

NEW JERSEY STATE CANCER REGISTRY MANUAL
Instructions for Health Care Facilities
2008

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INTRODUCTION TO THE NEW JERSEY STATE CANCER REGISTRY

The New Jersey State Cancer Registry (NJSCR) is a population-based registry and includes all cancer cases diagnosed in New Jersey residents since October 1, 1978. The NJSCR serves the entire State of New Jersey, which includes a population of approximately 8.4 million people.

The purpose of the NJSCR is to track cancer in New Jersey in an effort to promote the following activities: scientific research; public and professional education programs; planning and implementation of cancer control and prevention activities. The NJSCR strives to improve the quality and enhance the usefulness of its data.

The NJSCR was established by legislation (NJSA 26:2-104 et.seq.) in 1977 in response to concern that New Jersey was suffering from the highest cancer incidence and mortality rates in the country. New Jersey regulations require the reporting of all newly-diagnosed cancer cases to the Registry within six months of diagnosis. All primary malignant and in situ neoplasms are reportable to the NJSCR, except in situ and localized basal cell and squamous cell carcinomas of the skin and carcinoma in situ of the cervix (since 1995). Benign and borderline intracranial and Central Nervous System tumors are reportable if diagnosed January 1, 2004 and later. Hospitals, physicians, dentists and independent laboratories also file reports with the NJSCR. In addition, reporting agreements are maintained with neighboring states so that New Jersey residents diagnosed in facilities out of state are identified.

The information collected by the NJSCR includes the following: demographic characteristics of the patient, medical information on each cancer such as primary site, histologic type, collaborative stage and treatment information. The vital status of each patient is followed annually until death. The cause of death is also incorporated into the data set if the information is available.

In February 2001, the NJSCR became a SEER (Surveillance, Epidemiology, and End Results) Registry. The SEER Program of the National Cancer Institute is the most authoritative source of information on cancer incidence and survival in the United States. Geographic areas selected for inclusion in the SEER Program is based on the Registries ability to operate and maintain a high-quality population-based cancer reporting system and for their epidemiologically significant population subgroups. The SEER Program currently collects and publishes cancer incidence and survival data from 14 population-based cancer registries and three supplemental registries covering approximately 26 percent of the US population. Information on more than 3 million in situ and invasive cancer cases is included in the SEER database, and approximately 170,000 new cases are added each year within the SEER coverage areas.

The NJSCR participates in the National Program of Cancer Registries (NPCR), established by the Centers for Disease Control (CDC) in 1992 by the Federal Cancer Registries Amendment Act (Public Law 102-515). NPCR promotes statewide, population-based registries to collect uniform data elements in a standardized format. The NJSCR is also a member of the North American Association of Central Cancer Registries (NAACCR). The North American Association of Central Cancer Registries, Inc. (NAACCR, Inc.), is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training;

certifies population-based registries; and publishes data from central cancer registries.

Confidentiality

The New Jersey Cancer Registry Statute N.J.S.A.26:2-107 stipulates that reports of individual patients made to the NJSCR are held in the strictest confidence. Reports made pursuant to this act are used only by the State Department of Health and Senior Services and such other agencies as designated by the Commissioner of Health. N.J.S.A.26:2-108 stipulates that no individual or organization providing information to the State Department of Health in accordance with this act shall be held liable for divulging confidential information. Please note: reporting information about cases of cancer in accordance with the NJSCR authorizing statute and regulations *is permitted* by the Health Insurance Portability and Accountability Act. The privacy rule contains a specific provision authorizing covered entities to disclose protected health information as required by law. Public Health reporting under the authority of State law is specifically exempted from the Privacy Rule regulations 45CFR154.512(b)(1)(i). A copy of the Cancer Reporting Statute, Regulations and Reportable List can be found on the NJSCR Website at <http://www.state.nj.us/health/cancer/regs.pdf>.

General Requirements for Reporting to the New Jersey State Cancer Registry

The New Jersey State Cancer Registry Manual 2008 contains coding instructions for all cases diagnosed January 1, 2007 and later. Documentation and codes for historical items can be found in The New Jersey State Cancer Registry Manual 2005.

A case *must* be reported to the NJSCR if it is **diagnosed on or after October 1, 1978**.

What Cancer Should Be Reported to the NJSCR?

All histologies with a **behavior code of /2 or /3** in the *International Classification of Diseases for Oncology*, Third Edition (ICD-O-3).

The following are **exclusions**:

- Carcinoma in situ (any/2) and CIN III of the cervix (C5.30-C53.9) (cases diagnosed after April 1, 1995)
- Prostatic intraepithelial neoplasia (PIN III) of the prostate (C619) (Collection stopped effective with cases diagnosed 1/1/2001 and later)
- Neoplasms, malignant NOS of the skin (C44.0-C44.9)
- Epithelial carcinomas of the skin (C44.0-C44.9) unless regional or distant spread
- Papillary and squamous cell carcinomas of the skin (C44.0-C44.9) unless regional or distant spread
- In situ or localized basal cell carcinoma of the skin (C44.0-C44.9)

Note: The above lesions are reportable for skin of the genital sites: vagina, clitoris, vulva, prepuce, penis, and scrotum (sites C52.9, C5.10-C51.9, C60.0, C60.9, C63.2).

- **Benign and borderline primary intracranial and CNS tumors** with a behavior code of /0 or /1 in ICD-O-3 are collected effective with cases diagnosed 1/1/2004 and later).
 - **Pilocytic/Juvenile astrocytomas** are reportable; code the histology and behavior code 9421/3.

- **Note:** Benign and borderline tumors of the cranial bones (C410) are **not reportable**.
- All cancer patients diagnosed or treated in the **inpatient** or **outpatient department, emergency room, clinic** or **ambulatory care centers** must be reported including patients receiving transient care.
- **Certain borderline conditions are reportable.** Refer to the reportable list in on the NJSCR website <http://www.state.nj.us/health/cancer/regs.pdf> for a list of these conditions.
- New Jersey residents and non-residents must be reported including residents of foreign countries.
- Cases diagnosed at **autopsy** must be reported and patients dead on arrival (DOA) with a cancer diagnosis must be reported.
- Patients diagnosed elsewhere and admitted for additional work-up and/ or treatment, cancer-directed or non cancer-directed must be reported.
- Patients with a **clinical diagnosis** of cancer which was based on clinical judgment only must be reported.
- Patients with a **history of cancer with active disease** must be reported.
- If more than one primary cancer is diagnosed in a patient, **a separate report must be submitted for each primary.**
- **Consult-only cases are reportable.** A consult may be done to confirm a diagnosis or treatment plan.
- Private outpatient specimens are reportable. Generally, these specimens are submitted from a physician's office to be read by the hospital pathologist and the patient is not registered as an inpatient or outpatient at the hospital.
- **Slide reviews** are **encouraged** to be reported but are not required. Slide review cases are slides that have been sent to your hospital's pathologist for an opinion. Please do not confuse these with private outpatient or consult-only cases.
- When the distinction between a free-standing facility and hospital-based department cannot be made such as a radiation therapy group practice versus a hospital unit, the ownership of the medical record should be used to determine who is responsible for reporting the case.
- Ambiguous terms that must be reported include the following: **apparent(ly), appears, appears to, comparable with, malignant appearing, compatible with, consistent with, most likely, probable, suspected, suspicious, presumed, favor(s), typical of.**
 - **Note:** If the **ambiguous** diagnosis is proven to be **not reportable** by biopsy, cytology, or physician's statement, **do not accession** the case.

When to Report to the New Jersey State Cancer Registry

All cases of cancer and other specified tumors and precancerous diseases must be reported to the NJSCR within six months of diagnosis.

A health care facility that fails to report cases of cancer electronically, as required by regulation, within six months of the confirmed diagnosis shall be liable to pay a penalty as stated in N.J.S.A. 26:2-106 (Reference the NJSCR website <http://www.state.nj.us/health/cancer/regs.pdf> for the Statute, Regulations and Reportable List).

How to Report to the New Jersey State Cancer Registry

A cancer registry abstract must be completed for each newly-diagnosed case of cancer. A separate abstract must be completed for each primary. All abstracts from health care facilities must be submitted electronically in the latest NAACCR format (currently Version 11). All cases must be submitted electronically to the NJSCR via e-mail with either attached encrypted file or with an e-mail link to a secure encrypted e-mail server on a monthly basis.

Who Reports to the New Jersey State Cancer Registry

Health care facilities, physicians, dentists, independent clinical laboratories that diagnose or provide treatment for cancer patients should report cancer cases to the NJSCR. All abstracting work performed by a health care facility which diagnoses or treats 100 or more cases per year must be performed by a certified tumor registrar who is certified by the National Cancer Registrars Association.

Methods of Reporting Changes, Updates, Deletions and Follow-ups to the NJSCR

Changes, deletions or updates to cases must be submitted in *paper format*. A printed copy of the hospital abstract highlighting the fields that have been changed, deleted and/or updated must be submitted via mail to the NJSCR address (given on the cover sheet of this manual) or faxed to (609) 588-3638. It is important that you notify the NJSCR of any changes in your data base so that the NJSCR can maintain an up-to-date registry.

Methods to Receive Follow-up Information from NJSCR

The NJSCR can provide hospitals with vital status and dates of last follow-up on cases submitted by their own facilities. Hospitals interested in receiving this information should contact the NJSCR for further instructions regarding compression software and required passwords to ensure confidentiality in the transmission of this data.

NJSCR Guidelines for the Submission of Text Information

The New Jersey State Cancer Registry (NJSCR) requires the submission of text information to validate coded data items. Text is used for quality control purposes to justify codes for various data items. Text is also used to identify errors, to determine multiple primaries and to resolve discrepancies in data submitted on the same patient by multiple facilities.

All cancer registry software must include specific fields, which have been designed to record text information. These fields are transmitted to the NJSCR along with the other required data fields when you make your monthly electronic submission. Please refer to the table on the NAACCR Website <http://www.naacr.org/filesystem/pdf/Standards%20Volume%20I%20Versoin%2011.2.pdf>, starting page 26 for the maximum number of characters per field. Please refer to http://www.training.seer.cancer.gov/module_cancer_terminology/unit07_sec01.html for a list of acceptable abbreviations. Recording text information should include but not be limited to the following:

- Record text to support primary site, laterality, histology, grade, collaborative stage, and treatment codes.
- Record text to justify any unusual information about the case which could result in potential questions, e.g. record text to support unusual site/histology combinations, such as age/site combinations, gender/site combinations.
- Record text to clarify modifications or dates on the abstract.
- If limited information is available in the medical record about a case, utilize the text field to state that limited information was available in the medical record.

Case Finding

Case finding is the system used to identify patients with reportable neoplasms. Case finding involves thorough, systematic monitoring of records maintained by various departments throughout the hospital. Multiple sources must be used to ensure complete reporting of all cases.

Case finding sources include, but are not limited to:

- Admission and discharge documents
- Disease indices
- Surgery schedules/ logs
- Pathology and Cytology reports
- Hematology reports
- Autopsy reports
- Outpatient medical records/logs, including Radiation Oncology and Medical Oncology logs
- Nuclear medicine documents

Screening Lists of ICD-9-CM and ICD-10-CM Codes for Case Finding

Certain ICD-9-CM* and/or ICD-10-CM** codes are used by medical records departments for discharge diagnoses to identify cases of neoplasms that are reportable. Case finding procedures should include the review of medical records coded with the ICD-9-CM or ICD-10 CM codes found on the following pages.

***ICD-9-CM Codes:**

International Classification of Disease, 9th Revision, Clinical Modification (4th ed., October 1991)

****ICD-10 CM Codes:**

International Classification of Diseases, Tenth Revision, Clinical Modification (June 2003)

ICD-9-CM Codes	Diagnosis (in preferred ICD-O-3 terminology)
042	AIDS (review cases for AIDS-related malignancies)
140.0 - 208.9	Malignant neoplasms
203.1	Plasma cell leukemia (9733/3)
205.1	<u>Chronic neutrophilic leukemia (9963/3)</u>
210.0 - 229.9	Benign neoplasms
230.0 - 234.9	Carcinoma in situ
235.0 - 238.9	Neoplasms of uncertain behavior
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmacytoma (9731/3)
238.6	Extramedullary plasmacytoma (9734/3)
238.7	Chronic myeloproliferative disease (9960/3)
238.7	Myelosclerosis with myeloid metaplasia (9961/3)
238.7	Essential thrombocythemia (9962/3)
238.7	<u>Refractory cytopenia with multilineage dysplasia (9985/3)</u>
238.7	<u>Myelodysplastic syndrome with 5q- syndrome (9986/3)</u>
238.7	<u>Therapy-related myelodysplastic syndrome (9987/3)</u>
239.0 - 239.9	Neoplasms of unspecified behavior
273.2	Gamma heavy chain disease; Franklin's disease
273.3	Waldenstrom's macroglobulinemia
273.9	Unspecified disorder of plasma protein metabolism (screen for potential 273.3 miscodes)
284.9	Refractory anemia (9980/3)
285.0	Refractory anemia with ringed sideroblasts (9982/3)
285.0	Refractory anemia with excess blasts (9983/3)
285.0	Refractory anemia with excess blasts in transformation (9984/3)
288.3	<u>Hypereosinophilic syndrome (9964/3)</u>
289.8	Acute myelofibrosis (9932/3)
V07.3	Other prophylactic chemotherapy (screen carefully for miscoded malignancies)
V07.8	Other specified prophylactic measure
V10.0 - V10.9	Personal history of malignancy (review these for recurrences, subsequent primaries, and/or subsequent treatment)
V58.0	Admission for radiotherapy
V58.1	Admission for chemotherapy
V66.1	Convalescence following radiotherapy
V66.2	Convalescence following chemotherapy
V67.1	Radiation therapy follow-up
V67.2	Chemotherapy follow-up
V71.1	Observation for suspected malignant neoplasm
V76.0 - V76.9	Special screening for malignant neoplasm

ICD-10 Codes	Diagnosis
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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
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

Source:

http://www.training.seer.cancer.gov/module_casefinding/icd_9_and_10_casefinding.html

Class of Case

The NJSCR requires the submission of analytic and non-analytic cases. The following defines analytic (0, 1 and 2) and non-analytic cases (3,4,5, 6, 8 and 9).

Class 0 cases are diagnosed at the reporting institution and are treated elsewhere. Cases include:

- Patients who choose to be treated elsewhere.
- Patients who are referred elsewhere for treatment.

Class 1 cases are diagnosed at the reporting institution. They also fulfill one of the following treatment situations:

- Patient received all or part of his or her first-course of treatment at the reporting institution.
- Patient refused any therapy.
- Patient diagnosed at the reporting institution whose treatment plan is either to treat or watchful waiting.
- Patient was untreatable because of age, advanced disease, or other medical conditions or who were given palliative care.
- Specific therapy was recommended but not received at the reporting institution and it is unknown if therapy was ever administered.
- It is unknown if therapy was recommended or administered.
- Patient diagnosed at the reporting institution prior to the registry's reference date, all or part of first-course of treatment received at the reporting institution after the registry's reference date.
- Patient first diagnosed and had staging workup at the reporting institution and all or part of the first-course of treatment was received in a staff physician's office.
- Patient diagnosed in a staff physician's office and then treated at the reporting institution.
- Patient diagnosed and treatment plan developed and documented at the reporting institution. Therapy was delivered elsewhere in accordance with the treatment plan.

Class 2 cases are diagnosed elsewhere. They also fulfill one of the following treatment situations:

- The reporting institution administered part or all of the first-course of treatment.
- The reporting institution provided palliative care in lieu of first-course of treatment, or as part of first-course of treatment.

Class 3 cases are patients who were diagnosed and received all of their first-course of treatment elsewhere. They are then seen at the reporting institution for additional therapy or management and have active disease. This class of case includes:

- No information is available on his or her first-course of treatment. Patient is now treated or managed at the reporting institution.
- The reporting institution is treating or managing the recurrence, progression, or subsequent treatment of a previously-diagnosed malignancy.
- Patients for whom the reporting institution developed a treatment plan or provided "second opinion" services but the diagnosis and treatment were performed elsewhere.

Class 4 includes cases that were diagnosed and/or received their first-course of treatment at the reporting institution **BEFORE** the registry's reference date. The reporting institution manages or treats a recurrence or progression of that cancer **AFTER** the registry's reference date.

- Assign a class of case 4 also if it is unknown whether the reporting institution delivered the first-course of treatment.

Class 5 refers to an incidental finding of cancer at autopsy. There was no suspicion of cancer before the autopsy.

Class 6 includes patients who were both diagnosed and received all of their first-course of treatment in a staff physician's office. "Staff physician" refers to any medical staff with admitting privileges at the reporting facility.

Class 7 includes pathology report only. The patient does not enter the reporting facility at any time for diagnosis or treatment. This excludes patients diagnosed as autopsy only.

Class 8 should be used only by a central registry (e.g. NJSCR) and includes:

- Diagnoses based on death certificates only.

Class 9 can be used for consult only cases otherwise it should be used only by a central registry and includes:

- Unknown if previously diagnosed.
- Previously diagnosed, date unknown.
- Unknown if previously treated.

Demographic Data

Last Name, First Name, Middle Name

Record patient's last name, first name and middle name, if the middle name is not available, use the middle initial of the patient. Do not use any spaces or punctuation (e.g. ONEIL). Hyphenated names are allowed (e.g. SMITH-BROWN). Please spell names correctly.

Alias or Maiden Name

If maiden or alias name is known, record the name. If the patient uses an alias for the first, last name or both first and last name, record the last name alias followed by a blank space and the first name (alias). Leave the space blank if the patient does not have a maiden name or uses an alias.

Name - Prefix/Suffix

Abbreviated titles may be used. Do not use periods or spaces (e.g., MS, MD).

Address at Diagnosis

SEER registries collect information of place of residence at diagnosis. The SEER rules for

determining residency at diagnosis are either identical or comparable to rules used by the US Census Bureau.

Record the patient's residence when the tumor was first diagnosed and treated. It should be noted the patient's address at diagnosis may be different than the patient's current address. The address should be the residence, not the mailing address. If the patient has multiple tumors, the address at diagnosis may be different for each subsequent primary. If the address is unknown, record UNKNOWN.

Special Notes About Address:

- A patient originally diagnosed in a foreign country may come to the US for a second opinion and/or treatment. If possible, the patient's home address should be recorded. Do not record a temporary residence, such as a friend's or relative's address.
 - For "state", there are special abbreviations for the following locations: American Samoa, Guam, Mexico, Puerto Rico, and the Virgin Islands.
 - If the patient is a resident of a country other than the US (including US territories, commonwealths, or possessions), or is a resident of a country other than Canada, AND the country is **known**, record **XX** in the "state" field.
 - If the patient is a resident of a country other than the US (including US territories, commonwealths, or possessions), or is a resident of a country other than Canada, AND the country is **unknown**, record **YY** in the "state" field.
 - If the residence is **unknown**, code the "state" field as **ZZ**.
- Use a street address if available when a P.O. Box is given. Post Office Box is not a reliable source to identify the residency at diagnosis; it does not provide accurate geographical information for analyzing cancer incidence.
- Please see the SEER Program Manual 2007 for additional information concerning address.

Number and Street Address

Record the number and street address at the time of diagnosis. Use a blank between numbers and words (e.g. 123 Fifth Avenue NW, Apt. 7B).

A street address should include:

- street number
- prefix directional (e.g., E, W, SE, NW, etc.)
- street name
- street type (e.g., St, Ave, Ln, Tpk., etc.)
- suffix directional (e.g., W, NE, S, etc.)

For example, an address with four of the most commonly given components would look like:

427 E Maple St. or 211 Broadway Ave SW

Apartment numbers, building numbers, etc., can be included but they **MUST** be added at the end if there is space. Whenever possible, avoid using facility names (e.g., nursing home, hospital), Rural Routes and P.O. Box numbers in the ADDRESS field. Enter the patient's street address of residence whenever possible.

City

Enter the name of the city or town of residence, not the location of the post office box number. Do not use abbreviations. If city is unknown, type out the word UNKNOWN.

County

Record the *three-digit* county code for the address at diagnosis listed below:

COUNTY NAME	CODE	COUNTY NAME	CODE
Atlantic	001	Middlesex	023
Bergen	003	Monmouth	025
Burlington	005	Morris	027
Camden	007	Ocean	029
Cape May	009	Passaic	031
Cumberland	011	Salem	033
Essex	013	Somerset	035
Gloucester	015	Sussex	037
Hudson	017	Union	039
Hunterdon	019	Warren	041
Mercer	021	Non-NJ Resident	998

ZIP Code

Record the patient's five-digit or nine-digit ZIP code corresponding to the street address. Code 999999999 if the patient is a US or Canadian resident but the postal code is unknown. Code 888888888 if the patient is a foreign resident and the foreign country's postal code is unknown.

State

Record the standard two-letter U.S. Postal Service abbreviation for the patient's state of residence at the time of diagnosis. For foreign residents, code the state abbreviation as XX.

Alabama	AL	Kentucky	KY	North Dakota	ND
Alaska	AK	Louisiana	LA	Ohio	OH
Arizona	AZ	Maine	ME	Oklahoma	OK
Arkansas	AR	Maryland	MD	Oregon	OR
California	CA	Massachusetts	MA	Pennsylvania	PA
Colorado	CO	Michigan	MI	Rhode Island	RI
Connecticut	CT	Minnesota	MN	South Carolina	SC
Delaware	DE	Mississippi	MS	South Dakota	SD
District of Columbia	DC	Missouri	MO	Tennessee	TN
Florida	FL	Montana	MT	Texas	TX
Georgia	GA	Nebraska	NE	Utah	UT
Hawaii	HI	Nevada	NV	Vermont	VT

Idaho	ID	New Hampshire	NH	Virginia	VA
Illinois	IL	New Jersey	NJ	Washington	WA
Indiana	IN	New Mexico	NM	West Virginia	WV
Iowa	IA	New York	NY	Wisconsin	WI
Kansas	KS	North Carolina	NC	Wyoming	WY

Canada:

Alberta	AB	Nova Scotia	NS
British Columbia	BC	Ontario	ON
Labrador	LB	Prince Edward Island	PE
Manitoba	MB	Quebec	PQ
New Brunswick	NB	Saskatchewan	SK
Newfoundland	NF	Yukon	YT
Northwest Territories	NT	Canada, NOS	CN

Other:

American Samoa	AS
Guam	GU
Mexico	MX
Puerto Rico	PR
Virgin Islands	VI
Resident of a country other than the US (including US territories, commonwealths, or possessions); OR Resident of a country other than Canada; AND The country is known	XX
Resident of a country other than the US (including US territories, commonwealths, or possessions); OR Resident of a country other than Canada; AND The country is unknown	YY
Residence unknown	ZZ

Current Address

This field is different from Patient's Address at Diagnosis and should be updated throughout the lifetime of the patient. It provides useful information necessary for follow-up. List the patient's current street name and number, city, state and zip code.

Social Security Number

Record the patient's social security number. This is an important identification field. Numbers should be accurately listed without the use of dashes. Use 9's for unknown numbers. Do not enter a Social Security number that ends with a B or D. This is the spouse's social security number.

Please Note: The Medicare claim number is *not* always identical to the social security number.

Sex

Record the patient's sex.

- | | |
|-------------------------|---|
| 1 Male | 4 Transsexual (Surgically altered gender) |
| 2 Female | 9 Not stated/ Unknown |
| 3 Other (hermaphrodite) | |

Age at Diagnosis

Record the patient's age at the time of initial diagnosis, in completed years. Some registry software automatically calculate age when date of birth and date of diagnosis are recorded.

- 000 Less than one year old
- 001 One year old, but less than two years old
- 002 Two years old
- " (Actual age in years)
- 100 One hundred years old
- 999 Unknown age

If year of birth and year of diagnosis are known, but age is unknown, calculate age at diagnosis.

Date of Birth

Record the exact date of the patient's birth in month, day, century and year. Estimate the year of birth when exact information is not available. It is preferable to estimate rather than to code the year as unknown. If there is no basis for estimating birth year, enter **9999** for the year.

Example: Patient is 50 years old when diagnosed on May 1, 2005. The medical record does not contain the birth date. Record **99** for month, **99** for day and estimate the birth year as 1955. The complete birth date would be 99/99/1955.

Place of Birth

Enter the name of the state, county or territory where the patient was born. Assign the most specific code possible using the three-digit SEER Geocodes for Place of Birth in http://seer.cancer.gov/manuals/2007/SPCSM_2007_AppendixB.pdf. These codes contain all states as well as foreign countries.

Race 1, 2, 3, 4, 5

Code the primary race(s) of the patient in fields Race 1, Race 2, Race 3, Race 4, and Race 5. Race (and ethnicity) is defined by specific physical, hereditary and cultural traditions or origins, not necessarily by birthplace, place of residence, or citizenship. If race is not recorded on the face sheet of the medical record, please check to see if it has been recorded elsewhere in the chart. Every attempt should be made to obtain the correct race code.

Please note that race is coded separately from "Hispanic ethnicity". "Hispanic" is NOT a race and should not be coded in the race field. Persons of Spanish or Hispanic origin may be of any race, although persons of Mexican, Central American, South American, Puerto Rican, or Cuban origin are usually white. Do NOT code a patient stated to be Hispanic or Latino as 98 Other Race in Race 1 and 88 in Race 2 through Race 5.

Spanish/Hispanic Surname

Code Spanish/Hispanic origin in this field. All available information should be used to determine the Spanish/Hispanic origin including the stated ethnicity in the medical record, stated Hispanic Origin on the death certificate, birthplace information in the history, and or language spoken. A person of Spanish/Hispanic origin may be of any race. Record applicable codes 1-8 if the patient has identified himself/herself as a specific Hispanic subgroup. Code 7 is assigned by the NJSCR.

* Code Portuguese, Brazilians and Filipinos as non-Spanish, 0.

Marital Status

The field reflects the patient's marital status at diagnosis for each primary tumor.

- | | |
|----------------------------------|------------|
| 1 Single (never married) | 4 Divorced |
| 2 Married (including common law) | 5 Widowed |
| 3 Separated | 9 Unknown |

Persons of the opposite sex living together as part of a long-term personal relationship would be coded to 2, Married (including common law).

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

Usual Occupation

Record the patient's usual occupation regardless of whether the patient is currently employed or retired. Usual occupation refers to the type of job the individual performed during most of his/her working life. If the patient was a housewife/house husband and did **NOT** work outside the home for most of her/his adult life, record housewife or house husband. If the patient is a student and has never been employed, record as "never worked." If no information is available record "unknown." This data item applies only to patients who are 14 years or older at the time of diagnosis.

Usual Industry

Record the type of activity carried on by the business/industry where the patient was employed for the longest time before diagnosis of this tumor (e.g. school, auto repair, food preparation). If possible, try to distinguish among "manufacturing," "wholesale," "retail," and "service". If type of industry is not known, record the name of company. If no information is available, code unknown. Do not record retired.

Managing Physician

This is the person responsible for the overall management of the patient during diagnosis and/or treatment of this primary. The physician's name may change with subsequent primaries. If so, record physician's name for each primary separately.

Medical Record Number

Record the medical record number or patient's identification number found in the patient's chart. This number is usually assigned by the reporting institution's Health Information Management (HIM) Department. If a patient has not been assigned one, record UNK. Record standard abbreviations for departments that do not use HIM medical record numbers such as Radiation Therapy.

COLLABORATIVE STAGE

Please refer to the Collaborative Staging Manual and Coding Instructions for codes and instructions. Schemas for the collaborative staging system apply to cases diagnosed January 1, 2004 and later. For cases diagnosed prior to January 1, 2004 please refer to the coding system applicable to the time of diagnosis.

The Collaborative Staging System is a carefully selected set of data items that describe how far a cancer has spread at the time of diagnosis. Most of the data items have traditionally been collected by cancer registries, including tumor size, extension, lymph node status, and metastatic status. New items were created to collect information necessary for the conversion algorithms, including the evaluation fields that describe how the collected data were determined, and site/histology-specific factors that are necessary to derive the final stage grouping for certain primary cancers. In addition to the items coded by the registrar, this unified data set also includes several data items derived from the computer algorithms that classify each case in multiple staging systems: the sixth edition of the AJCC TNM system (TNM), Summary Stage 1977 (SS77), and SEER Summary Stage 2000 (SS2000).

FIRST COURSE OF THERAPY: SPECIAL NOTES FOR NJ FACILITIES

No Cancer-Directed Therapy

"Cancer tissue" means proliferating malignant cells or an area of active production of malignant cells such as adjacent tissues or distant sites. In some instances, malignant cells are found in tissues where they did not originate and where they do not reproduce, such as malignant cells found at thoracentesis or paracentesis. Procedures that remove malignant cells, but do not treat a site of proliferating cells are not considered cancer therapy.

If the patient only receives supportive or symptomatic therapy, it is not considered cancer therapy. The term "palliative" can mean either non-curative or alleviation of symptoms. Therefore "palliative" can fall within the definition of cancer-directed treatment or non-cancer directed therapy. Surgical procedures performed to diagnose/stage disease (exploratory) or for relief of symptoms (palliative) are considered diagnostic, staging, and palliative procedures.

Date Therapy Initiated

Record the start date of the first-course of therapy. This may be the start date of any type of treatment for this tumor; surgery, chemotherapy, radiation therapy, or other types of therapy. Treatment might be given in a hospital or non-hospital setting. Date fields are recorded in the month, day, century, year format (MMDDCCYY) with 99 for unknown day or month and 9999 for unknown year.

According to the Commission on Cancer,

"In cases of nontreatment, in which a physician decides not to treat a patient or a patient's family or guardian declines all treatment, the date of first course of treatment is the date this decision was made." *FORDS 2007, page 129*

NJDHSS Cancer Registry is a SEER Registry, and must abide by SEER coding rules. Please see the SEER coding instructions below:

Special Codes

00000000 No date, no first-course treatment performed
99999999 Unknown date

Coding Instructions

1. Code **00000000** if no 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

2. Code the **start date** of the first therapy. The first therapy may be coded in the following data items:
 - Surgery of Primary Site
 - Scope of Regional Lymph Node Surgery
 - Surgical Procedure of Other Site
 - Radiation Therapy
 - Chemotherapy
 - Hormone Therapy
 - Immunotherapy,
 - Hematologic Transplant and Endocrine Procedures
 - 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. 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

When an unproven therapy (e.g., laetrile) is the first-course of therapy, code the date the patient started taking that therapy (these treatments are coded in the field "Other Cancer-Directed Therapy").

Cancer-Directed Therapy

General Surgery Coding Rules

The NJSCR collects the following site specific surgery scheme:

Surgery of Primary Site	2 digits
Scope of Regional Lymph Node Surgery	1 digit
Number of Regional Lymph Nodes Examined	2 digits
Surgical Procedure of Other Site	1 digit

The surgery codes that should be used can be found in site specific chapter or the SEER Program Coding and Staging Manual 2007 or FORDS 2007. The NJSCR does not require surgical approach or margins to be coded. Surgery Codes for cases diagnosed prior to 2007 can be found at <http://seer.cancer.gov/tools/SEER2003.surg.prim.site.codes.pdf> .

- Once it is determined that cancer-directed surgery was performed, use the best information in the operative/pathology reports to determine the operative procedure. *Do NOT depend on the name of the procedure since it may be incomplete.*
- If the operative report is unclear as to what was excised or if there is a discrepancy between the operative and pathology reports, use the pathology report, unless there is reason to doubt its accuracy.
- If a surgical procedure removes the remaining portion of an organ which had been partially resected previously for any condition, code as total removal of the organ. If none of the primary organ remains, the code should indicate that this is the case.

For example:

1. Resection of a stomach which had been partially excised previously is coded as total removal of stomach.
 2. Removal of a cervical stump is coded as total removal of uterus.
 3. Lobectomy of a lung with a previous wedge resection is coded as total removal of lobe.
- Any lymph node dissection done as a separate procedure within the first-course of cancer-directed therapy is to be coded.
 - If an excisional biopsy is followed by "re-excision" or "wide excision" within the first-course of cancer-directed therapy, include that later information in coding site-specific surgery.
 - If multiple primaries are excised at the same time, code the appropriate surgery for each site.
For example: 1) If a total abdominal hysterectomy was done for a patient with two primaries, one of the cervix and one of the endometrium, code each as having had a total abdominal hysterectomy. 2) If a total colectomy was done for a patient with multiple primaries in several segments of the colon, code total colectomy for each of the primary segments.
 - Ignore the use of laser if used only for the initial incision.

- Surgical procedures performed solely for the purpose of establishing a diagnosis/stage or for the relief of symptoms, and procedures such as brushings, washings, and aspiration of cells as well as hematologic findings (peripheral blood smears) are not considered cancer therapy and are not to be coded.
- Surgery for extranodal lymphomas should be coded using the scheme for the extranodal site.
For example: a lymphoma of the stomach is to be coded using the scheme for stomach.

Radiation Therapy

Record the type and date (MMDDCCYY) of radiation administered to the primary or metastatic site. Record any type of radiation in this field regardless of source, field being treated or intent of treatment (curative or palliative). Include all procedures that are a part of the first-course of treatment, whether delivered at the reporting institution or at others.

REGIONAL TREATMENT MODALITY

Coding Instructions:

Radiation treatment modality will typically be found in the radiation oncologist's summary letter for the first-course of treatment. Segregation of treatment components into regional and boost and determination of the respective treatment modality may require assistance from the radiation oncologist to ensure consistent coding.

In the event multiple radiation therapy modalities were employed in the treatment of the patient, record only the dominant modality.

Note that in some circumstances the boost treatment may precede the regional treatment.

For purposes of this data item, photons and x-rays are equivalent. Code IMRT or conformal 3D whenever either is explicitly mentioned. For additional information regarding these codes, please see the FORDS Manual.

Code	Label
00	No radiation treatment
20	External beam, NOS
21	Orthovoltage
22	CobaltB60, CesiumB137
23	Photons (2-5 MV)
24	Photons (6-10 MV)
25	Photons (11-19 MV)
26	Photons (>19 MV)
27	Photons (mixed energies)
28	Electrons
29	Photons and electrons mixed
30	Neutrons, with or without photons/electrons
31	IMRT
32	Conformal or 3BD therapy
40	Protons

41	Stereotactic radiosurgery, NOS
42	Linac radiosurgery
43	Gamma Knife
50	Brachytherapy, NOS
51	Brachytherapy, Intracavitary, LDR
52	Brachytherapy, Intracavitary, HDR
53	Brachytherapy, Interstitial, LDR
54	Brachytherapy, Interstitial, HDR
55	Radium
60	Radioisotopes, NOS
61	StrontiumB89
62	StrontiumB90
80*	Combination modality, specified*
85*	Combination modality, NOS*

**Note:* Codes 80 and 85 should not be used to record regional radiation for cases diagnosed on or after 01/01/2003. These codes describe specific converted descriptions of radiation therapy coded according to Volume II, ROADS and DAM rules and FORDS 2007 Manual, page 156.

98	Other, NOS
99	Unknown (It is unknown whether radiation therapy was administered.)

BOOST TREATMENT MODALITY

Coding Instructions:

Radiation boost treatment modalities will typically be found in the radiation oncologist's summary letter for the first-course of treatment. Segregation of treatment components into regional and boost and determination of the respective treatment modality may require assistance from the radiation oncologist to ensure consistent coding.

In the event multiple radiation therapy boost modalities were employed in the treatment of the patient, record only the dominant modality.

Note that in some circumstances the boost treatment may precede the regional treatment.

For purposes of this data item, photons and x-rays are equivalent. For additional information regarding these codes, please see the FORDS 2007 Manual.

Code	Label
00	No radiation treatment
20	External beam, NOS
21	Orthovoltage
22	CobaltB60, CesiumB137
23	Photons (2B5 MV)
24	Photons (6B10 MV)
25	Photons (11B19 MV)
26	Photons (>19 MV)

27	Photons (mixed energies)
28	Electrons
29	Photons and electrons mixed
30	Neutrons, with or without photons/electrons
31	IMRT
32	Conformal or 3BD therapy
40	Protons
41	Stereotactic radiosurgery, NOS
42	Linac radiosurgery
43	Gamma Knife
50	Brachytherapy, NOS
51	Brachytherapy, Intracavitary, LDR
52	Brachytherapy, Intracavitary, HDR
53	Brachytherapy, Interstitial, LDR
54	Brachytherapy, Interstitial, HDR
55	Radium
60	Radioisotopes, NOS
61	StrontiumB89
62	StrontiumB90
98	Other, NOS
99	Unknown (It is unknown whether radiation therapy was administered.)

RX Summ - Radiation (For Central Registry Purposes) This will be determined by the Central Registry based on the information provided in the Regional Treatment Modality and Boost Treatment Modality fields.

Code

0	None; diagnosed at autopsy
1	Beam radiation
2	Radioactive implants
3	Radioisotopes
4	Combination of 1 with 2 or 3
5	Radiation, NOS - method or source not specified
7	Patient or patient's guardian refused radiation therapy
8	Radiation recommended, unknown if administered
9	Unknown if radiation administered

This field was previously named "Radiation."

Coding Guidelines

Record any type of radiation therapy in this field regardless of source, field being treated, or intent of treatment (curative or palliative). For cases diagnosed 1/1/1998 and after, include prophylactic radiation to the brain and/or central nervous system in this field.

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. Discussion does not equal a recommendation.
 - d. Only information available is that the patient was referred to a radiation oncologist. Referral does not equal a recommendation.
 - e. Watchful waiting (prostate)
 - f. Patient diagnosed at autopsy
2. Assign **code 1** for beam radiation directed to cancer tissue. The source of the beam radiation is not used for coding purposes. Sources may include, but are not limited to: X-ray, Cobalt, linear accelerator, neutron beam, betatron, spray radiation, stereotactic radiosurgery such as gamma knife and proton beam.
3. Assign **code 2** when the radiation is delivered by interstitial implant, molds, seeds, needles or intracavitary applicators. The radioactive material used in implants includes, but is not limited to: cesium, radium, radon, radioactive gold, and iodine.
4. Assign **code 3** when radioactive isotopes are given orally, intracavitary or by intravenous injection. Radioactive isotopes include but are not limited to: I-131 or P-32.
5. Assign **code 4** when beam radiation is given in combination with either radioactive implants or radioactive isotopes.
6. Assign **code 5** when the type of radiation, method or source is not specified.
7. If the patient has more than two radiation types, code the dominant type (the greatest dose of radiation). Determination of the respective treatment modalities may require assistance from the radiation oncologist to ensure consistent coding.
8. For cases diagnosed prior to 1/1/1998, radiation to the brain and/or central nervous system for lung and leukemia cases was coded in the field Radiation to the Brain and/or Central Nervous System.

9. Assign **code 9**

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

Radiation treatment descriptions will typically be found in the radiation oncologist's summary letter for the first-course of treatment.

Translation of Regional Treatment Modality and/or Boost Treatment Modality Field to RX Summ -Radiation

RX Summ -Radiation	Code	Regional Treatment Modality and/or Boost Treatment
0 None	00	No radiation treatment
1 Beam radiation	20	External beam, NOS
	21	Orthovoltage
	22	Cobalt-60, Cesium-137
	23	Photons (2-5 MV)
	24	Photons (6-10 MV)
	25	Photons (11-19 MV)
	26	Photons (>19 MV)
	27	Photons (mixed energies)
	28	Electrons
	29	Photons and electrons mixed
	30	Neutrons, with or without photons/electrons
	31	IMRT
	32	Conformal or 3-D therapy
	40	Protons
	41	Stereotactic radiosurgery, NOS
	42	Linac radiosurgery
	43	Gamma Knife
2 Radioactive implants	50	Brachytherapy, NOS
	51	Brachytherapy, intracavitary, LDR
	52	Brachytherapy, intracavitary, HDR
	53	Brachytherapy, interstitial, LDR
	54	Brachytherapy, interstitial, HDR
55	Radium	
3 Radioisotopes	60	Radioisotopes, NOS
	61	Strontium-89
	62	Strontium-90
4 Combination of 1 with 2 or 3	80	Combination modality, specified
	85	Combination modality, NOS
5 Radiation therapy, NOS, method or source unspecified	98	Other, NOS
9 Unknown	99	Unknown

If a code for TX Summ-Radiation is not received from hospital registrars, the code can be derived from the following sources if radiation is not received from hospital registries. The code for RX Summ—Radiation is derived from Rad-Boost RX Modality, Rad-Regional TX Modality, and/or Reason For No Radiation.

DATE SYSTEMIC THERAPY STARTED

Records the date of initiation for systemic therapy that is part of the first-course of treatment. Systemic therapy includes the administration of chemotherapy agents, hormonal agents, biological response modifiers, bone marrow transplants, stem cell harvests and surgical and/or radiation endocrine therapy. This data field should include dates for agents that have been administered locally such as those given intravesical or intrathecal therapy, such as BCG instilled into the bladder.

Record the first or earliest date on which systemic therapy was administered. Systemic therapy includes Chemotherapy, Hormonal Therapy, Immunotherapy, Hematologic Transplant and Endocrine Procedures.

Code 88888888 if systemic therapy was planned, but not started at the time of the most recent follow-up. The date should be revised at the next follow-up. The updated abstract should then be printed with the correction highlighted then mailed to the NJSCR.

Code	Definition
MMDDCCYY	The date systemic therapy started is the month, day, and year that systemic therapy was first administered. The first two digits are the month, the third and fourth digits are the day, and the last four digits are the year. If the exact date on which systemic therapy was started is not available, then record an approximate date.
00000000	When no systemic therapy is administered. Diagnosed at autopsy.
88888888	When systemic therapy is planned as part of the first-course of therapy, but had not been started at the time of the most recent follow-up. The date should be revised at the next follow-up.
99999999	When it is unknown if any systemic therapy was administered, the date is unknown, or the case was identified by death-certificate only.

CHEMOTHERAPY

The data item Chemotherapy records the chemotherapy given as a part of the first-course of treatment or the reason that chemotherapy was not given. See SEER*Rx <http://seer.cancer.gov/tools/seerrx/> for chemotherapy drug codes for cases diagnosed 1/1/2005 and after.

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

Codes

- 00 None, chemotherapy was not part of the planned first-course of therapy; diagnosed at autopsy
- 01 Chemotherapy administered as first-course therapy, but the type and number of agents is not documented in the patient's record.
- 02 Single agent chemotherapy administered as first-course therapy.
- 03 Multiagent chemotherapy administered as first-course therapy.
- 82 Chemotherapy was not recommended/administered because it was contraindicated due to patient's risk factors (comorbid conditions, advanced age, etc.).
- 85 Chemotherapy was not administered because the patient died prior to planned or recommended therapy.
- 86 Chemotherapy was not administered. It was recommended by the patient's physician, but was not administered as part of the first-course of therapy. No reason was stated in patient's record.
- 87 Chemotherapy was not administered. It was recommended by the patient's physician, but the treatment was refused by the patient, a patient's family member, or the patient's guardian. The refusal was noted in the patient's record.
- 88 Chemotherapy was recommended, but it is unknown if it was administered.
- 99 It is unknown whether a chemotherapeutic agent(s) was recommended or administered because it is not stated in the patient's record. Death certificate only.

Definitions

Chemotherapy recommended: There was a consult recommending chemotherapy or the attending physician documented that chemotherapy was recommended. ***A referral to a clinical oncologist does not equal a recommendation.***

Multiple agent chemotherapy: Two or more chemotherapeutic agents were administered to destroy cancer tissue during the first-course of therapy. The chemotherapeutic agents may or may not have been administered with other drugs classified as immunotherapy, hormone therapy, ancillary or other treatment.

Single agent chemotherapy: Only one chemotherapeutic agent was administered to destroy cancer tissue during the first-course of therapy. The chemotherapeutic agent may or may not have been administered with other drugs classified as immunotherapy, hormone therapy,

ancillary, or other treatment.

Hormone Therapy

The data item Hormone Therapy records therapy administered as first-course treatment that affects cancer tissue by changing the patient's hormone balance. See SEER*Rx www.seer.cancer.gov/tools/seerrx for hormone therapy drug codes for cases diagnosed 1/1/2005 and after.

Hormones may be divided into three categories:

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

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 not coded in this data item. Code these procedures in the data field Hematologic Transplant and Endocrine Procedures.

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.

Code the hormonal agent given as part of combination chemotherapy, e.g., CHOP (Cyclophosphamide, Adriamycin, Oncovin, Prednisone) or M-BACOD (Methotrexate, Bleomycin, Adriamycin, Cyclophosphamide, Oncovin, Dexamethasone) whether it affects the cancer cells or not.

Special Note about Hormonal Therapy Coding:

Some drugs are used as hormonal treatments in cancer; however, they have other properties as well. **Do not code** these drugs if they are given for reasons other than cancer-directed treatment. Some examples:

- Megace may be given as a hormonal therapy for patients with breast or endometrial primaries; however, it is also used for the treatment of anorexia, cachexia, and significant weight loss in patients with acquired immunodeficiency syndrome.

- Dexamethasone (Decadron) has a multitude of uses, including use as an antiemetic during chemotherapy.

For cases diagnosed prior to 01/01/2003, endocrine surgery or radiation is to be coded in this field for breast and prostate only.

Breast:
oophorectomy
adrenalectomy
hypophysectomy

Prostate:
orchiectomy
adrenalectomy
hypophysectomy

Immunotherapy (Biological Response Modifier Therapy)

The data item Immunotherapy records immunotherapeutic (biological therapy, biotherapy or biological response modifier) agents administered as first-course of therapy. See SEER*RX for immunotherapy codes.

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** cancer cells' **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.

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 as 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.

Monoclonal Antibodies: Monoclonal antibodies are produced in a laboratory. The artificial antibodies are used in a variety of ways in systemic therapy. Some are injected into the patient to seek out and disrupt cancer cell activities, such as rituximab (Rituxan) for lymphoma and trastuzumab (Herceptin) for breast. **When the monoclonal antibody disrupts tumor growth, it is coded as chemotherapy.**

Other Mabs are linked to radioisotopes (conjugated monoclonal antibodies). The Mab finds and attaches to the target tumor cells and brings with it the radioisotope that actually kills the tumor cell. The monoclonal antibody itself does nothing to enhance the immune system. **Conjugated monoclonal antibodies such as tositumomab (Bexxar) or ibritumomab (Zevalin) are coded to the part of the drug that actually kills the cells, usually radioisotopes.**

A third function of Mabs is to enhance the immune response against the cancer, either by identifying tumor cells that are mimicking normal cells, or by boosting the body's natural defenses that destroy foreign cells. At the present time (2006), there are no FDA-approved monoclonal antibodies that are pure immunotherapy for cancer. **Consult SEER*Rx for the treatment category in which each monoclonal antibody should be coded.**

Special Notes about Immunotherapy (Biological Response Modifiers):

Drugs such as Neulasta (a growth factor) and Procrit (stimulates red blood cell production) are ancillary agents. **Do not code these drugs as immunotherapy agents.** If unsure, please consult SEER*Rx for the correct treatment category.

Other Therapy

Other Therapy identifies other treatment given that cannot be classified as surgery, radiation, systemic therapy, or ancillary treatment.

Codes

- 0 None
- 1 Other
- 2 Other-Experimental
- 3 Other-Double Blind
- 6 Other-Unproven
- 7 Refusal
- 8 Recommended, unknown if administered
- 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. Discussion does not equal a recommendation.
 - d. Only information available is that the patient was referred for consideration of other therapy. Referral does not equal a recommendation.
 - e. Patient diagnosed at autopsy
2. Assign **code 1**
 - a. Hematopoietic treatments such as: phlebotomy, transfusions, or aspirin
 - b. Patient had cancer treatment that could not be assigned to the previous treatment fields (surgery, radiation, chemotherapy, immunotherapy, or systemic therapy)
3. Assign **Code 2** for 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 an experimental treatment.
4. Assign **code 3** when the patient is enrolled in a double blind clinical **trial**. When the trial is complete and the code is broken, review and recode the therapy.
5. Assign **code 6** for **unconventional** methods whether they are the single therapy or given in combination with conventional therapy.
6. Assign **code 8** when other 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 other therapy was recommended or performed
 - b. Death certificate only.

The following explanations and definitions are quoted from the website for the National Center for Complimentary and Alternative Medicine (NCCAM). 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/whatiscom/>

Unconventional Methods

Cancel
Carnivora
Glyoxylide
Iscador
Koch synthetic antitoxins
Krebiozen
Laetrile
Malonide
Parabenzoquinone

Reference: NCI CancerNet articles on unconventional methods

Alternative and Complementary Therapies

Alternative Systems
Acupuncture
Ayurveda
Environmental medicine
Homeopathic medicine
Natural Products
Native American, Latin American, or traditional Oriental medicine

Bioelectromagnetic Applications
Blue light treatment
Electroacupuncture
Magnetoresonance spectroscopy

Diet, Nutrition, Lifestyle
Changes in lifestyle
Diet
Gerson Therapy
Macrobiotics
Megavitamins
Nutritional Supplements

Herbal Medicine
Ginger
Ginkgo Biloba extract
Ginseng root

Manual Healing
Acupressure
Biofield Therapeutics
Massage therapy
Relexology
Zone therapy

Mind/Body Control
Biofeedback
Humor therapy
Meditation
Relaxation techniques
Yoga

Pharmacological and Biological Treatments
Anti-oxidizing agents

Cell treatment
Metabolic therapy
Oxidizing agents

Reference: National Institutes of Health Office of Alternative Medicine

Date of Last Follow-up or Death

The date of last follow-up or death consists of eight digits recorded in the month, day, century, year format (MMDDCCYY) with 99 for unknown day or month and 9999 for unknown year. This data item records the date of last follow up or the date of death.

NJSCR is required by SEER to update the follow up information on all cases on an annual basis. The exception is carcinoma in situ of the cervix diagnosed on or after 1/1/1996. Follow-up is a very important aspect of the NJSCR reporting system. Follow-up is the annual monitoring of patients throughout their life to ascertain and calculate survival rates. Hospital programs approved by ACoS must also update follow-up data annually. Information on vital status can be obtained from the medical records (patient may be readmitted), the patient's physician, contact letters, and telephone calls. The NJSCR obtains follow up information from passive sources using a case matching software. However, hospitals will be contacted for follow up information for special populations such as pediatric cases and as needed for specific studies. This contact will be initiated by a phone call usually followed by a faxed list of cases that had been reported by that facility.

If a second/multiple primary is diagnosed, a separate abstract must be submitted electronically for the new primary.

Coding instructions

1. Code the date the patient was actually seen by the physician or contacted by the hospital registry as the follow up date. Do not code the date the follow up report was received.
2. Do not change the follow up date unless new information is available.
3. The field is associated with the patient, not the cancer, so all records (primary sites) for the same patient will have the same follow up date.

Follow-up Source

Identifies the source of the latest follow-up information.

- 0 Reported hospitalization
- 1 Readmission
- 2 Physician
- 3 Patient
- 4 Department of Motor Vehicles
- 5 Medicare/Medicaid file
- 7 Death certificate
- 8 Other
- 9 Unknown

Patient's Vital Status

Record the patient's vital status as of the date recorded in the "Date of Last Contact or Death" field. Use the most accurate information available.

- 1 Alive
- 0 Dead

Underlying Cause of Death

Record the cause of death listed on the death certificate by recording the underlying cause of death ICD code. This is the official underlying cause of death coded from the death certificate using ICD-10 for all deaths beginning the year of 1999. For prior years use the respective versions of ICD-7, ICDA-8, or ICD-9 codes based on year of death.

Beginning for deaths in 1999, the United States agreed to code all deaths using the *International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10). The ICD-10 codes have up to four characters: a letter followed by 2 or 3 digits.

Special Codes

0000	Patient alive at last follow-up
7777	State death certificate or listing not available
7797	State death certificate or listing available, but underlying cause of death not coded

Coding Instructions for ICD-10

1. Use the underlying cause of death as coded by a State Health Department even if the code seems to be in error.
2. Report the coded underlying cause of death code from another source such as NDI plus or state data exchange if the coded death certificate is not available.
3. If the coded underlying cause of death code is not on the death certificate and is not available from other sources, code 7797.
4. If neither the death certificate nor the coded underlying cause of death is available, code 7777.

Example: Medical doctor states patient died, but death certificate not available (not on state death file, not available through federal or state agencies), code 7777.

5. Ignore (do not record) decimal points when copying codes.
6. The cause of death code is commonly four characters. Ignore (do not code) a fifth character if present.

7. Left justify the codes; if less than four characters, left justify and add a 9 to the right.
8. If the underlying cause of death code is not available, do not attempt to code the underlying cause of death unless you have a trained ICD-10 nosologist on staff or on consult.

The ICD-10 codes consist of four characters- a letter followed by two or three digits.

Examples:

UNDERLYING CAUSE OF DEATH	ICD-10	CODE
Cancer of the thyroid	C73	C739
Adenocarcinoma of stomach	C16.9	C169

Death Certificate-Only Cases

Death certificate-only cases contain information which was derived from a death certificate that was reported to the New Jersey Bureau of Vital Statistics with a cancer diagnosis. On a periodic basis the NJSCR electronically matches death certificates with a cancer diagnosis to its files to update vital status. This also serves as another source of case finding. Cases that are not linked to existing cases are termed as "death certificate-only" cases. "Death certificate-only" cases may include but not be limited to: malignancies diagnosed prior to a hospital registry date, prior to the NJSCR reference date October 1978, patients dead on arrival in the Emergency Department, or to patients who were erroneously coded as having a malignancy. On occasion, a patient may be on the "death certificate-only" list that has already been reported to the NJSCR but was not properly linked during the electronic matching process. Periodically, hospitals will be sent a listing of patients who have been identified as "death certificate-only" cases. Every effort should be made to locate information on these patients. Once the case is identified, it should be abstracted and then submitted electronically to the NJSCR.