Cancer Registries and reflects that the treatment and follow-up data items are required for all cases diagnosed January 1, 2007 forward. Slight modifications were made in July 2009 to clarify descriptions for four data items (**REGISTRY PATIENT NUMBER**, **PATIENT'S ADDRESS (at diagnosis)**, **RESIDENTIAL STATUS (current)**, **HOSPITAL DATA ITEMS**) made by the Cancer Registry of Cyprus

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*Required for cases diagnosed January 1, 2007 forward

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Brief History of the Middle East Cancer Consortium (MECC):

The Middle East Cancer Society started in Cairo, Egypt in 1994 as an idea among doctors, including Drs. Kahan, El-Bolkainy, Ibrahim, El-Najjar, and Polliack. Following meetings in Cairo, Bethesda, and Israel, when Dr. Klausner participated along with the Ministers of Health from Cyprus and Israel, the concept of the Middle East Cancer Consortium emerged.

Thus, on 20 May 1996, a new intergovernmental organization, the Middle East Cancer Consortium (MECC), was established by agreement in Geneva, Switzerland.

The agreement was signed by the Ministers of Health of:

- Cyprus
- Egypt
- Israel
- Jordan
- Palestinian Authority (Gaza and the West Bank)

The U.S. Secretary of Health and Human Services and the Director of the U.S. National Cancer Institute witnessed the agreement.

The Republic of Turkey officially joined the Consortium in June 2004.

The goal of the MECC is to raise cancer awareness in the Middle East and, ultimately, to reduce the burden of cancer in the region. Its first activity was the establishment of population-based cancer registries in all six jurisdictions.

Cancer Registry Project

The MECC Cancer Registry Project (CRP) opened on 1 January 1998. CRP's primary objective is to standardize data items, definitions, and codes to ensure that reliable comparisons can be made among jurisdictions. The quality of the data—its coverage and accuracy—is of primary importance to the MECC.

What is “Cancer”?

There are many elaborate definitions of “cancer”. The easiest definition is that “cancer” is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. For the purposes of defining reportable neoplasms, any tumor listed in the International Classification of Diseases for Oncology, Third Edition (ICD-O-3) with a behavior code (fifth digit) of 2 or 3 is considered to be a reportable neoplasm.

What is a “Cancer Registry”?

Cancer registries have been defined as organized systems for the collection, storage, analysis, and interpretation of data on persons with cancer, usually covering a hospital or group of hospitals. A population-based cancer registry collects the data from many hospitals and non-hospital sources in a defined geographic area and can serve to show incidence trends for cancer of different sites over time or between population subdivisions. With this information, incidence rates can be calculated. If the cases are then regularly followed, information on remission, exacerbation, prevalence, and survival can be obtained.

Registries are important public health tools:

- To verify and analyze the occurrence of cancer clusters.
- To target public health programs (education, screening, etc.) in order to make the best use of limited public funds.
- To compare acceptance rates and results of different cancer treatments (hospital, local, state, national, international).

What is a Diagnosis of Cancer?

The simplest way to state the answer is that a patient has cancer if a recognized medical practitioner says so. Then the question changes to “How can one tell from the medical record that the physician has stated a cancer diagnosis?” In most cases the patient’s record clearly presents the diagnosis by use of specific terms which are synonymous with cancer. However, not always is the physician certain or the recorded language definitive. Rules concerning the usage of vague or inconclusive diagnostic language are as follows:

Using Ambiguous Terminology to Determine Reportability of Cancer

All MECC Registries

Consider as diagnostic of cancer

apparent(ly)	malignant appearing
appears to	most likely
favours	presumed
comparable with	probable
compatible with	suspect(ed)
consistent with favor(s)	suspicious (for)
	typical (of)

Do **NOT** consider as diagnostic of cancer without additional information*

cannot be ruled out	questionable
equivocal	rule out
possible	suggests
potentially malignant	worrisome

* Do not include patients who have a diagnosis consisting only of these terms. If a phrase such as “strongly suggestive” or “highly worrisome” is used, disregard the modifier (“-ly”) and refer to the guidelines above regarding the primary term.

In addition,

For Gharbiah only

Consider as diagnostic of cancer

consider	impressive of
coping with	is considered
could be	mostly

How Changeable are the Diagnostic Items?

Most of the diagnostic information items are restricted to information available or procedures performed within the time limits defined for each item. However, with the passage of time the patient’s medical record gets more complete in regard to information originally missing or uncertain. It is therefore established practice to accept the thinking and information about the case at the time of the most complete or detailed information. Thus, there may be changes in the coding of primary site, histology, extent of disease, residence, etc., over time as the information becomes more certain.

Sometimes, careful re-examination of medical records indicates that a case originally reported as cancer was not, in fact, a malignancy. This occurs most often if ambiguous terms are used or if the case was ascertained on the basis of a death certificate. Such cases must be deleted from the file and the sequence number of any remaining cases for the same person adjusted accordingly. On the other hand, if upon medical and/or pathological review of a previous condition the patient is deemed to have had cancer at an earlier date, then the earlier date is the date of diagnosis, i.e., the date of diagnosis is back-dated.

What is Cancer so far as Reporting to MECC is Concerned?

All cases with a behavior code of ‘2’ or ‘3’ in the International Classification of Diseases for Oncology, Third Edition (ICD-O-3) are reportable neoplasms. However, the following are optional:

- ▶ 8050-8082 Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)
- ▶ 8090-8110 Basal cell carcinomas of the skin (C44.0-C44.9)
- ▶ Carcinoma in situ (any /2) and CIN III of the cervix (C53.0-C53.9).

Note 1: The above lesions are reportable for skin of the genital sites: vagina, clitoris, vulva, prepuce, penis, and scrotum (sites C52.9, C51.0-C51.9, C60.0, C60.9, C63.2).

Note 2: If a '0' or '1' behavior code term in ICD-O-3 is verified as in situ, '2', or malignant, '3', by a pathologist, the case is reportable.

Note 3: Basal or squamous cell skin cancers should not be sequenced with other malignancies. In situ/CIN III lesions of the uterine cervix should not be sequenced with other malignancies. See "Sequence of Tumor".

Many hospitals code their discharge diagnoses using ICD-10 codes. A list of ICD-10 codes which must be screened in order to identify all reportable cancer cases is shown in Appendix II.

Reference Date: What Dates of Diagnoses are Included in MECC?

In general, the reference date for MECC is January 1, 1996, the reference date for Jordan. However, the reference date for Israel is January 1, 1960. For the registries in the Palestinian Authority and Cyprus, the reference date is January 1, 1998, for Egypt (Tanta, Gharbiah) the reference date is January 1, 1999, and for Turkey (Izmir) the reference date is January 1, 1993.

Does Residency of the Patient Affect Reportability?

All cancers diagnosed and/or treated in persons who are residents of the reporting area at time of diagnosis are reportable, irrespective of the country or region where diagnosis was made. Further, any non-resident who is diagnosed and/or treated within the reporting area should be reported and registered, but should be excluded from the calculation of the number of incident cases and incidence rates. They should be included in calculations of numbers of patients diagnosed and/or treated in the country's healthcare facilities in order to measure the true burden of cancer for the country.

What is the Policy When There is More Than One Cancer?

The determination of how many primary cancers a patient has is, of course, a medical decision, but operational rules are needed in order to ensure consistency of reporting by all participants. Basic factors include the site of origin, the date of diagnosis, the histologic type, and the behavior of the neoplasm (i.e., in situ versus malignant).

In general, if there is a difference in the site where the cancer originates, it is fairly easy to determine whether it is a separate primary, regardless of dates of detection and differences in histology. Likewise, if there is a clear-cut difference in histology, other data such as site and time of detection are not essential. In some neoplasms, however, one must be careful since different histologic terms are used, for example, "leukemic phase

of' or 'converting to,' to describe progressive stages or phases of the same disease process.

How Are Multiple Primary Cancers Determined?

Rules recommended by the International Association of Cancer Registries will be used to determine the number of primary cancers reported within MECC. In general, only one cancer per primary site (utilizing the definition below) is reported over the lifetime of the patient. However, if a second primary of a different histologic group (utilizing the definition below) occurs either simultaneously or at a later date, a second primary in the same site should be reported.

Definitions:

- 1. Site differences:** Each primary site category (first three digits) as delineated in ICD-O-3 is considered to be a separate site. The exception to this rule involves certain sites that were combined in the first edition of ICD-O. A second exception involves the urinary sites which are lined with transitional epithelium and are frequently the site(s) of multiple tumors. ICD-O-3 site codes that should be considered to be the same "three-digit" grouping when determining multiple primaries and the primary site code to be assigned are shown on the following page:

ICD-O-3 Site Code	Primary Site	If diagnosed at different times, code first diagnosis. If diagnosed at the Same time, use codes given below.
C01	Base of tongue	
C02	Other and unspecified parts of tongue	C02.9
C00	Lip	
C03	Gum	
C04	Floor of mouth	
C05	Palate	
C06	Other and unspecified parts of mouth	C06.9
C09	Tonsil	
C10	Oropharynx	C10.9
C12	Pyriiform sinus	
C13	Hypopharynx	
C14	Other and ill-defined sites in lip, oral cavity and pharynx	C14.0
C19	Rectosigmoid junction	
C20	Rectum	C20.9
C23	Gallbladder	
C24	Other and unspecified parts of biliary tract	C24.9
C33	Trachea	
C34	Bronchus and lung	C34.9
C40	Bones, joints & articular cartilage of limbs	
C41	Bones, joints & articular cartilage of other & unspec'd sites	C41.9
C65	Renal pelvis	
C66	Ureter	
C67	Bladder	
C68	Other and unspecified urinary organs	C68.9

2. Histologic group differences: Differences in histologic group refer to differences between the 17 groups listed below which in turn are based on the first three digits of the ICD-O-3 morphology code:

Carcinomas

1. Squamous and transitional cell carcinoma 8051-8084, 8120-8131
2. Basal cell carcinomas 8090-8110
3. Adenocarcinomas 8140-8149, 8160-8162, 8190-8221, 8260-8337, 8350-8551, 8570-8576, 8940-8941
4. Other specific carcinomas 8030-8046, 8150-8157, 8170-8180, 8230-8255, 8340-8347, 8560-8562, 8580-8671
- (5) Unspecified carcinomas (NOS) 8010-8015, 8020-8022, 8050
6. **Sarcomas and soft tissue tumors** 8680-8713, 8800-8921, 8990-8991, 9040-9044, 9120-9125, 9130-9136, 9141-9252, 9370-9373, 9540-9582
7. **Mesothelioma** 9050-9055

Tumors of hematopoietic and lymphoid tissues

8. Myeloid 9840, 9861-9931, 9945-9946, 9950, 9961-9964, 9980-9987
9. B-cell neoplasms 9670-9699, 9728, 9731-9734, 9761-9767, 9769, 9823-9826, 9833, 9836, 9940
10. T-cell and NK-cell neoplasms 9700-9719, 9729, 9768, 9827-9831, 9834, 9837, 9948
11. Hodgkin lymphoma 9650-9667
12. Mast-cell Tumors 9740-9742
13. Histiocytes and Accessory Lymphoid cells 9750-9758
- (14) Unspecified types 9590-9591, 9596, 9727, 9760, 9800-9801, 9805, 9820, 9832, 9835, 9860, 9960, 9970, 9975, 9989
15. **Kaposi sarcoma** 9140
16. **Other specified** types of cancer 8720-8790, 8930-8936, 8950-8983, 9000-9030, 9060-9110, 9260-9365, 9380- 9539
- (17) **Unspecified** types of cancer 8000-8005

Note: Groups 5, 14, and 17 are non-specific groups and cannot be satisfactorily distinguished from the other groups. If a cancer classified in either group 5 or 17 occurs either simultaneously or later than one in group 1-4, ignore the unspecified cancer. The groups on the previous page were adapted from Berg JW. Morphologic classification of human cancer. In: Schottenfeld D & Fraumeni JF Jr. Cancer Epidemiology and Prevention, 2nd edition, Chapter 3 of Section 1: Basic Concepts. Oxford, New York, Oxford University Press, pp. 28-44, 1996).

Rules for Determining Multiple Primary Cancers:

1. A single lesion of one histologic type is considered a single primary, even if the lesion crosses site boundaries.
2. A single lesion composed of multiple histologic types is to be considered as a single primary.
3. If a new cancer of the same histology group as an earlier one is diagnosed in the same site, consider this to be the same primary cancer.

EXCEPTION 1: If an in situ tumor is followed by an invasive cancer in the same site more than two months apart, report as two primaries even if stated to be a recurrence. The invasive primary should be reported with the date of the invasive diagnosis.

4. Multiple lesions of the same histologic type
 - a. Simultaneous multiple lesions of the same histologic group within the same site (i.e., multifocal tumors) will be considered a single primary. Further, if one lesion has a behavior code of in situ and another a behavior code of malignant, still consider this to be a single primary whose behavior is malignant.
 - b. Multiple lesions of the same histologic group occurring in different primary sites are considered to be separate primaries unless stated to be metastatic.
5. Multiple lesions of different histologic groups
 - a. Multiple lesions of different histologic groups within a single site are to be considered separate primaries whether occurring simultaneously or at different times.
 - b. Multiple lesions of different histologic groups occurring in different sites are considered separate primaries whether occurring simultaneously or at different times.

DATA ITEMS

There are many data items that a cancer registry or cancer surveillance system can collect. The data items that follow are those that are agreed upon by MECC.

REQUIRED, CORE, or OPTIONAL

The term “**Required**” indicates that the data item is REQUIRED for **submission to MECC**

The term “**Core**” indicates that the data item is not required by MECC but is an essential CORE data item for cancer registry and cancer surveillance uses.

The term “**Optional**” indicates that the data item is not necessarily required by MECC, but is an OPTIONAL data item that may be of particular use or interest to a registry.

Any of the CORE or REQUIRED data items may be collected in greater detail if a registry so desires, but the REQUIRED data items must be submitted to MECC utilizing the codes in this manual. If a registry decides to collect an OPTIONAL data item, the data should be collected in such a manner that it can be converted to the suggested codes in this manual in order to allow for comparison among and between registries.

MECC REGISTRY IDENTIFICATION NUMBER — Required

Definition: A specific 2-digit code assigned to each MECC registry. The combination of this number plus the Registry Patient Number identifies a unique patient in the MECC data base.

Codes:

- 01 Cyprus**
- 02 Egypt (Gharbiah)**
- 03 Israel**
- 04 Jordan**
- 05 Palestinian Authority-Gaza**
- 06 Palestinian Authority-West Bank**
- 07 Turkey (Izmir)**

REGISTRY PATIENT NUMBER — Required

Definition:

The Registry Patient Number is issued by the registry to uniquely identify a person. All computer records pertaining to the same person must have an identical Registry Patient Number. This number may be assigned manually or by computer software.

The Registry Patient Number uniquely identifies a patient. The Registry Patient Number PLUS the Sequence Number uniquely identifies a reportable cancer.

Note: If, for some reason, a patient is deleted from the registry, that person's Registry Patient Number should NOT be assigned to any other individual.

Country-specific details:

Cyprus:

Note:

Cyprus, at present, uses a unique 10 digit number to identify each case of in situ or malignant cancer recorded. The first two digits of this number are always '01'. The next four digits denote the incidence year. The last 4 digits (with leading zeros) are unique serial numbers for each case of cancer in the denoted incidence year. This field is named "RegiNo". Therefore, one patient may have more than one "RegiNo".

With the forthcoming introduction of the new version of the software, CanReg5, Cyprus will adopt the MECC definition as given above.

SEQUENCE NUMBER (Lifetime Sequence) — Required

Definition:

Sequence number describes the chronology of diagnoses of all primary malignant and/or in situ cancers over the ENTIRE LIFETIME of the person, including the years before population-based cancer registration began.

If two or more independent primaries are diagnosed at the same time, the lowest sequence number will be assigned to the diagnosis with the worst prognosis. This means that extent of disease and morphology must be considered. If no difference in prognosis is evident, the decision must be arbitrary.

Note: Whenever a patient previously reported as having only one primary cancer is registered with a second primary, the sequence number of the first cancer should be changed from “00” to “01.”

Basal cell carcinomas of the skin, squamous cell carcinomas of the skin, and in situ carcinomas of the uterine cervix are NOT sequenced as other in situ or malignant primary cancers. Only one basal cell carcinoma should be registered over the lifetime of the patient and should be assigned the sequence number of 97. Similarly, only one squamous cell carcinoma should be registered over the lifetime of the patient and should be assigned the sequence number of 98.

Benign tumors of the brain and CNS, if collected, are also NOT sequenced as other cancers.

Codes:

- 00 One primary only**
- 01 First of two or more primaries**
- 02 Second of two or more primaries**
- ...
- ...
- ...
- 10 Tenth of two or more primaries**
- ...
- ...
- 95 Benign tumor of the brain or nervous system (optional collection)**
- 96 Carcinoma in situ of the uterine cervix (optional collection)**
- 97 Basal cell carcinoma of the skin cancer (optional collection)**
- 98 Squamous cell carcinoma of the skin cancer (optional collection)**
- 99 Unspecified sequence number**

PATIENT'S NAME — Core

Definition:

Document the name of the patient as provided in the source medical documents.

Country-specific Details:

Cyprus:

Patient's First Name (15 alphabetic characters)
Patient's Family Name (15 alphabetic characters)
Patient's Father's Name (15 alphabetic characters)

Current software utilized by the Cyprus Cancer Registry does not allow names to be recorded in Greek. Greek names are transliterated into Roman characters using the UN standard ELOT-743.

Egypt (Gharbiah), Jordan, and Palestinian Authority (Gaza and West Bank):

Patient's First Name (12 alphabetic characters)
Patient's Last (Family) Name (12 alphabetic characters)
Patient's Father's Name (12 alphabetic characters)

Patient's Grandfather's Name (12 alphabetic characters)

For Female Patients:

Patient's Husband's First Name (12 alphabetic characters)

CanReg3 required the names to be recorded in English. CanReg4 and CanReg5 allow the names to be recorded in Arabic.

Israel:

Patient's First Name (30 alphabetic characters)
Patient's Last Name (30 alphabetic characters)
First name of Mother (30 alphabetic characters)
First name of Father (30 alphabetic characters)

Current software utilized by the Israel Cancer Registry allows names to be recorded in Hebrew

Turkey (Izmir):

Patient's First Name (12 alphabetic characters)
Patient's Last Name (13 alphabetic characters)
Father's Name (10 alphabetic characters)

CanReg4 currently does not allow the name to be recorded in Turkish so the name is recorded in Latin characters only.

PATIENT'S NATIONAL IDENTITY NUMBER — Core

Definition:

Document the unique National Identification Number of the patient.

Country-specific Details:

Cyprus: (10 numerical characters)

In Cyprus, the National Identity Number is assigned at birth and is seven digits in length. It was initiated in 1960 following Independence. The practice of assigning this number at birth was introduced in 2000.

In the absence of such a number the following alternatives can be used:

- a) the mother's ID number plus an eighth digit indicating the order of birth of the child.
- b) passport number (unique, useful for foreign patients, resident or non-resident)
- c) other unique number (methodology to be decided).

Egypt (Gharbiah):

(14 numerical characters)

Israel: (9 numerical characters)

Jordan: (10 numerical characters and 1 alphabetic character)

Palestinian Authority (Gaza and West Bank):

(9 numerical characters; sometimes only 8-digits are recorded)

In the West Bank of the Palestinian Authority, the National Identity Number was initiated in 1967. All ID numbers issued between 1967 and 1989 begin with the number 9. All ID numbers issued between 1990 and 1994 begin with the number 8. All ID numbers issued from 1995 until the present start with the number 4.

Turkey (Izmir):

(11 numerical characters)

AGE AT DIAGNOSIS — Required

Definition:

The age of the patient at diagnosis is measured in complete years of life, i.e., age at LAST birthday. For patients less than one year of age, code age as 000. For patients whose age is completely unknown, code age as 999. For patients aged 99, code age as 099.

If age is unknown/not stated, but year of birth and year of diagnosis are known, calculate age at diagnosis.

Codes:

(3 numeric characters)

- 000** Less than one year old
- 001** One year old, but less than two years
- 002** Two years old
- ...
- ... (actual age in years)
- ...
- 099** Ninety-nine years old
- 100** One hundred years old
- ...
- ...
- 120** One hundred twenty years old
- ...
- ...
- 999** Unknown age

DATE OF BIRTH — Required

Definition:

Indicate the date of birth of the patient. Date of birth is an 8-digit field. The first two digits indicate the day, the second two the month; the last four digits identify the year including century. Use only the DD/MM/YYYY (2-digit day/2-digit month/4-digit year) format. For example, the date of birth of a patient born on August 10, 1939 should be recorded as: 10/08/1939.

If date of birth is unknown, but age is known, estimate year of birth by subtracting the age from the current year, and code day as 99 and month as 99. If age is also unknown, code year as 9999.

Codes and Details:

DAY	(Two-digit day) 99 Unknown day
MONTH	01 January 02 February 03 March 04 April 05 May 06 June 07 July 08 August 09 September 10 October 11 November 12 December 99 Unknown month
YEAR	All four digits of year (including century) 9999 Unknown year

SEX — Required

Definition:

Document the sex of the patient from the source medical documents.

Codes:

- 1 Male**
- 2 Female**
- 3 Hermaphrodite* (optional)**
- 9 Unknown**

* A hermaphrodite is the result of a genetic anomaly that results in the presence of male and female sex organs on the same person. Although relatively rare (approximately 1 in 250,000 people), hermaphrodites are known to have different and unique cancer patterns and therefore are interesting to study.

MARITAL STATUS (at diagnosis) — Optional

Definition:

Collect and code the marital status of the patient at the time of diagnosis.

Persons of the opposite sex living together as part of a long-term personal relationship should be coded to “2” as married.

Persons of the same sex living together as part of a long-term personal relationship should be coded according to their legal status (usually single, separated, divorced, or widowed).

Codes:

- 1 Single - never married**
- 2 Married**
- 3 Separated**
- 4 Divorced**
- 5 Widowed**
- 9 Unknown**

PATIENT'S ADDRESS (at diagnosis) — Core

Definition:

Record the place where the patient was living when the diagnosis was made. For example, if a person is a resident or citizen of Saudi Arabia but is living and working in Jordan at the time of diagnosis, record the address in Jordan even though this person may not be considered a legal resident of Jordan. Residential status is recorded in the Residential Status field.

Country-specific details:

Cyprus: **Street Name and House Number TEXT** (45 alphanumeric characters - left justified, Romanized)
 Post Code TEXT (4 numeric characters)
 Street code (7 alphanumeric characters - left justified, from a coded list)
 This unique, 7 character code (introduced by the Health Monitoring Unit for its own needs) defines the following variables:
 a) Name of the Street (as published by the Postal Services)
 b) Post Code (as published by the Postal Services)
 c) Name of the municipality/town/village (as published by CYSTAT)
 d) Four digit Geographical Code number (as published by CYSTAT)

Egypt (Gharbiah):

 Street name (30 alphanumeric characters - left justified)
 House number (4 alphanumeric characters - left justified)
 Zip Code (5 numeric characters)
 City or Village (15 alphanumeric characters)
 Governate (15 alphanumeric characters)

Israel: Settlement or city code (4 characters) [Can be converted to district code]
 Street name (30 alphanumeric characters)
 House number (4 alphanumeric characters)

 In Israel, the patient's address is copied in from the Population Registry after linkage through the patient identity number. A complete address history for the patient is maintained.

Jordan: City name (12 alphabetic characters)
 Village name (12 alphabetic characters)

Palestinian Authority (Gaza and West Bank):

 Street name (if present) and Village - (13 alphabetic characters - left justified)

Note: In the West Bank there are no house numbers. Street name and village are recorded in English.

PATIENT'S ADDRESS (at diagnosis) — Core – Continued

Turkey (Izmir): House number, Street name, and Village name (if available) - (37 alphanumeric characters)
Province (2 numeric characters)
District (2 numeric characters)
District within Izmir (2 numeric characters)
Village (2 numeric characters)

PATIENT’S TELEPHONE NUMBER (current) — Optional

Definition:

Collect and record the patient’s most current telephone number. This may be useful for follow-up activities.

Country-specific Details:

16-digit numeric characters (left justify the digits)

Cyprus: (10 numeric characters)

Egypt (Gharbiah): (10 numeric characters)

Israel: Not collected/recorded

Jordan: (10 numeric characters)

Palestinian Authority:

Gaza: (9 numeric characters)

West Bank: (9 numeric characters)

Turkey (Izmir): (10 numeric characters)

RESIDENTIAL STATUS (current) — Required

Definition:

Document the residence of the patient from the source medical documents.

Country-specific Details:

Cyprus: Residential status of a patient at the time of cancer diagnosis is based on the definition of CYPSTAT. This definition has been adapted for the purposes of the Cyprus Cancer Registry as follows:

Residents of Cyprus are patients who, at the time of cancer diagnosis, have stayed in Cyprus for at least one year or have entered Cyprus with the intention to settle in Cyprus or to stay for one year or more.

The residential status of the patient at the time of diagnosis may, in practice, be recorded in the clinical notes by the registration clerk of the treating facility. The clerk should ask the patient (or relatives), to clearly state, where the patient resides, in accordance with the above definition.

Registration in the Cancer Registry is done by using the following codes.

Codes:

- 1 Government controlled areas of the Republic of Cyprus**
- 2 Areas of the Republic of Cyprus not under Government control**
- 3 Restricted British Sovereign Base Areas (excluded from the Census)**
- 4 Other European Union member states**
- 8 Other countries**
- 9 Unknown residential status**

Code 1 makes up the population base of the Cyprus Cancer Registry.

Egypt (Gharbiah):

Based on registry ID number- Six-month residency required.

Israel:

Legal residence is based on National Identity Number. If the patient has been issued an ID card, then he/she is an Israeli resident. Non-residents can be identified according to their passport number or some other document.

Jordan:

For Jordanians who live abroad, record their current place of residence in Jordan at the time of diagnosis. For Jordanians in Jordan, record their usual place of residence at the time of diagnosis.

Palestinian Authority: --- no information ---

Turkey (Izmir): Based on patient's province code.

PLACE OF BIRTH — Optional

Definition:

Record the patient's place of birth from the source medical documents.

Country-specific Details:

Cyprus: Place of birth, for a patient born in Cyprus, is the name of the municipality, city or village of birth. A 4 digit code is recorded from a coded list.
For patients born abroad, the coded list includes a code for 'born abroad'.
If necessary codes for other specified countries may be added to the coded list as required.

Egypt (Gharbiah): The governate of birth is recorded. There are 29 governates coded 1-29.

Israel: Country of birth, for those born abroad (coded list)
If born in Israel, --- no info ---

Note: For those born abroad, date of "Aliya" (immigration to Israel) is also collected.

Jordan: Not Collected

Palestinian Authority:

West Bank:

Born within the Palestinian Authority, code governate
Born outside Palestinian Authority, code country of birth using country codes
Name of the country and village is recorded in English

Turkey (Izmir):

Born within Turkey: Province of Birth
Born outside of Turkey: Code 0010

ORIGIN/ETHNICITY/NATIONALITY — Optional

Definition:

Record the origin and/or ethnicity of the patient from the source medical documents.

Country-specific codes:

Cyprus:

Cypriots

- 1 Greek
- 2 Turkish
- 3 Maronite
- 4 Armenian
- 5 Latin (Catholic)
- 6 Other Cypriot

Foreigners

- 7 Foreigner, other than European Union
- 8 European Union

Unknown

- 9 Unknown

Egypt (Gharbiah):

Not Collected

Israel:

Not collected/recorded.

The country of birth is used to indicate a "race group" like Ashkenazi, etc. For Arabs, there is a certain code that indicates that s/he was born in Israel and is an Arab.

Jordan:

Not Collected

Palestinian Authority (Gaza and West Bank):

Not Collected

Turkey (Izmir): Not Collected

RELIGION — Optional

Definition:

Record the religion of the patient from the source medical documents.

Country-specific Codes:

Cyprus:

Not collected

Egypt (Gharbiah):

- 0 No religion
- 1 Christian (includes Coptic, Greek Orthodox, Roman Orthodox, Protestant)
- 2 Jewish
- 3 Muslim
- 9 Unknown

Israel: Not collected

Jordan:

Not Collected

Palestinian Authority (Gaza and West Bank):

- 0 No religion
- 1 Christian (includes Coptic, Greek Orthodox, Roman Orthodox, Protestant)
- 2 Jewish
- 3 Muslim
- 8 Other (Samery, etc.)
- 9 Unknown

Turkey (Izmir):

Not Collected

SMOKING HISTORY — Optional

Definition:

Ideally only cigarette smoking should be recorded in this field, although cigar, pipe, and narghile smoking may be included inadvertently.

Codes:

- 0 Never smoked**
- 1 Current smoker**
- 2 Former smoker**
- 9 Unknown smoking history**

Note: Israel collects more detail than the above (not provided).

OCCUPATION — Optional

Definition:

Record in text format the occupation as reported in the medical record or on the death certificate. If the patient has had more than one occupation, ideally the longest held occupation should be recorded. For the purpose of cancer risk understanding, the registry is more interested in type of work rather than a stated profession. For example, if the patient states his profession to be a teacher but he has worked most of his life as a taxi driver, he should be recorded as a driver in public transportation.

Details:

This is a free-text data item. There are 25 characters allotted. Occupation text may be recorded in any available language.

Country-specific details:

Cyprus, and Israel have coded Occupation and Industry each using their own specific 3-digit codes.

Egypt (Gharbiah) has recorded occupation by both text and their own code.

Jordan and Gaza record text.

Turkey (Izmir) does not collect occupation.

DATE OF DIAGNOSIS — Required

Definition:

The diagnosis date refers to the first diagnosis of this cancer by any recognized medical practitioner. This is often a clinical diagnosis and may not ever be confirmed histologically. Even if confirmed later, the diagnosis date refers to the date of the first clinical diagnosis and not to the date of confirmation. If medical and/or pathological review of a previous condition indicates that the patient had cancer at an earlier date, then the earlier date is the date of diagnosis, i.e., the date of diagnosis is back-dated.

Details:

DAY	Two-digit day 99 Unknown day
MONTH	01 January 02 February 03 March 04 April 05 May 06 June 07 July 08 August 09 September 10 October 11 November 12 December 99 Unknown month
YEAR	All four digits of year (including century) 9999 Unknown year

Coding Instructions:

The diagnosis date refers to the first diagnosis by any recognized medical practitioner.

1. Code the date of diagnosis for this cancer.
2. The first diagnosis of cancer may be clinical (i.e. based on physical exam, scans or laboratory results for hematopoietic malignancies)
 - a. Do not change the date of diagnosis when a clinical diagnosis is confirmed later by positive histology or cytology.

Example: On May 15, 2004, the physician states that the patient has lung cancer based on clinical findings. The patient has a positive biopsy of the lung in June 3, 2004. The date of diagnosis remains May 15, 2004 (150552004).

DATE OF DIAGNOSIS — Required – Continued

- b. If the patient receives first course treatment and there is no information about the date of diagnosis, use the date of admission as the date of diagnosis.
 - c. If the patient receives first course of treatment and there is no information about the date of diagnosis nor is there an admission date, code the date of first treatment as the date of diagnosis.
3. Positive tumor markers alone are not diagnostic of cancer. Use the date of clinical, histologic, or positive cytologic confirmation as the date of diagnosis.
4. Suspicious cytology only is not diagnostic of cancer. Use the date of clinical, histologic, or positive cytologic confirmation as the date of diagnosis.
Note: Suspicious cytology alone is never used for case ascertainment.
5. If a recognized medical practitioner says that, in retrospect, the patient had cancer at an earlier date, code the date of diagnosis as the earlier date. If the original slides are reviewed and the pathologist documents cancer, code the diagnosis date as the date the original slides were made.

Example: The patient had an excision of a benign fibrous histiocytoma in January 2004. Six months later, a wide reexcision was positive for malignant fibrous histiocytoma. The physician documents in the chart that the previous tumor (benign fibrous histiocytoma) must have been malignant. Code the diagnosis date as January 2004.

6. If there is no review of previous slides with a revised diagnosis of cancer, and no physician's statement that, in retrospect, the previous tumor was malignant, or if information on the previous tumor is unclear, do not back-date the date of diagnosis.

Example: The patient had a total hysterectomy and a bilateral salpingo oophorectomy (BSO) in June 2004 with pathology diagnosis of papillary cystadenoma of the ovaries. In December 2004 the patient is diagnosed with widespread metastatic papillary cystadenocarcinoma. The slides from June 2004 are not reviewed and there is no physician statement saying the previous tumor was malignant. The date of diagnosis is December 2004.

7. Code the **date of death** as the date of diagnosis for:
- a. Autopsy only cases
 - b. Death Certificate Only cases

DATE OF DIAGNOSIS — Required – Continued

8. Estimate the date of diagnosis if an exact date is not available.
 - a. Estimating the month
 - i. Code “spring of” to April
 - ii. Code “summer” or “middle of the year” to July
 - iii. Code “fall” or “autumn” as October
 - iv. For “winter of,” try to determine whether the physician means the first of the year or the end of the year and code January or December as appropriate.
 - v. Code “early in year” to January
 - vi. Code “late in year” to December
 - vii. Use whatever information is available to calculate the month of diagnosis
 - viii. Code the month of admission when there is no basis for estimation
 - ix. Code month as 99 if there is no basis for approximation
 - b. Estimating the year
 - i. Code “a couple of years” to two years earlier
 - ii. Code “a few years” to three years earlier
 - iii. Use whatever information is available to calculate the year of diagnosis
 - iv. Code the year of admission when there is no basis for estimation
 - v. Code year as 9999 when there is no basis for approximation of the year.
 - c. Estimating both the month and year: use whatever information is available to calculate the month and year of diagnosis.

BASIS OF DIAGNOSIS — Required

Definition:

The basis of diagnosis indicates whether AT ANY TIME during the patient's medical history there was microscopic confirmation of the morphology of this cancer. It also indicates the nature of the best evidence available.

Details and Codes:

0 Death certificate only

Non-microscopic

1 Clinical only

2 Clinical investigation (including X-ray, ultrasound, etc.)

3 Exploratory surgery/autopsy

4 Specific biochemical and/or immunological tests

Microscopic

5 Cytology or hematology

6 Histology of metastasis

7 Histology of primary

8 Autopsy with concurrent or previous histology

Unknown

9 Unknown

Coding Instructions:

1. The codes are in priority order; code 8 has the highest priority. Always code the procedure with the higher numeric value when presence of cancer is confirmed with multiple diagnostic methods.
2. Change to a higher code, if at ANY TIME during the course of disease the patient has a diagnostic confirmation which has a higher priority.
3. Assign **code 1** when the case was diagnosed by any clinical method not mentioned in one of the following codes. The diagnostic confirmation is coded 1 when the only confirmation of disease is a physician's clinical diagnosis.
4. Assign **code 2** when the only confirmation of malignancy was diagnostic imaging such as computerized axial tomography (CT scans), magnetic resonance imaging (MRI scans), or ultrasounds/sonography.
5. Assign **code 3** when the diagnosis is based only on
 - a. The surgeon's operative report from a surgical exploration or endoscopy such as colonoscopy, mediastinoscopy, or peritoneoscopy, and no tissue was examined.
 - b. Gross autopsy findings (no tissue or cytologic confirmation).

BASIS OF DIAGNOSIS — Required – Continued

6. Assign **code 4** when the diagnosis of cancer is based on laboratory tests or marker studies which are clinically diagnostic for that specific cancer.

Example 1: The presence of alpha-fetoprotein for liver cancer.

Example 2: An abnormal electrophoretic spike for multiple myeloma or Waldenstrom macroglobulinemia.

Example 3: If the workup for a prostate cancer patient is limited to a highly elevated PSA and the physician diagnoses and/or treats the patient based only on that PSA, code the diagnostic confirmation to 4.

- 7.** Assign **code 5** when the microscopic diagnosis is based on
- a.** Examination of cells (rather than tissue) including but not limited to: sputum smears, bronchial brushings, bronchial washings, prostatic secretions, breast secretions, gastric fluid, spinal fluid, peritoneal fluid, pleural fluid, urinary sediment, cervical smears and vaginal smears.
 - b.** Paraffin block specimens from concentrated spinal, pleural, or peritoneal fluid.
- 8.** Assign **code 6 or 7** when the microscopic diagnosis is based on
- a.** Tissue specimens from biopsy, frozen section, surgery, autopsy or D&C.
 - b.** Bone marrow specimens (aspiration and biopsy).
 - c.** For leukemia only, positive hematologic findings including peripheral blood smears, CBCs and WBCs.
- 9.** Assign **code 8** whenever the diagnosis is first made at autopsy with histologic confirmation or whenever autopsy confirms histologic diagnosis made prior to death.
- 10.** Assign **code 9:**
- a.** It is unknown if the diagnosis was confirmed microscopically.
- 11.** Assign **code 0** for death certificate only cases.

LATERALITY — Optional

Definition:

Collect and record the side of origin of a cancer occurring in a paired site.

Codes:

Not a paired site:

0 Not a paired site

Paired site:

1 Right

2 Left

3 Only one side involved, right or left origin unspecified

4 Bilateral involvement, laterality of origin unknown but stated to be a single primary

Both ovaries involved simultaneously, single histology

Bilateral retinoblastoma

Bilateral Wilms tumor

9 No information concerning laterality; midline tumor

Laterality codes of '1' - '9' must be used for the following sites except as noted. Only major ICD-O-3 headings are listed. However, laterality should be coded for all anatomic subsites included in ICD-O-3 unless specifically excluded. Such exclusions must be coded '0.'

C07.9	Parotid gland
C08.0	Submandibular gland
C08.1	Tonsillar fossa
C09.1	Tonsillar pillar
C09.8	Overlapping lesion of tonsil
C09.9	Tonsil, NOS
C30.0	Nasal cavity (excluding nasal cartilage, nasal septum)
C30.1	Middle ear
C31.0	Maxillary sinus
C31.2	Frontal sinus
C34.0	Main bronchus (excluding carina)
C34.1-C34.9	Lung
C38.4	Pleura
C40.0	Long bones of upper limb, scapula and associated joints
C40.1	Short bones of upper limb and associated joints
C40.2	Long bones of lower limb and associated joints
C40.3	Short bones of lower limb and associated joints
C41.3	Rib, Clavicle (excluding sternum)
C41.4	Pelvic bones (excluding sacrum, coccyx, and symphysis pubis)
C44.1	Skin of eyelid
C44.2	Skin of external ear

LATERALITY — Optional - Continued

C44.3	Skin of other and unspecified parts of face (if midline, use code ‘9’)
C44.5	Skin of trunk (if midline, use code ‘9’)
C44.6	Skin of upper limb and shoulder
C44.7	Skin of lower limb and hip
C47.1	Peripheral nerves and autonomic nervous system of upper limb and shoulder
C47.2	Peripheral nerves and autonomic nervous system of lower limb and hip
C49.1	Connective, subcutaneous, and other soft tissues of upper limb and shoulder
C49.2	Connective, subcutaneous, and other soft tissues of lower limb and hip
C50.0-C50.9	Breast
C56.9	Ovary
C57.0	Fallopian tube
C62.0-C62.9	Testis
C63.0	Epididymis
C63.1	Spermatic cord
C64.9	Kidney, NOS
C65.9	Renal pelvis
C66.9	Ureter
C69.0-C69.9	Eye
C700	Cerebral meninges, NOS (Effective with cases diagnosed 1/1/2005)
C710	Cerebrum (Effective with cases diagnosed 1/1/2005)
C711	Frontal lobe (Effective with cases diagnosed 1/1/2005)
C712	Temporal lobe (Effective with cases diagnosed 1/1/2005)
C713	Parietal lobe (Effective with cases diagnosed 1/1/2005)
C714	Occipital lobe (Effective with cases diagnosed 1/1/2005)
C722	Olfactory nerve (Effective with cases diagnosed 1/1/2005)
C723	Optic nerve (Effective with cases diagnosed 1/1/2005)
C724	Acoustic nerve (Effective with cases diagnosed 1/1/2005)
C725	Cranial nerve, NOS (Effective with cases diagnosed 1/1/2005)
C74.0-C74.9	Adrenal gland
C75.4	Carotid body

Laterality **may** also be coded for sites other than those above, for example, “right colon” and “left colon;” “right cervical lymph nodes.”

PRIMARY SITE TEXT — Core

Definition:

Record in English the exact primary site of the cancer including laterality. Use standard abbreviations whenever available or possible. For example, if the primary site of the cancer is the “upper outer quadrant of the right breast”, then record: UOQ of R breast.

Details:

25 alphabetic character field

Note: Text information contained in this field documents the exact primary site and may be different from the “labeled” site generated by CANREG or other software which assigns the preferred term from ICD-O-3 to the coded primary site.

Example 1: The primary site text is cardioesophageal junction. The assigned ICD-O-3 topography code will be C16.0. The computer generated label for code C16.0 will be Cardia, NOS which is the ICD-O-3 preferred term.

Example 2: The primary site is malignant melanoma of the skin of the right index finger. The assigned ICD-O-3 code is C44.6. The computer generated label will be Skin of upper limb and shoulder which is the ICD-O-3 preferred term.

PRIMARY SITE CODE — Required

Definition:

The Topography section of the International Classification of Diseases for Oncology, Third Edition (ICD-O-3) is used for coding the primary site of all reportable cancers. Site codes may be found in the Topography - Numeric Section of ICD-O-3 or in the Alphabetic Index of ICD-O-3 which includes both Topography and Morphology terms. Topography codes are indicated by a 'C' as part of the code. For all site codes in ICD-O-3 ignore the decimal point when assigning the appropriate topography code.

Identify cases ONLY according to the primary site and NOT a metastatic site. If the site of origin cannot be determined exactly, it may be possible to use the NOS category of an organ system or the Ill-Defined Sites ('C76.0'- 'C76.8'). (See page xx of ICD-O-3). If the primary site is unknown or if the only information available pertains to a metastatic site, code the primary site as unknown ('C80.9').

Details and Codes:

Refer to, and use, International Classification of Diseases for Oncology, Third Edition (ICD-O-3).

Coding Instructions:

Refer to “Determining Multiple Primaries” in the first section of this manual to determine the number of primaries. Use all of the information for a single primary to code the site.

1. Code the site in which the primary tumor originated, even if it extends into an adjacent “subsite.”
2. Use the **MECC Site Grouping Table** in the Rules for Determining Multiple Primaries section to code the primary site specified in the table in those rare cases when:
 - a. A single tumor overlaps adjacent sites in the same group.
 - b. Multiple tumors reported as a single primary involve adjacent sites in the same group.

Example: The patient has a 5cm tumor overlapping the base of tongue and anterior 2/3 of tongue. Use the MECC Site Grouping Table to determine the correct code for the primary site, C029 (Tongue, NOS).

3. Code the last digit of the primary site code to '8' when a single tumor overlaps an adjacent subsite(s) of an organ and the point of origin cannot be determined.,

Example: The patient has a 5cm tumor that involves the dorsal surface and anterior 2/3 of tongue. Code the primary site to C028 (overlapping lesion of tongue).

PRIMARY SITE CODE — Required – Continued

4. Code the last digit of the primary site code to ‘9’ for single primaries, when multiple tumors arise in different subsites of the same anatomic site, unless the subsite is defined in one of the site groups listed in the MECC Site Grouping Table.

Example 1: During a TURB, the physician describes multiple papillary tumors in the bladder neck (C675) and the lateral wall of the bladder (C672). Code the primary site as bladder, NOS (C679).

Example 2: Patient has an infiltrating duct tumor in the upper outer quadrant (C504) of the right breast and another infiltrating duct carcinoma in the lower inner (C503) quadrant of the right breast. Code the primary site as breast, NOS (C509).

5. Some histology/behavior terms in ICD-O-3 have a related site code in parenthesis; for example: hepatoma (C220).

- a. Code the site as documented in the medical record and ignore the suggested ICD-O-3 code when a primary site is specified in the medical record.

Example: The pathology report says “infiltrating ductal adenocarcinoma of the head of the pancreas.” The listing in ICD-O-3 is infiltrating ductal adenocarcinoma 8500/3 (C50_). Code the primary site to head of pancreas, NOT to breast as suggested by the ICD-O-3.

- b. Use the site code suggested by ICD-O-3 when the primary site is the same as the site code suggested or the primary site is unknown

Example 1: The biopsy is positive for hepatoma, but there is no information available about the primary site. Code the primary site to liver (C220) as suggested by ICD-O-3.

Example 2: The patient has an excision of the right axillary nodes which reveals metastatic infiltrating duct carcinoma. The right breast is negative. The ICD-O-3 shows duct carcinoma (8500) with a suggested site of breast (C50_). Code the primary site as breast, NOS (C509).

6. Code the primary site, not the metastatic site. If a tumor is metastatic and the primary site is unknown, code the primary site as unknown (C809).

7. When the medical record does not contain enough information to assign a primary site:

- a. Consult a physician advisor to assign the site code
- b. Use the NOS category for the organ system or the Ill Defined Sites (C760-C768.) if the physician advisor cannot identify a primary site,
- c. Code Unknown Primary Site (C809) if there is not enough information to assign an NOS or Ill Defined Site category.

PRIMARY SITE CODE — Required – Continued

Leukemia

Code leukemia primaries to bone marrow (C421); blood cells originate in the bone marrow.

Lymphoma

Definitions:

Extralymphatic: Originating in tissue or an organ that is not a part of the lymphatic system.

Extranodal lymphoma: Lymphoma originating in tissue or organ other than lymph nodes. Lymphatic system organs may be extranodal. (e.g.: Spleen is a lymphatic system organ and is also extranodal.)

Lymphatic system: An umbrella term that includes: lymph nodes, spleen, thymus, tonsils, Waldeyer's ring, and Peyer's patches.

Nodal lymphoma: A lymphoma originating in lymph nodes.

Lymphoma Coding Instructions

1. When a single lymph node chain is involved, code that chain as the primary site.
2. When multiple lymph node chains are involved at the time of diagnosis, do not simply code the lymph node chain that was biopsied.
 - a. If it is possible to determine where the disease originated, code the primary site to that lymph node chain.
 - b. If multiple lymph node chains are involved and all involved chains are located in the same lymph node region (i.e. the same primary site code) and it is not possible to determine the lymph node chain where the disease originated, code the primary site to lymph nodes of the specified nodal region (C77_).
 - c. If multiple lymph node chains are involved and the involved chains are in different lymph node regions, code C778 (lymph nodes of multiple regions).
3. When the lymphoma is extranodal and is
 - a. Confined to the organ of origin, code the organ of origin.

PRIMARY SITE CODE — Required – Continued

Example: Pathology from a stomach resection shows lymphoma. No other pathologic or clinical disease identified. Code the primary site as stomach, NOS (C169).

- b. Present in an extranodal organ/site and in that organ/site's regional lymph nodes code the extranodal organ/site as the primary site.

Lymphomas that are primary in an extranodal organ/site may metastasize to that organ/site's regional lymph nodes. In rare cases a lymphoma may spread from the lymph node to an extranodal site or extralymphatic organ by direct extension.

Example 1: Lymphoma is present in the spleen and splenic lymph nodes. Code the primary site to spleen (C422).

Example 2: Lymphoma is present in the stomach and the gastric lymph nodes. Code the primary site to stomach, NOS (C169).

- c. Present in extranodal organ(s)/site and non-regional lymph nodes, consult the physician to determine the primary site. If a site cannot be determined, code primary site to Lymph Node, NOS (C779).
4. If the primary site is unknown or not given:
 - a. Code retroperitoneal lymph nodes if described as retroperitoneal mass.
 - b. Code inguinal lymph nodes if described as inguinal mass.
 - c. Code mediastinal lymph nodes if described as mediastinal mass.
 - d. Code mesenteric lymph nodes if described as mesenteric mass.
 - e. If the primary site is unknown code Lymph Nodes, NOS (C779).

Exception: Code unknown primary site (C809) only when there is no evidence of lymphoma in lymph nodes and/or the medical record documents that the physician suspects that it is an extranodal lymphoma

Esophagus

There are two systems that divide the esophagus into three subsites. The first system divides the esophagus into the upper third, middle third, and lower third. The second system describes the subsites as the cervical esophagus, the thoracic esophagus and the abdominal esophagus. The subsites for these two different systems are not identical. Assign the ICD-O-3 topography code that describes the primary site documented in the medical record. See the SEER Self Instructional Manual for Tumor Registrars, Book 4 for illustrated descriptions of each system.

PRIMARY SITE CODE — Required - Continued

Kaposi Sarcoma

Kaposi sarcoma is a rare condition. When not AIDS-related, it usually presents as localized disease with an easily recognized primary site.

AIDS-related Kaposi sarcoma usually presents as a disseminated disease with involvement of mucosal surfaces, visceral surfaces of organs, and skin. It is important to review consecutive records carefully to determine the extent of involvement at diagnosis. Review of a single record may reveal only the site being treated during that admission.

1. Code Kaposi to the site in which it arises.
2. If the Kaposi is present in the skin and another site simultaneously, code to the specified skin site, (C44_).
3. If the primary site is unknown or cannot be determined, code skin, NOS (C449).

Sarcoma

The majority of sarcomas arise in mesenchymal or connective tissues that are located in the musculoskeletal system. The musculoskeletal system includes the fat, muscles, blood vessels, deep skin tissues, nerves, bones and cartilage. The default code for sarcomas of unknown primary site is C499 rather than C809.

Sarcomas may also arise in the walls of hollow organs and in the viscera covering an organ. Code the primary site to the organ of origin.

Example: The pathology identifies a mixed Mullerian tumor of the uterus. Code the site to uterus, NOS (C559).

Note: Some registry software requires only the three numeric digits to be entered since the first digit is always a C and therefore not necessary to identify a specific primary site.

MORPHOLOGY TEXT — Core

Definition:

Record the exact histologic type, behavior, and grade/differentiation/cell type of the cancer. Use standard abbreviations whenever available or possible. For example, a “poorly differentiated squamous cell carcinoma” can be recorded as:

PD SCC

Details:

25 alphanumeric characters

MORPHOLOGY CODES — Required

Definition:

The International Classification of Diseases for Oncology, Third Edition (ICD-O-3) is used for coding the morphology of all cancers. In the Alphabetic Index all morphology codes are indicated by an ‘M-’ preceding the code number. The ‘M-’ should not be coded. The ‘/’ appearing between the histology and behavior codes is also not recorded.

To code morphology (histology, behavior and grade), use the best information from the entire pathology report (microscopic description, final diagnosis, comments). If the final diagnosis gives a specific histology, code it. Similarly, if grade is specified in the final diagnosis, code it. Exceptions are found on the following pages under “Histologic Type,” “Behavior Code,” and “Grade, Differentiation, or Cell Indicator.”

Details and Codes:

Morphology is a 6-digit code consisting of **three** parts:

- A** Histologic type (4 digits)
- B** Behavior code (1 digit)
- C** Grading or differentiation or cell indicator (1 digit)

Note: The morphology of a tumor can be coded only after the determination of multiple primaries has been completed. (Refer to the Rules for Determining Multiple Primaries to determine the number of primaries.)

Refer to, and use, International Classification of Diseases for Oncology, Third Edition (ICD-O-3).

HISTOLOGIC TYPE — Required

Definition:

The data item Histologic Type describes the microscopic composition of cells and/or tissue for a specific primary. In the rare instance where there is no tissue pathology, code the histology the medical practitioner uses to describe the tumor. The tumor type or histology is a basis for staging and determination of treatment options. It affects the prognosis and course of the disease.

When coding Histologic Type, usually the FINAL pathologic diagnosis is coded. All pathology reports for the primary under consideration should be used. Although the report from the most representative tissue is usually the best, sometimes all of the cancerous tissue may be removed at biopsy (excisional biopsy) and the report from the biopsy must be used. If a definitive statement of a more specific histologic type (higher code in ICD-O-3) is found in the microscopic description or in the comment, the more specific histologic diagnosis should be coded.

Details and Codes:

The International Classification of Diseases for Oncology, Third Edition (ICD-O-3) is the standard reference for coding the histology for tumors diagnosed in 2001 and later. Do not record the ‘M’ that precedes the histology code. Refer to ICD-O-3 for guidance in coding the histology. See sections Coding Guidelines for Topography and Morphology, and Summary of Principal Rules for Using the ICD-O, Third Edition.

The histology can be coded only after the determination of multiple primaries has been made.

Definitions

Cancer, NOS (8000) and carcinoma, NOS (8010) are not interchangeable.

Carcinoma, NOS (8010) and adenocarcinoma (8140) are interchangeable (See ICD-O-3).

Complex (mixed, combined) histology: The pathologist uses multiple histologic terms to describe a tumor. The histologic terms are frequently connected by the word “and” (for example ductal and lobular carcinoma).

Different subtypes: The NOS cell types often have multiple subtypes; for example, scirrhous adenocarcinoma (8143), adenocarcinoma, intestinal type (8144), and linitis plastica (8141) are subtypes of Adenocarcinoma, NOS (8140).

Mixed/combined histology: Different cell types in one tumor; terms used interchangeably. In most cases, the terms mixed and combined are used as synonyms; however the term mixed may designate a specific tumor.

HISTOLOGIC TYPE — Required – Continued

Not Otherwise Specified (NOS): “Not Otherwise Specified

Majority of Tumor:

Terms that mean the majority of tumor

Terms that **DO NOT** mean the majority of tumor

Predominantly
With features of
Major
Type
With Differentiation

With foci of
Focus of/focal
Areas of
Elements of
Component

Coding Instructions

Refer to “Determining Multiple Primaries” in the first section of this manual to determine the number of primaries. Use all of the information for a single primary to code the histology.

1. If there is no tumor specimen, code the histology described by the medical practitioner.

Example 1: The patient has a CT scan of the brain with a final diagnosis of glioblastoma multiforme (9440). The patient refuses all further workup or treatment. Code the histology to glioblastoma multiforme (9440).

Example 2: If the physician says that the patient has carcinoma, code carcinoma, NOS (8010).

2. Use the histology stated in the final diagnosis from the pathology report. Use the pathology from the procedure that resected the majority of the primary tumor. If a more specific histologic type is definitively described in the microscopic portion of the pathology report or the comment, code the more specific diagnosis.

3. Lymphomas may be classified by the WHO Classification, REAL system, Rappaport, or Working Formulation. The WHO Classification is preferred. See page 13 in the ICD-O-3 for a discussion of hematologic malignancies.

4. Cases reported to MECC cannot have a metastatic (/6) behavior code. If the only pathology specimen is from a metastatic site, code the appropriate histology code and the malignant behavior code /3. The primary site and its metastatic site(s) have the same basic histology.

HISTOLOGIC TYPE — Required – Continued

Histology Coding Rules for Single Tumor

- The rules are in hierarchical order. Rule 1 has the highest priority.
 - Use the rules in priority order.
 - Use the first rule that applies to the case. (Do not apply any additional rules.)
1. Code the histology if only one type is mentioned in the pathology report.
 2. Code the invasive histology when both invasive and in situ tumor are present.

Example: Pathology report reads infiltrating ductal carcinoma and cribriform ductal carcinoma in situ. Code the invasive histology 8500/3.

Exception: If the histology of the invasive component is an ‘NOS’ term (e.g., carcinoma, adenocarcinoma, melanoma, sarcoma), then code the histology of the specific term associated with the in situ component and an invasive behavior code.

3. Use a **mixed** histology code if one exists.

Examples of mixed codes: (This is not a complete list, these are examples only.)

8490 Mixed tumor, NOS
9085 Mixed germ cell tumor
8855 Mixed liposarcoma
8990 Mixed mesenchymal sarcoma
8951 Mixed mesodermal tumor
8950 Mixed Mullerian tumor
9362 Mixed pineal tumor
8940 Mixed salivary gland tumor, NOS
9081 Teratocarcinoma, mixed embryonal carcinoma and teratoma

4. Use a **combination** histology code if one exists.

Examples of combination codes: (This is not a complete list; these are examples only.)

8255 Renal cell carcinoma, mixed clear cell and chromophobe types
8523 Infiltrating duct carcinoma mixed with other types of carcinoma
8524 Infiltrating lobular carcinoma mixed with other types of carcinoma
8560 Adenosquamous carcinoma
8045 Combined small cell carcinoma, combined small cell-large cell

5. Code the **more specific** term when one of the terms is ‘NOS’ and the other is a more specific description of the same histology.

HISTOLOGIC TYPE — Required – Continued

Example 1: Pathology report reads poorly differentiated carcinoma, probably squamous in origin. Code the histology as squamous cell carcinoma rather than the non-specific term “carcinoma.”

Example 2: The pathology report from a nephrectomy reads renal cell carcinoma (8312) (renal cell identifies the affected organ system rather than the histologic cell type) in one portion of the report and clear cell carcinoma (8310) (a histologic cell type) in another section of the report. Code clear cell carcinoma (8310); renal cell carcinoma (8312) refers to the renal system rather than the cell type, so renal cell is the less specific code.

6. Code the **majority** of tumor.
 - a. Based on the pathology report description of the tumor.
 - b. Based on the use of majority terms. See definition for majority terms.
7. Code the **numerically higher** ICD-O-3 code. This is the rule with the lowest priority and should be used infrequently.

Histology Coding Rules for Multiple Tumors with Different Behaviors in the Same Organ Reported as a Single Primary

Code the histology of the invasive tumor when one lesion is in situ (/2) and the other is invasive (/3).

Example: At mastectomy for removal of a 2 cm invasive ductal carcinoma, an additional 5 cm area of intraductal carcinoma was noted. Code histology and behavior as invasive ductal carcinoma (8500/3).

Histology Coding Rules for Multiple Tumors in Same Organ Reported as a Single Primary

1. Code the histology when multiple tumors have the same histology.
2. Code the histology to adenocarcinoma (8140/_; in situ or invasive) when there is an adenocarcinoma and an adenocarcinoma in a polyp (8210/_, 8261/_, 8263/) in the same segment of the colon or rectum.
3. Code the histology to carcinoma (8010/_; in situ or invasive) when there is a carcinoma and a carcinoma in a polyp (8210/_) in the same segment of the colon or rectum.
4. Use a **combination** code for the following:
 - a. **Bladder:** Papillary and urothelial (transitional cell) carcinoma (8130)
 - b. **Breast:** Paget Disease and duct carcinoma (8541)
 - c. **Breast:** Duct carcinoma and lobular carcinoma (8522)
 - d. **Thyroid:** Follicular and papillary carcinoma (8340)

HISTOLOGIC TYPE — Required – Continued

5. Code the **more specific** term when one of the terms is ‘NOS’ and the other is a more specific description of the same histology.

6. Code all other multiple tumors with different histologies as multiple primaries.

Leukemia/Lymphoma (Chronic Lymphocytic Leukemia [CLL] and Small Lymphocytic Lymphoma [SLL])

Code the diagnosis of chronic lymphocytic leukemia (9823/3) and/or small lymphocytic lymphoma (9670/3) to SLL if there are positive lymph nodes or deposits of lymphoma/leukemia in organs or in other tissue. Code the histology to CLL if there are no physical manifestations of the disease other than a positive blood study or positive bone marrow.

Histology for non-microscopically confirmed cases

If a specific histology is stated for cases without microscopic confirmation, code the specific histology. It is possible to determine the specific histology of certain cancers by their radiographic appearance (astrocytomas), biochemical markers/laboratory tests (multiple myeloma), or visualization (Kaposi’s sarcoma).

BEHAVIOR — Required

Definition:

The usual behavior codes are listed in both the numeric and alphabetic indices of ICD-O-3, following the histology code. If a pathologist calls a cancer in situ ('2') or malignant ('3') when it is not listed as such in ICD-O-3, code the stated behavior. (See Table 1, pages xxvi and xxvii, in ICD-O-3.)

Details and Codes:

- 0 Benign (For optional reporting of intracranial and CNS sites only)**
- 1 Uncertain whether benign or malignant, borderline malignancy, low malignant potential, and uncertain malignant potential (For optional reporting of intracranial and CNS sites only)**
- 2 Carcinoma in situ; intraepithelial; noninfiltrating; noninvasive**
- 3 Malignant, primary site (invasive)**

Coding Instructions:

Behavior codes 0 (benign) and 1 (borderline) are for the optional reporting of intracranial and CNS sites **only**.

Do not use behavior codes '6' or '9.' If the only specimen was from a metastatic site, code the histologic type of the metastatic site and code a '3' for the behavior code. The primary site is assumed to have the same histologic type as the metastatic site.

Metastatic or Nonprimary Sites

Cases reported to MECC cannot have a metastatic (/6) behavior code. If the only pathologic specimen is from a metastatic site, code the appropriate histology code and the malignant behavior code /3. The primary site and its metastatic site(s) have the same basic histology. See note on Krukenberg Tumor below.

In situ

Clinical evidence alone cannot identify the behavior as in situ; the code must be based on pathologic examination and documentation.

In situ and Invasive

Code the behavior as malignant /3 if any portion of the primary tumor is invasive no matter how limited; i.e. microinvasion.

Example: Pathology from mastectomy: Large mass composed of intraductal carcinoma with a single focus of invasion. Code the behavior as malignant /3.

BEHAVIOR — Required – Continued

ICD-O-3 Histology/Behavior Code Listing (Matrix Principle)

ICD-O-3 may have only one behavior code, either in situ /2 or malignant /3, listed for a specific histology. However, if the pathology report describes the histology as in situ /2 and the ICD-O-3 histology code is only listed with a malignant /3 behavior code, assign the histology code listed and change the behavior code to in situ /2. If the pathology report describes histology as malignant /3 and the ICD-O-3 histology code is only listed with an in situ /2 behavior code, assign the histology code listed and change the behavior code to malignant /3. See the Morphology and Behavior Code Matrix discussion on page 29 in ICD-O-3.

Example: The pathology report says large cell carcinoma in situ. The ICD-O-3 lists large cell carcinoma as 8013/3; there is only a malignant listing. Change the /3 to /2 and code the histology and behavior code to 8013/2 as specified by the physician.

Note: “In situ” is a concept based on histologic evidence. Therefore, clinical evidence alone cannot justify the use of this term.

Synonymous terms for in situ (behavior code ‘2’) are:

- AIN III (C21.1)
- Bowen’s disease (not reportable for C44.0-C44.9)
- Clark’s level 1 for melanoma (limited to epithelium)
- Confined to epithelium
- Hutchinson’s melanotic freckle, NOS (C44._)
- intracystic, non-infiltrating
- intraductal
- intraepidermal, NOS
- intraepithelial, NOS
- involvement up to but not including the basement membrane
- lentigo maligna (C44._)
- lobular, noninfiltrating (C50.0_)
- noninfiltrating
- noninvasive
- no stromal invasion
- papillary, noninfiltrating or intraductal
- precancerous melanosis (C44._)
- Queyrat’s erythroplasia (C60._)
- VAIN III (C52.9)
- VIN III (C51._)
- CIN III (C53._) (Reporting optional)

BEHAVIOR — Required – Continued

Krukenberg Tumor

Metastatic tumors to the ovary are uncommon, but there is one situation in which a metastatic adenocarcinoma to the ovary appears as a large mass and resembles a primary tumor: a so-called "Krukenberg" tumor of the ovary which has a signet ring histologic pattern and usually is metastatic from a primary in the gastrointestinal (GI) tract (most often, stomach). Since cancer registries typically **only collect** and report the in situ (/2 in the behavior code) and invasive cancers (/3 in the behavior code), the /6 in the behavior code of the Krukenberg tumor morphology code on page 79 and again on page 156 of ICD-0-3 often confuses inexperienced registrars. The /6 behavior code accurately indicates that Krukenberg tumor is a metastasis, and the suggested site code (the C56.9 in parentheses) accurately indicates that the metastasis presents itself in the ovary. However, registrars should report the **primary tumor**, not the metastatic tumor. So, the morphology code for a Krukenberg tumor would be M-8490/3 and the primary site code should indicate where in the **GI tract** the tumor is thought to have originated. A careful review of the source documents will generally reveal the precise location of the tumor in the GI tract. In the absence of a precise location in the GI tract, the site should be coded to Gastrointestinal Tract, NOS, C26.9.

GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required

Definition:

Grade, Differentiation (Codes 1, 2, 3, 4, 9)

Pathologic testing determines the grade, or degree of differentiation, of the tumor. For cancers, the grade is a measurement of how closely the tumor cells resemble the parent tissue (organ of origin). Well differentiated tumor cells closely resemble the tissue from the organ of origin. Poorly differentiated and undifferentiated tumor cells are disorganized and abnormal looking; they bear little or no resemblance to the tissue from the organ of origin.

Pathologists describe the tumor grade by levels of similarity. Pathologists may define the tumor by describing two levels of similarity (two-grade system which may be used for colon); by describing three levels of similarity (three-grade system); or by describing four levels of similarity (four-grade system). The four-grade system describes the tumor as grade I, grade II, grade III, and grade IV (also called well differentiated, moderately differentiated, poorly differentiated, and undifferentiated/anaplastic). These similarities/differences may be based on pattern (architecture), cytology, or nuclear features or a combination of these elements depending upon the grading system that is used. The information from this data item is useful for determining prognosis.

Cell Indicator (Codes 5, 6, 7, 8, 9)

Describes the lineage or phenotype of the cell that became malignant. Cell indicator codes apply to lymphomas and leukemias and for these diagnoses, cell indicator takes precedence over grade/differentiation.

Codes

- 1 Grade I; grade i; grade 1; well differentiated; differentiated, NOS**
- 2 Grade II; grade ii; grade 2; moderately differentiated; moderately well differentiated; intermediate differentiation**
- 3 Grade III; grade iii, grade 3; poorly differentiated; dedifferentiated**
- 4 Grade IV; grade iv; grade 4; undifferentiated; anaplastic**
- 5 T-cell; T-precursor**
- 6 B-Cell; Pre-B; B-precursor**
- 7 Null cell; Non T-non B**
- 8 NK cell (natural killer cell) (effective with diagnosis 1/1/1995 and after)**
- 9 Grade/differentiations unknown, not stated, or not applicable**

GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required – Continued

General Coding Rules:

- 1.** The site-specific coding guidelines for coding grade for breast, kidney, prostate, lymphoma, leukemia, astrocytomas, and sarcomas are given below.
- 2.** Code the grade from the final diagnosis in the pathology report. If there is more than one path report, and the grades in the final diagnoses differ, code the highest grade for the primary site from any pathology report.
- 3.** If grade is not stated in the final pathology diagnosis, use the information in the microscopic section, addendum, or comment to code grade.
- 4.** If more than one grade is recorded for a single tumor, code the **highest grade**, even if it is a focus.

Example: Pathology report reads: Grade II adenocarcinoma with a focus of undifferentiated adenocarcinoma. Code the tumor grade as grade 4.

- 5.** Code the grade from the primary tumor only, **never from a metastatic site** or a recurrence.
- 6.** Code the grade for all **unknown primaries** to 9 (unknown grade) unless grade is explicit by histology (i.e. anaplastic carcinoma (grade = 4)).
- 7.** Code the grade of the **invasive component** when the tumor has both in situ and invasive portions. If the invasive component grade is unknown, code the grade as unknown (9).
- 8.** Code the information from the consult if the specimen is sent to a specialty pathology department for a consult.
- 9.** If there are multiple pathology consults, ask the pathologist or physician advisor to determine which information should be used.
- 10.** Do not code the grade assigned to dysplasia, i.e.: High grade dysplasia (adenocarcinoma in situ) would be coded to 9 (unknown grade).

Coding Grade for Cases without Pathology or Cytology Confirmation

Code the grade of tumor given on a Magnetic Resonance Imaging (MRI) or Positron Emission Tomography (PET) report if there is no tissue diagnosis (pathology or cytology report). Use the MRI or PET grade **ONLY** when there is no tissue diagnosis.

**GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required
– Continued**

In situ Tumors

In situ tumors are not always graded. Code the grade if it is specified for an in situ lesion unless there is an invasive component. Do not code the in situ grade if the tumor has both in situ and invasive components.

Terminology Conversion Table

Description	Grade	Code
Differentiated, NOS	I	1
Well differentiated	I	1
Fairly differentiated	II	2
Intermediate differentiation	II	2
Low grade	I-II	2
Mid differentiated	II	2
Moderately differentiated	II	2
Moderately well differentiated	II	2
Partially differentiated	II	2
Partially well differentiated	I-II	2
Relatively or generally well differentiated	II	2
Medium grade, intermediate grade	II-III	3
Moderately poorly differentiated	III	3
Moderately undifferentiated	III	3
Pleomorphic	III	3
Poorly differentiated	III	3
Relatively poorly differentiated	III	3
Relatively undifferentiated	III	3
Slightly differentiated	III	3
Dedifferentiated	III	3
High grade	III-IV	4
Undifferentiated, anaplastic, not differentiated	IV	4
Non-high grade		4

GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required – Continued

Some cancers are graded using a two-grade system, for an example, colon cancer. If the grade is listed as 1/2 or as low grade, assign code 2. If the grade is listed as 2/2 or as high grade, assign code 4.

Two-Grade Conversion Table

Grade	Differentiation	Description	Code
1/2	I/II	Low grade	2
2/2	II/II	High grade	4

Three-Grade System

There are several sites for which a three-grade system is used, such as peritoneum, endometrium, fallopian tube, prostate, bladder and soft tissue sarcoma. The patterns of cell growth are measured on a scale of 1, 2, and 3 (also referred to as low, medium, and high grade). This system measures the proportion of cancer cells that are growing and making new cells and how closely they resemble the cells of the host tissue. Thus, it is similar to a four-grade system, but simply divides the spectrum into 3 rather than 4 categories (see Three-Grade Conversion Table below). The expected outcome is more favorable for lower grades.

If a grade is written as 2/3 that means this is a grade 2 of a three-grade system. Do not simply code the numerator. Use the following table to convert the grade to SEER codes:

Three-Grade Conversion Table

Grade	Differentiation	Description	Code
1/3	I/III	Low grade	2
2/3	II/III	Intermediate grade	3
3/3	III,III	High grade	4

Do not use for breast primaries.

GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required – Continued

Breast Cancer

Priority Order for Coding Breast Cancer Grade

Code grade in the following priority order:

1. Bloom-Richardson scores 3-9 converted to grade (See following table)
2. Bloom Richardson grade (low, intermediate, high)
3. Nuclear grade only
4. Terminology
 - a. Differentiation (well differentiated, moderately differentiated, etc).
5. Histologic grade
 - a. Grade 1/I/i, grade 2/II/ii, grade 3/III/iii, grade 4/IV/iv

Bloom-Richardson (BR)

1. BR may also be called: modified Bloom-Richardson, Scarff-Bloom-Richardson, SBR grading, BR grading, Elston-Ellis modification of Bloom Richardson score, the Nottingham modification of Bloom Richardson score, Nottingham-Tenovus, or Nottingham grade.

2. BR may be expressed in scores (range 3-9).

3. The score is based on three morphologic features of “invasive no-special-type” breast cancers (degree of tubule formation/histologic grade, mitotic activity, nuclear pleomorphism of tumor cells).

4. Use the Breast Grading Conversion Table to convert the score, grade or term into the MECC code.

5. BR may be expressed as a grade (low, intermediate, high).

6. BR grade is derived from the BR score. Note that the conversion of low, intermediate, and high for breast is different from the conversion used for all other tumors.

Breast Grading Conversion Table

BR

Score	BR grade	Nuclear grade	Terminology	Histologic grade	Code
3-5	Low	1/3; 1/2	Well differentiated	I/III; 1/3	1
6,7	Intermediate	2/3	Moderately differentiated	II/II; 2/3	2
8,9	High	3/3; 2/2	Poorly differentiated	III/III; 3/3	3

GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required – Continued

Kidney Cancer

Priority Order for Coding Kidney Cancer Grade

Code grade in the following priority order:

1. Fuhrman's grade
2. Nuclear grade
3. Terminology (well diff, mod diff)
4. Histologic grade (grade 1, grade 2)

These prioritization rules **do not apply to Wilms tumor** (8960). Use the general rules for coding grade for Wilms tumor.

Prostate

Priority Rules for Coding Prostate Cancer Grade

Code grade in the following priority order:

1. Gleason's grade (Use the table to convert Gleason's grade information into the appropriate code.)
2. Terminology
Differentiation (well differentiated, moderately differentiated, etc.)
3. Histologic grade
Grade 1/I/i, grade 2/II/ii, grade 3/III/iii, grade 4/IV/iv
4. Nuclear grade only

Gleason's Pattern

Prostate cancers are commonly graded using Gleason's score or pattern. Gleason's grading is based on a 5-component system, meaning it is based on 5 histologic patterns. The pathologist will evaluate the primary (majority) and secondary patterns for the tumor. The pattern is written as a range, with the majority pattern appearing first and the secondary pattern as the last number.

Example: A Gleason pattern of 2 + 4 means that the primary pattern is 2 and the secondary pattern is 4.

GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required – Continued

Gleason’s Score

The patterns are added together to create a score.

Example: If the pattern is 2 + 4, the pattern score is 6 (the sum of 2 and 4).

1. If the pathology report contains only one number, and that number is less than or equal to 5, it is a pattern.
2. If the pathology report contains only one number, and that number is greater than 5, it is a score.
3. If the pathology report specifies a specific number out of a total of 10, the first number given is the score.

Example: The pathology report says “Gleason’s 3/10”. The Gleason’s score would be 3.

4. If there are two numbers other than 10, assume they refer to two patterns. The first number is the primary pattern and the second is the secondary pattern.

Example: If the pathology report says “Gleason’s 3 + 5,” the Gleason’s score would be 8, the sum of 3 and 5.

Use the following table to convert Gleason’s pattern or score into MECC codes:

Gleason Conversion Table				
Gleason’s score	Gleason’s pattern	Histologic grade	Terminology	Code
2, 3, 4	1,2	I	Well differentiated	1
5, 6	3	II	Moderately differentiated	2
7, 8, 9, 10	4,5	III	Poorly differentiated	3

Note: Gleason’s score 7 was previously coded to moderately differentiated (2). Effective with cases diagnosed 01/01/2005, Gleason’s score 7 is coded to poorly differentiated (3).

Astrocytoma

Grade astrocytomas according to ICD-O-3 rules

1. Do not use the WHO grade to code this field.
2. Do not automatically code glioblastoma multiforme as grade IV. If no grade is given, code unknown, 9.
3. If no grade is given, code unknown, 9.

GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required – Continued

Lymphoma and Leukemia

1. Do **NOT** use the terms “high grade,” “low grade,” and “intermediate grade” to code differentiation. These terms refer to histology, not grade.

2. The designation of T-cell, B-cell, null cell, or NK cell has **precedence** over any statement of differentiation.

a. Code ANY statement of T-cell, B-cell, null cell, or NK cell:

T-cell (code 5)

Cortical T

Mature T

Pre-T

Pro-T

T-cell phenotype

T-precursor

B-Cell (code 6)

B-cell phenotype

B-precursor

Pre-B

Pre-pre-B

Pro-B

Null-Cell; Non-T-non-B (code 7)

Null-cell

Non T-non-B

Common cell

NK (Natural Killer) cell (code 8)

NK/T cell

Cell type not determined, not stated or not applicable (code 9)

Combined B cell and T cell

b. Use any source to code information on cell type whether or not marker studies are documented in the patient record.

Example: The history portion of the medical record documents that the patient has a T-cell lymphoma. There are no marker studies on the chart. Code the grade as T-cell.

**GRADE, DIFFERENTIATION, OR CELL INDICATOR — Required
– Continued**

Sarcoma

If sarcomas are graded low, intermediate or high grade by the pathologist use the three-grade system table.

SUMMARY STAGE AT DIAGNOSIS — Required

Definition:

The SEER Summary Staging Manual - 2000 (SSSM2000) published by the SEER Program of the United States National Cancer Institute should be used for determining summary stage. The SSSM2000 should be used on cases diagnosed on or after January 1, 2001.

When determining Summary Stage, consider all clinical and pathologic information obtained within four months of the date of diagnosis of the cancer UNLESS such information represents progression of disease following diagnosis or through completion of surgery(ies) in first course of treatment, whichever is longer. Metastasis known to have developed after the diagnosis was established should be excluded.

The priority for using information is pathologic, operative, and clinical findings. Autopsy reports may be used in coding extent of disease, applying the same rules for inclusion and exclusion.

Details and Codes:

- 0 In situ**
- 1 Localized (Stage I for Lymphomas)**
- 2 Regional by direct extension**
- 3 Regional by lymph nodes**
- 4 Regional by both direct extension and lymph nodes**
- 5 Regional, not otherwise specified (Stage II for Lymphomas)**
- 7 Distant (Stage III or IV for Lymphomas)**
- 8 (Optional code for benign and uncertain tumors of the brain and nervous system)**
- 9 Unknown, undetermined**

Leukemias and multiple myelomas are considered systemic disease and should be coded to ‘7.’

Cancers of unknown site (‘C80.9’) should be coded to ‘9.’

Death Certificate Only cases should be coded to ‘9.’

Note: The diagnosis of malignant pleura effusion for a primary cancer of the lung (‘C34.’) is considered to be diagnostic of metastatic disease. Thus, if malignant pleural effusion (or pleural effusion, NOS) is present, code summary stage as ‘7.’

SUMMARY STAGE AT DIAGNOSIS — Required – Continued

Use of Ambiguous Terminology in Determining Summary Stage

Determination of the cancer stage is both a subjective and objective assessment of how far the cancer has spread. Sometimes the clinician is hesitant to commit to a definite statement that a particular organ or tissue is involved by the cancer and uses what data collectors refer to as ambiguous terminology. The following lists can generally be used to interpret the intent of the clinician; however, if individual clinicians use these terms differently, the clinician's definitions and choice of therapy should be recognized. If a term used in a diagnostic statement is not listed below, consult the clinician to determine the intent of the statement.

Consider as involvement

adherent
apparent(ly)
appears to
comparable with
compatible with
consistent with
contiguous/continuous with
encroaching upon*
extension to, into, onto, out onto
features of
fixation to another structure**
fixed**
impending perforation of
impinging upon
impose/imposing on
incipient invasion
induration
infringe/infringing
into*
intrude
invasion to into, onto, out onto
most likely
onto*
overstep
presumed
probable
protruding into (unless encapsulated)
suspected
suspicious
to*
up to

DO NOT Consider as Involvement

abuts
approaches
approximates
attached
cannot be excluded/ruled out
efface/effacing/effacement
encased/encasing
encompass(ed)
entrapped
equivocal
extension to without invasion/
involvement of
kiss/kissing
matted (except for lymph node)
possible
questionable
reaching
rule out
suggests
very close to
worrisome

* interpreted as involvement whether the description is clinical or operative/pathological.

** interpreted as involvement of other organ or tissue.

SUMMARY STAGE AT DIAGNOSIS — Required – Continued

In addition, at the 2008 MECC Cancer Registry Steering Committee in Larnaca, Cyprus the following terms were agreed to for use by MECC Registries:

Consider as involvement

breaching
could not be separated from
eroding
impressive of
indent
inseparable from
involve
locally advanced
no line of cleavage between the lesion and
obliterate
seems to infiltrate

DO NOT Consider as Involvement

compress
displace
intimately related
keeping with
touching

HOSPITAL DATA ITEMS — Core

PLACE (HOSPITAL) OF DIAGNOSIS — Core

25 alphanumeric characters, left justify

Record the name of the hospital making the **initial (first)** diagnosis of the patient.

3-digit code in Cyprus (includes hospitals, clinics and doctors' offices as a group)

MEDICAL RECORD NUMBER — Core

12-digit alphanumeric medical record number

Left justify the field

Cyprus: optionally records the Patient's Record Numbers of the 'Place (hospital) of Diagnosis', of the 'Hospital referred From' and of the 'Hospital referred To', separately if applicable.

HOSPITAL REFERRED FROM (Code) — Core

Record the code number of the hospital from which the patient was referred.

3-digit code in Cyprus, Egypt (Gharbiah), Jordan, and Gaza

2-digit code in West Bank

--- no info--- from Israel

Turkey (Izmir) does not collect this data item.

HOSPITAL REFERRED TO (Code) — Core

Record the code number of the hospital to which the patient was referred.

3-digit code in Cyprus, Egypt (Gharbiah), Jordan, and Gaza

2-digit code in West Bank

--- no info--- from Israel

Turkey (Izmir) does not collect this data item.

CONTACT PHYSICIAN — Core

Text field - 25 alphabetic characters

Record the name of the principal physician taking care of the patient.

This is useful for follow-up.

In Cyprus, a 4-digit code is used.

TREATMENT DATA — Required (Beginning with cases diagnosed January 1, 2007 forward)

Definition of FIRST COURSE OF CANCER-DIRECTED THERAPY:

**For All Diseases (including Benign and borderline intracranial & CNS tumors)
Except Leukemia and Hematopoietic Diseases**

Definitions

Cancer tissue: Proliferating malignant cells; an area of active production of malignant cells. Cancer tissue includes primary tumor and metastatic sites where cancer tissue grows. Cells in fluid such as pleural fluid or ascitic fluid are not “cancer tissue” because the cells do not grow and proliferate in the fluid.

Disease recurrence: The patient must have had a disease-free interval or remission (the cancer was not clinically evident). Following a disease-free interval, there is documentation that the initial/original tumor gave rise to the later tumor.

First course of therapy: All of the treatments administered to the patient after the original diagnosis of cancer in an attempt to destroy or modify the cancer tissue. See below for detailed information on timing and treatment plan documentation requirements.

Palliative treatment: The World Health Organization describes palliative care as treatment that improves the quality of life by preventing or relieving suffering. Palliative therapy is also part of the first course of therapy when the treatment destroys or modifies cancer tissue. Palliative therapy may also be part of the first course of therapy if it destroys proliferating cancer tissue.

Example: The patient was diagnosed with stage IV cancer of the prostate with painful boney metastases. The patient starts radiation treatment intended to shrink the tumor in the bone and relieve the intense pain. The radiation treatments are palliative because they relieve the bone pain; the radiation is also first course of therapy because it destroys proliferating cancer tissue.

Treatment: Procedures that destroy or modify primary (primary site) or secondary (metastatic) cancer tissue.

Treatment failure: The treatment modalities did not destroy or modify the cancer cells. The tumor either became larger (disease progression) or stayed the same size after treatment.

Watchful waiting: A treatment option for patients with slow, indolent diseases, such as prostate cancer and chronic lymphocytic leukemia (CLL). The physician closely monitors

TREATMENT DATA – Required (Beginning with cases diagnosed January 1, 2007 forward) - Continued

the patient and delays treatment until the patient becomes symptomatic or there are other signs of disease progression, such as rising PSA.

Treatment Timing

Use the following instructions in hierarchical order.

1. Use the documented first course of therapy from the medical record. First course ends when the treatment plan is **completed**. (No matter how long it takes to complete the plan).

Example 1: First course of treatment for childhood leukemia typically spans two years from induction, consolidation, to maintenance.

Example 2: The first course of therapy for a breast cancer patient is surgery, chemotherapy, and radiation. The patient completes surgery and chemotherapy. Bone metastases are diagnosed before the radiation was started. The physician says that the patient will start the radiation treatment as planned. Code the radiation as first course of therapy since it was given in agreement with the treatment plan and the treatment plan was not changed as a result of disease progression.

2. First course of therapy ends when there is documentation of disease progression, recurrence or treatment failure.

Example 1: The documented treatment plan for sarcoma is chemotherapy, surgery, then radiation or chemotherapy depending upon the pathology from surgery. Scans show the tumor is not regressing after chemotherapy. Plans for surgery are cancelled and a different type of chemotherapy is started. Code only the first chemotherapy as first course. Do not code the second chemotherapy as first course because it is administered after documented treatment failure.

Example 2: The documented treatment plan for a patient with locally advanced breast cancer includes mastectomy, chemotherapy, radiation to the chest wall and axilla, and hormone therapy. The patient has the mastectomy and completes chemotherapy. During the course of radiation therapy, the liver enzymes are rising. Workup proves liver metastases. The physician stops the radiation and does not continue with hormone therapy (the treatment plan is altered). The patient is placed on a clinical trial to receive Herceptin for metastatic breast cancer. Code the mastectomy, chemotherapy, and radiation as first course of treatment. Do not code the Herceptin as first course of therapy because it is administered after documented disease progression.

TREATMENT DATA — Required (Beginning with cases diagnosed January 1, 2007 forward) - Continued

3. When there is **no documentation** of a treatment plan, a progression, recurrence or a treatment failure, first course ends one year after the date of diagnosis. Any treatment given after one year is second course of therapy in the absence of a documented treatment plan or a standard of treatment.

Coding Instructions

1. When physician decides to do watchful waiting for a patient who has prostate cancer, the first course of therapy is no treatment. Code all of the treatment fields to 00, not done. When the disease progresses and the patient is symptomatic; any prescribed treatment is second course.

2. When the patient refuses treatment the first course of therapy is no treatment. Code the treatment fields to refused. If the patient later changes his/her mind and decides to have the prescribed treatment code:

- a.** Code the treatment as first course of therapy if it has been less than one year since the cancer was diagnosed and there has been no documented disease progression.
- b.** Code the treatment as second course of therapy if it has been more than one year since the original cancer was diagnosed or if there has been documented disease progression.

3. Code all treatment that was started and administered.

Example: The patient completed only the first dose of a planned 30 day chemotherapy regimen. Code chemotherapy as having been administered.

4. If a patient has multiple primaries and the treatment given for one primary also affects/treats the other primary, code the treatment for both primary sites.

Example 1: The patient had prostate and bladder cancer. The bladder cancer was treated with a TURB. The prostate cancer was treated with radiation to the prostate and pelvis. The pelvic radiation includes the regional lymph nodes for the bladder. Code the radiation as treatment for both the bladder and prostate cases.

Example 2: The patient had a hysterectomy for ovarian cancer. The pathology report reveals a previously unsuspected microinvasive cancer of the cervix. Code the hysterectomy as surgical treatment for both the ovarian and cervix primaries.

5. If a patient has multiple primaries and the treatment given affects only one of the primaries, code the treatments only on the site that is affected.

TREATMENT DATA — Required (Beginning with cases diagnosed January 1, 2007 forward) - Continued

Example: The patient has colon and tonsil primaries. The colon cancer is treated with a hemicolectomy and the tonsil primary is treated with radiation to the tonsil and regional nodes. Do not code the radiation for the colon. Do not code the hemicolectomy for the tonsil.

6. If a patient is diagnosed with an unknown primary, code the treatment given as first course even if the correct primary is identified later.

Example: The patient is diagnosed with metastatic carcinoma, unknown primary site. After a full course of chemotherapy, the primary site is identified as prostate. Hormonal treatment is started. Code the chemotherapy as first course of treatment. The hormone therapy is second course.

First Course for Leukemia and Hematopoietic Diseases

Leukemia:

Leukemia is grouped or typed by how quickly the disease develops and gets worse. **Chronic** leukemia gets worse **slowly**. **Acute** leukemia gets worse **quickly**.

Leukemias are also grouped by the **type** of **white blood cell** that is affected. The groupings are: **lymphoid** leukemia and **myeloid** leukemia.

Definitions

Consolidation: Repetitive cycles of chemotherapy given immediately after the remission.

Induction: Initial intensive course of chemotherapy.

Maintenance: Chemotherapy given for a period of months or years to maintain remission.

Remission: The bone marrow is normocellular with less than 5% blasts, there are no signs or symptoms of the disease, no signs or symptoms of central nervous system leukemia or other extramedullary infiltration, and all of the following laboratory values are within normal limits: white blood cell count and differential, hematocrit/hemoglobin level, and platelet count.

Treatment for leukemia is divided into three phases:

1. Remission induction (chemotherapy and/or biologic response modifiers)
2. CNS prophylaxis or consolidation (irradiation to brain, chemotherapy)
3. Remission continuation or maintenance (chemotherapy or bone marrow transplants).

TREATMENT DATA — Required (Beginning with cases diagnosed January 1, 2007 forward) – Continued

Coding First Course of Therapy for Leukemia and Hematopoietic Diseases:

1. If a patient **has** a partial or complete **remission** during the first course of therapy:
 - a. Code all therapy that is “remission-inducing” as first course.
 - b. Code all therapy that is “consolidation” as first course.
 - c. Code all therapy that is “remission-maintaining” as first course.

Note: Do not record treatment given after the patient relapses (is no longer in remission).

2. Some patients do not have a remission. A change in the treatment plan indicates a failure to induce remission. If the patient does not have a remission:
 - a. Record the treatment given in an attempt to induce a remission.
 - b. Do not record treatment administered after the change in treatment plan.

Other Hematopoietic

Record all treatments as described above. The following treatments are coded as “other” in Other Treatment even though they do not “modify, control, remove, or destroy proliferating cancer tissue.” Follow the guidelines in the Abstracting and Coding Guide for the Hematopoietic Diseases to identify treatments. Some examples of “other” treatment include:

Example 1: Phlebotomy may be called blood removal, blood letting, or venisection.

Example 2: Transfusions may include whole blood, RBCs, platelets, plateletpheresis, fresh frozen plasma (FFP), plasmapheresis, and cryoprecipitate.

Example 3: Aspirin (also known as ASA, acetylsalicylic acid, or by a brand name) is used as a treatment for essential thrombocythemia.

Only record aspirin therapy if it is given to thin the blood for symptomatic control of thrombocythemia. Use the following guidelines to determine whether aspirin is administered for thinning of blood for thrombocythemia rather than for pain control or cardiovascular protection:

1. Aspirin treatment for essential thrombocythemia is low dose, approximately 70-100 mg/day.
2. The dosage for pain control is approximately 325-1000 mg every 3-4 hours.
3. Cardiovascular protection starts at about 160 mg/day.

**DATE FIRST COURSE OF CANCER-DIRECTED THERAPY
BEGAN — Required (Beginning with cases diagnosed January 1, 2007
forward)**

Definition:

Date First Course of Cancer-Directed Therapy Began is an 8-digit field. The first two digits indicate the day, the second two the month; the last four digits identify the year including century.

Details and Codes:

Record the earliest date that any of the first course of cancer-directed therapy began regardless of modality. In some instances, the date of diagnosis and the date of first course of cancer-directed therapy will be the same. The first course of therapy usually takes place over a two to four month interval and is based on the stage of the disease at the time of diagnosis. When determining the date that the first course of therapy began, consider all treatment which is stated to be part of the planned first course of therapy, but **DO NOT** consider treatment which is given because of disease progression or because of failure of the first course of treatment.

DAY	Two-digit day 99 Unknown day
MONTH	01 January 02 February 03 March 04 April 05 May 06 June 07 July 08 August 09 September 10 October 11 November 12 December 99 Unknown month
YEAR	All four digits of year (including century) 9999 Unknown year

Coding Instruction

1. Assign **code 00000000** if no cancer-directed therapy was given.
 - a. If there was no first course therapy. For example, the patient had ONLY biopsy, bypass, or “watchful waiting.”
 - b. Autopsy only cases.

**DATE FIRST COURSE OF CANCER-DIRECTED THERAPY
BEGAN — Required (Beginning with cases diagnosed January 1, 2007
forward) - Continued**

2. Code the start date of the **first** cancer-directed therapy. The first cancer-directed therapy may be coded in the following data items:

- Surgery (may be of the primary site, other sites, or lymph nodes)
- Radiation Therapy
- Chemotherapy
- Hormone Therapy
- Immunotherapy
- Other Therapy

3. Code the date of **excisional biopsy** as the date therapy initiated if it is the first treatment. Code the date of a biopsy documented as incisional if further surgery reveals no residual or only microscopic residual.

Example: Breast core needle biopsy with diagnosis of infiltrating duct carcinoma; subsequent re-excision with no residual tumor noted. Code the date of the needle biopsy as the excisional biopsy date.

4. Code the date unproven therapy was initiated as the date therapy initiated.

5. If the exact date of the first treatment is unknown, code the date of admission to the hospital for inpatient or outpatient treatment.

6. Assign code 99999999

- a.** It is known the patient had first course therapy, but it is impossible to estimate the date.
- b.** Death certificate only cases.

CANCER-DIRECTED SURGERY — Required (Beginning with cases diagnosed January 1, 2007 forward)

Definition:

Record the surgery performed on the cancer. Surgeries that modify, control, remove, or destroy cancer tissue are considered cancer-directed. Surgery may be of the primary site, regional lymph node(s), regional site(s), distant site(s) and/or distant lymph node(s).

Details and Codes:

- 0 No cancer-directed surgery**
- 1 Cancer-directed surgery**
- 7 Patient refused**
- 8 Recommended, unknown if received**
- 9 Unknown**

Coding Instructions

- 1.** Assign **code 0** if **no surgery** is performed on the primary site, regional lymph nodes, regional sites, distant sites or lymph nodes, or if the case was **diagnosed at autopsy**.
- 2.** Assign **code 7**
 - a. If the patient refused recommended cancer-directed surgery.
 - b. If the patient made a blanket refusal of all recommended treatment.
 - c. If the patient refused all treatment before any was recommended.
- 3.** Assign **code 8** when cancer-directed surgery was recommended by the physician but there is no information that the treatment was given.
- 4.** Assign **code 9**
 - a. When there is no documentation that radiation was recommended or performed.
 - b. Death certificate only.

RADIOTHERAPY — Required (Beginning with cases diagnosed January 1, 2007 forward)

Definition:

Record cancer-directed radiation therapy. This includes **beam** and **implant**. Do not record radiation therapy to the male breasts following female hormone administration to shrink the breasts.

Details and Codes:

- 0 No radiotherapy given**
- 1 Radiotherapy**
- 7 Patient refused**
- 8 Recommended, unknown if received**
- 9 Unknown**

Coding Instructions

1. Assign **code 0**
 - a. There is no information in the patient's medical record about radiation AND
 - i. It is known that radiation is not usually performed for this type and/or stage of cancer, **OR**
 - ii. There is no reason to suspect that the patient would have had radiation.
 - b. If the treatment plan offered multiple treatment options and the patient selected treatment that did not include radiation.
 - c. Patient elects to pursue no treatment following the discussion of radiation treatment. **Note:** Discussion does not equal a recommendation.
 - d. Only information available is that the patient was referred to a radiation oncologist. **Note:** Referral does not equal a recommendation.
 - e. Watchful waiting (prostate).
 - f. Patient diagnosed at autopsy.
2. Assign **code 7**
 - a. If the patient refused recommended radiation therapy.
 - b. If the patient made a blanket refusal of all recommended treatment.
 - c. If the patient refused all treatment before any was recommended.
3. Assign **code 8** when radiation therapy was recommended by the physician but there is no information that the treatment was given.
4. Assign **code 9**
 - a. When there is no documentation that radiation was recommended or performed.
 - b. Death certificate only.

CHEMOTHERAPY — Required (Beginning with cases diagnosed January 1, 2007 forward)

Definition:

Record chemotherapy given to the patient. This includes **single agent and multi-agent** chemotherapy regimens.

Chemotherapeutic agents are chemicals that affect cancer tissue by means other than hormonal manipulation. The agents inhibit the production of cancer cells by interfering with DNA synthesis and mitosis. They may be divided into three classes with respect to their dependence on the cell cycle.

1. Alkylating agents are **not cell-cycle-specific**. Although they are toxic to all cells, they are especially toxic to proliferating cells.
2. Other drugs are **cell-cycle-specific**. Cells must be proliferating for these drugs to be effective.
3. Cell-cycle-specific drugs may also be **cell-cycle phase-specific**; such drugs are active only in one stage of the cell cycle.

Chemotherapy agents are also grouped by their ingredients and the way they attack the cells. Those groups are:

1. Alkylating
2. Antimetabolites
3. Natural products
4. Other miscellaneous

Details and Codes:

- 0 No chemotherapy**
- 1 Chemotherapy (single agent or multiple agents)**
- 7 Patient refused**
- 8 Recommended, unknown if received**
- 9 Unknown**

Coding Instructions

1. Code the chemotherapeutic agents whose actions are chemotherapeutic only.
2. When chemotherapeutic agents are used as radiosensitizers or radioprotectants, they are given at a much lower dosage and do not affect the cancer. Radiosensitizers and radioprotectants are classified as ancillary drugs. Do not code as chemotherapy.

CHEMOTHERAPY — Required (Beginning with cases diagnosed January 1, 2007 forward) - Continued

3. The physician may change a drug during the first course of therapy because the patient cannot tolerate the original agent. If the chemotherapeutic agent that is substituted belongs to the same group (alkylating, antimetabolites, natural products, or other miscellaneous), this is a continuation of the first course of therapy.

4. Assign **code 0** when

- a. There is no information in the patient's medical record about chemotherapy AND
 - i. It is known that chemotherapy is not usually performed for this type and/or stage of cancer, **OR**
 - ii. There is no reason to suspect that the patient would have had chemotherapy.
- b. If the treatment plan offered multiple treatment options and the patient selected treatment that did not include chemotherapy.
- c. Patient elects to pursue no treatment following the discussion of chemotherapy.
Note: Discussion does not equal a recommendation.
- d. Only information available is that the patient was referred to a clinical oncologist
Note: Referral does not equal a recommendation.
- e. Watchful waiting (CLL).
- f. Patient diagnosed at autopsy.

Example: Patient is diagnosed with multiple myeloma. There is no mention of treatment or treatment plans in the medical record. Follow-back finds that the patient died three months after diagnosis. There are no additional medical records or other pertinent information available. Assign code 0 since there is no reason to suspect that the patient had been treated.

5. Assign **code 7**

- a. If the patient refused recommended chemotherapy.
- b. If the patient made a blanket refusal of all recommended treatment.
- c. If the patient refused all treatment before any was recommended.

6. Assign **code 8** when chemotherapy therapy was recommended by the physician but there is no information that the treatment was given.

7. Assign **code 9**

- a. When there is no documentation that chemotherapy was recommended or performed.
- b. Death certificate only.

HORMONAL THERAPY — Required (Beginning with cases diagnosed January 1, 2007 forward)

Definition:

Record the administration of hormones to the patient. Be sure to record the Prednisone that is often given in combination with multi-agent chemotherapy. Also record hormone surgery such as orchiectomy for prostate cancer as hormone therapy.

Hormones are divided into three categories:

1. Hormones.
2. Antihormones.
3. Adrenocorticotrophic agents

Details and Codes:

- 0 No hormonal therapy**
- 1 Hormonal therapy (include prednisone given in combination with chemotherapy, e.g. MOPP; also, include hormone surgery such as orchiectomy or oophorectomy)**
- 7 Patient refused**
- 8 Recommended, unknown if received**
- 9 Unknown**

Coding Instructions

1. Assign **code 0** when:
 - a. There is no information in the patient's medical record about hormone therapy
AND
 - i. It is known that hormone therapy is not usually performed for this type and/or stage of cancer, **OR**
 - ii. There is no reason to suspect that the patient would have had hormone therapy.
 - b. If the treatment plan offered multiple treatment options and the patient selected treatment that did not include hormone therapy.
 - c. Patient elects to pursue no treatment following the discussion of hormone therapy treatment. **Note:** Discussion does not equal a recommendation.
 - d. Only information available is that the patient was referred to an oncologist. **Note:** Referral does not equal a recommendation.
 - e. Watchful waiting (prostate).
 - f. Patient diagnosed at autopsy.

HORMONAL THERAPY — Required (Beginning with cases diagnosed January 1, 2007 forward) - Continued

2. Assign **code 7**
 - a. If the patient refused recommended hormone therapy.
 - b. If the patient made a blanket refusal of all recommended treatment.
 - c. If the patient refused all treatment before any was recommended.

3. Assign **code 8** when hormone therapy was recommended by the physician but there is no information that the treatment was given.

4. Assign **code 9** when:
 - a. There is no documentation that hormone therapy was recommended or administered.
 - b. Death certificate only.

5. Some types of cancer **thrive and proliferate because of hormones** (estrogen, progesterone and testosterone) that naturally occur in the body. These types of cancer may be treated by **an antihormone** or by the surgical removal/radiation of the organ(s) that produce the hormone, such as the testes and ovaries. **Surgical removal of organs** for hormone manipulation is coded in this data item.

6. Other types of cancers are **slowed or suppressed by hormones**. These cancers are treated by administering hormones.

- Example 1: Endometrial cancer** may be treated with **progesterone**. Code all administration of progesterone to patients with endometrial cancer in this field. Even if the progesterone is given for menopausal symptoms, it has an effect on the growth or recurrence of endometrial cancer.

- Example 2: Follicular and papillary** cancers of the **thyroid** are often treated with thyroid hormone to suppress serum thyroid-stimulating hormone (TSH). If a patient with papillary and/or follicular cancer of the thyroid is given a thyroid hormone, code the treatment in this field.

7. Code the hormonal agent given as part of combination chemotherapy, e.g. MOPP, COPP whether it affects the cancer cells or not.

IMMUNOTHERAPY [BIOLOGICAL RESPONSE MODIFIER (BRM)] — Required (Beginning with cases diagnosed January 1, 2007 forward)

Definition:

This data item records immunotherapeutic (biological therapy, biotherapy or biological response modifier) agents administered as first course of therapy.

Immunotherapy uses the **body's immune system**, either directly or indirectly, to fight cancer or to lessen the side effects that may be caused by some cancer treatments. Record only those treatments that are administered to affect the cancer cells.

Immunotherapy is **designed** to:

1. Make **cancer cells** more **recognizable** and therefore more **susceptible** to destruction by the immune system.
2. **Boost** the killing power of **immune** system cells, such as T-cells, NK-cells, and macrophages.
3. **Alter growth patterns** of cancer cells to promote behavior like that of healthy cells
4. **Block** or **reverse** the process that changes a normal cell or a pre-cancerous cell into a cancerous cell.
5. **Enhance** the body's ability to **repair** or **replace** normal cells damaged or destroyed by other forms of cancer treatment, such as chemotherapy or radiation.
6. **Prevent** cancer cells from **spreading** to other parts of the body.

This data item also records systemic therapeutic procedures administered as part of the first course of treatment. These procedures include bone marrow transplants (BMT) and stem cell harvests with rescue (stem cell transplant), endocrine surgery and/or radiation performed for hormonal effect (when cancer originates at another site), as well as combination of transplants and endocrine therapy.

Types of immunotherapy

Cancer Vaccines: Cancer vaccines are still in the experimental phase and are not coded in this data item. They may be coded in the field Other Therapy. Currently clinical trials use cancer vaccines for brain, breast, colon, kidney, lung, melanoma and ovary.

Interferons: Interferons belong to a group of proteins called cytokines. They are produced naturally by the white blood cells in the body. Interferon-alpha is able to slow tumor growth directly as well activate the immune system. It is used for a number of cancers including multiple myeloma, chronic myelogenous leukemia (CML), hairy cell leukemia, and malignant melanoma.

Interleukins (IL-2) are often used to treat kidney cancer and melanoma.

IMMUNOTHERAPY [BIOLOGICAL RESPONSE MODIFIER (BRM)] — Required (Beginning with cases diagnosed January 1, 2007 forward) - Continued

Monoclonal Antibodies: Monoclonal antibodies are produced in a laboratory. The artificial antibodies are injected into the patient to seek out and disrupt cancer cell activities and to enhance the immune response against the cancer. For example, Rituximab (Rituxan) may be used for non-Hodgkin lymphoma, and trastuzumab (Herceptin) may be used for certain breast cancers.

Types of Hematologic Transplants and Procedures:

Bone marrow transplant (BMT): Procedure used to restore stem cells that were destroyed by chemotherapy and/or radiation. Replacing the stem cells allows the patient to undergo higher doses of chemotherapy.

BMT Allogeneic: Receives bone marrow or stem cells from a donor.

BMT Autologous: Uses the patient's own bone marrow and/or stem cells. The tumor cells are filtered out and the purified blood and stem cells are returned to the patient.

Note: Used for breast cancer, lymphoma, leukemia, aplastic anemia, myeloma, germ cell tumors, ovarian cancer, and small cell lung cancer.

Conditioning: High-dose chemotherapy with or without radiation administered prior to transplants such as BMT and stem cell to kill cancer cells. This conditioning also destroys normal bone marrow cells so the normal cells need to be replaced (rescue). The high dose chemotherapy is coded in the Chemotherapy field.

Hematopoietic Growth Factors: A group of substances that support hematopoietic (blood cell) colony formation. The group includes erythropoietin, interleukin-3, and colony-stimulating factors (CSFs). The growth-stimulating substances are ancillary drugs and not coded.

Non-Myeloablative Therapy: Uses immunosuppressive drugs pre- and post-transplant to ablate the bone marrow. These are not recorded as therapeutic agents.

Peripheral Blood Stem Cell Transplantation (PBSCT): Rescue that replaces stem cells after conditioning.

Rescue: Rescue is the actual BMT or stem cell transplant done after conditioning.

Stem Cells: Immature cells found in bone marrow, blood stream and umbilical cords. The stem cells mature into blood cells.

**IMMUNOTHERAPY [BIOLOGICAL RESPONSE MODIFIER
(BRM)] — Required (Beginning with cases diagnosed January 1, 2007
forward) – Continued**

Details and Codes:

- 0 No immunotherapy (BRM)**
- 1 Immunotherapy (BRM) given (includes bone marrow transplant)**
- 7 Patient refused**
- 8 Recommended, unknown if received**
- 9 Unknown**

Coding Instructions

- 1. Assign code 0**
 - a.** When there is no information in the patient’s medical record about immunotherapy, **AND**
 - i.** It is known that radiation is not usually performed for this type and/or stage of cancer, **OR**
 - ii.** There is no reason to suspect that the patient would have had immunotherapy.
 - b.** If the treatment plan offered multiple treatment options and the patient selected treatment that did not include immunotherapy.
 - c.** Patient elects to pursue no treatment following the discussion of immunotherapy.
Note: Discussion does not equal a recommendation.
 - d.** Only information available is that the patient was referred to an oncologist.
Note: Referral does not equal a recommendation.
 - e.** Watchful waiting (prostate).
 - f.** Patient diagnosed at autopsy.
- 2. Assign code 7**
 - a.** If the patient refused recommended immunotherapy.
 - b.** If the patient made a blanket refusal of all recommended treatment.
 - c.** If the patient refused all treatment before any was recommended.
- 3. Assign code 8** when immunotherapy therapy was recommended by the physician but there is no information that the treatment was given.
- 4. Assign code 9**
 - a.** When there is no documentation that immunotherapy was recommended or performed.
 - b.** Death certificate only.

OTHER TREATMENT — Required (Beginning with cases diagnosed January 1, 2007 forward)

Definition:

Other Therapy identifies other treatment given that cannot be classified as surgery, radiation, systemic therapy, or ancillary treatment. Record the administration of other complementary or alternative cancer-directed treatments here.

Details and Codes:

- 0 No other treatment given**
- 1 Other treatment given (such as laetrile, holistic healings, etc.)**
- 7 Patient refused**
- 8 Recommended, unknown if received**
- 9 Unknown**

Coding instructions:

1. Assign **code 0** when
 - a. There is no information in the patient's medical record about other therapy, **AND**
 - i. It is known that other therapy is not usually performed for this type and/or stage of cancer, **OR**
 - ii. There is no reason to suspect that the patient would have had other therapy.
 - b. If the treatment plan offered multiple treatment options and the patient selected treatment that did not include other therapy.
 - c. Patient elects to pursue no treatment following the discussion of other therapy. **Note:** Discussion does not equal a recommendation.
 - d. Only information available is that the patient was referred for consideration of other therapy. **Note:** Referral does not equal a recommendation.
 - e. Patient diagnosed at autopsy.
2. Assign **code 1** for
 - a. Hematopoietic treatments such as: **phlebotomy, transfusions, or aspirin**
 - b. Patients whose cancer treatment that could not be assigned to the previous treatment fields (surgery, radiation, chemotherapy, hormone therapy, or immunotherapy).
 - c. Any experimental or newly developed treatment that differs greatly from proven types of cancer therapy such as a clinical trial.

Note: Hyperbaric oxygen has been used to treat cancer in clinical trials, but it is also used to promote tissue healing following head and neck surgeries. Do not code the administration of hyperbaric oxygen to promote healing as "other treatment."

OTHER TREATMENT — Required (Beginning with cases diagnosed January 1, 2007 forward) - Continued

- d. Patients enrolled in a double blind clinical trial. When the trial is complete and the code is broken, review and recode the therapy.
 - e. Unconventional methods whether they are the single therapy or given in combination with conventional therapy.
3. Assign **code 7**
- a. If the patient refused recommended other therapy.
 - b. If the patient made a blanket refusal of all recommended treatment.
 - c. If the patient refused all treatment before any was recommended.
4. Assign **code 8** when other therapy was recommended by the physician but there is no information that the treatment was given.
5. Assign **code 9**
- a. When there is no documentation that other therapy was recommended or performed.
 - b. Death certificate only.

Note: The following explanations and definitions are quoted from the website for the National Center for Complimentary and Alternative Medicine (NCCAM) of the USA. Complementary and alternative medicine, as defined by NCCAM, is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. While some scientific evidence exists regarding some CAM therapies, for most there are key questions that are yet to be answered through well-designed scientific studies--questions such as whether they are safe and whether they work for the diseases or medical conditions for which they are used.

- **Complementary** medicine is used together with conventional medicine. An example of a complementary therapy is using aromatherapy to help lessen a patient's discomfort following surgery.
- **Alternative** medicine is used in place of conventional medicine. An example of an alternative therapy is using a special diet to treat cancer instead of undergoing surgery, radiation, or chemotherapy that has been recommended by a conventional doctor.

See complete information on types of complementary and alternative medicine at <http://nccam.nih.gov/health/whatisacam/>

DATE OF LAST CONTACT OR DEATH — Required (Beginning with cases diagnosed January 1, 2007 forward)

Definition:

Date of Last Contact or Death is an 8-digit field. The first two digits indicate the day, the second two the month; the last four digits identify the year including century.

DAY	Two-digit day 99 Unknown day
MONTH	01 January 02 February 03 March 04 April 05 May 06 June 07 July 08 August 09 September 10 October 11 November 12 December 99 Unknown month
YEAR	All four digits of year (including century) 9999 Unknown year

VITAL STATUS — Required (Beginning with cases diagnosed January 1, 2007 forward)

Record if the patient is last known to be alive or dead.

Codes:

0 Alive

1 Dead

UNDERLYING CAUSE OF DEATH — Required (Beginning with cases diagnosed January 1, 2007 forward)

Record the underlying cause of death from the source medical documents.

Codes:

- 0 Patient is still alive**
- 1 Patient died of cancer**
- 2 Patient died of non-cancer cause**
- 9 Patient died, cause of death not known**

APPENDIX I

HISTOLOGY CODES FOR LYMPHOMAS AND LEUKEMIAS

The following terms, synonyms and codes were added to the International Classification of Diseases for Oncology, Third Edition. Prior to the publication of ICD-O-3, special codes were added to ICD-O-2 to accommodate these diagnoses and were used in the United States and in MECC for cases diagnosed prior to the introduction of ICD-O-3 in 2001. When ICD-0-3 was introduced, some of the added codes were changed and some stayed the same. (See table below.)

New Lymphoma Terms:

ICD-O-2 Code	Term	ICD-O-3 Code
9673/3	Mantle cell lymphoma (*)	9673/3
9688/36	T-cell rich B-cell lymphoma	9680/36
9708/3	Subcutaneous panniculitic T-cell lymphoma	9708/3
9710/3	Marginal zone lymphoma, NOS	9699/3
9714/3	Anaplastic large cell lymphoma (ALCL), CD30+ (*)	9714/3
9715/3	Mucosal-Associated Lymphoid Tissue (MALT) lymphoma	9699/3
9716/3	Hepatosplenic (*) (gamma - delta) cell lymphoma	9716/3
9717/3	Intestinal T-cell lymphoma Enteropathy associated T-cell lymphoma	9717/3

New Leukemia Terms:

ICD-O-2 Code	Term	ICD-O-3 Code
9821/3	Acute lymphoblastic leukemia, L1 type (*) Acute lymphocytic leukemia, L1 type (*) Acute lymphoid leukemia, L1 type (*) Acute lymphatic leukemia, L1 type (*) Lymphoblastic leukemia, L1 type (*) FAB L1 (*)	9835/3
9826/3	FAB L3 (*)	9826/3
9828/3	Acute lymphoblastic leukemia, L2 type Acute lymphocytic leukemia, L2 type Acute lymphoid leukemia, L2 type Acute lymphatic leukemia, L2 type Lymphoblastic leukemia, L2 type FAB L2	9835/3
9840/3	FAB M6 (*)	9840/3
9861/3	Acute myeloid leukemia, NOS (*) Acute mesoblastic leukemia, NOS (*) Acute granulocytic leukemia, NOS (*) Acute myelogenous leukemia, NOS (*) Acute myelocytic leukemia, NOS (*)	9861/3

APPENDIX I (Continued)

ICD-O-2 Code	Term	ICD-O-3 Code
9866/3	FAB M3 (*)	9866/3
9867/3	Acute myelomonocytic leukemia, NOS (*) FAB M4 (*)	9867/3
9871/3	Acute myelomonocytic leukemia with eosinophils FAB M4E	9871/3
9872/3	Acute myeloid leukemia, minimal differentiation Acute mesoblastic leukemia, minimal differentiation Acute granulocytic leukemia, minimal differentiation Acute myelogenous leukemia, minimal differentiation Acute myelocytic leukemia, minimal differentiation FAB M0	9872/3
9873/3	Acute myeloid leukemia without maturation Acute mesoblastic leukemia without maturation Acute granulocytic leukemia, without maturation Acute myelogenous leukemia, without maturation Acute myelocytic leukemia, without maturation FAB M1	9873/3
9874/3	Acute myeloid leukemia with maturation Acute mesoblastic leukemia with maturation Acute granulocytic leukemia, with maturation Acute myelogenous leukemia, with maturation Acute myelocytic leukemia, with maturation FAB M2	9874/3
9891/3	FAB M5 (*) FAB M5A (*) FAB M5B (*)	9891/3
9910/3	Megakaryoblastic leukemia, NOS (C42.1) FAB M7	9910/3

(*) new term(s) for an existing ICD-O-2 code

APPENDIX II

ICD-10 CODES FOR CASEFINDING BY DISEASE INDEX SCREENING

Case finding in medical records/health information should be done using both inpatient and outpatient disease/diagnostic indexes. Review all records with the following International Classification of Diseases, Tenth Revision (ICD-10) codes. An asterisk (*) indicates conditions that are newly reportable as of January 1, 2001.

B21.0 – B21.9 HIV disease resulting in malignant neoplasms

C00.0 – C75.9 Malignant neoplasms of specified sites

C76.0 – C80 Malignant neoplasms of ill-defined, secondary and unspecified sites

C81.0 – C96.9 Malignant neoplasms of lymphoid, hematopoietic and related tissue
***C92.1** Chronic neutrophilic leukemia

C97 Malignant neoplasms of independent (primary) multiple sites

D00.0 – D09.9 In situ neoplasms

D37.0 – D48.9 Neoplasms of uncertain or unknown behavior

***D45** Polycythemia vera

***D46.0** Refractory anemia without sideroblasts, so stated

***D46.1** Refractory anemia with sideroblasts

***D46.2** Refractory anemia with excess blasts

***D46.3** Refractory anemia with excess blasts in transformation

***D46.4** Refractory anemia, unspecified

***D46.7** Myelodysplastic syndrome with 5q- syndrome

Therapy related myelodysplastic syndrome

***D46.9** Myelodysplastic syndrome, unspecified

Myelodysplasia, NOS

Preleukemia(syndrome), NOS

***D47.1** Chronic myeloproliferative disease

Myelosclerosis with myeloid metaplasia

Refractory cytopenia with multilineage dysplasia

***D47.3** Essential (Idiopathic) thrombocytopenia

***D72.1** Hypereosinophilic syndrome

APPENDIX II – Continued
ICD-10 CODES FOR CASEFINDING BY DISEASE INDEX
SCREENING

Z03.1	Observation for suspected malignant neoplasm
Z08.0-Z08.9	Follow-up examination after treatment for malignant neoplasm
Z12.0-Z12.9	Special screening for neoplasms
Z29.2	Other prophylactic chemotherapy (screen for miscoded chemotherapy for malignancy)
Z29.8	Other specified prophylactic measures
Z51.0	Radiotherapy session
Z51.1	Chemotherapy session for neoplasm
Z51.2	Other chemotherapy [maintenance]
Z54.1	Convalescence for radiotherapy
Z54.2	Convalescence for chemotherapy
Z85.0-Z85.9	Personal history of malignant neoplasm