Cancer Registry Abstracting

Florida Cancer Data System

A Joint Project of the Sylvester Comprehensive Cancer Center and the Florida Department of Health

UNIVERSITY OF MIAMI HEALTH SYSTEM

NATIONAL PROGRAM OF CANCER REGISTRIES
Learning Objectives

Integrate previously learned principles of cancer identification (anatomy, casefinding, site and histology identification principles, staging principles, and treatment methods) in order to accurately capture required cancer registry data from individual cancer cases.

Identify sources of standard cancer registry field definitions and coding instructions.

Interpret and apply the standard field definitions and coding instructions of the FCDS Data Acquisition Manual.
The Abstract

The abstract is usually created via cancer registry software programs, but may also be created as a paper document for later entry into a computer database.

Most of the data on an abstract are numerically coded to allow efficient analysis of data for production of cancer incidence, morbidity and mortality rates.
What is abstracting?

- Selecting relevant items of information from the records
- Recording the selected information in a standardized format in compliance with standard data collection rules
- Reviewing patient health records
Abstracting requires the integration of everything you know about cancer and cancer data management:

All come together to provide the foundation for abstracting.
In abstracting, you first apply previously learned rules for analyzing a cancer case (reportability, site and histology, staging, and treatment methods), and then apply more rules for coding the selected information.
What information does the abstract contain?

<table>
<thead>
<tr>
<th>Registry Information</th>
<th>• What facility is submitting the abstract?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Demographics</td>
<td>• Who is the patient?</td>
</tr>
<tr>
<td>Tumor Information</td>
<td>• What is the anatomic site, histologic type and extent (stage) of the cancer at the time of diagnosis?</td>
</tr>
<tr>
<td>First Course of Treatment</td>
<td>• What modalities were used to treat the cancer?</td>
</tr>
<tr>
<td>Follow-up</td>
<td>• What happens to the patient following treatment?</td>
</tr>
</tbody>
</table>
The abstract captures a “snapshot” of a single primary tumor at the time of initial diagnosis and provides a means to monitor the status of the tumor throughout the patient’s life.

Every abstract is the story of a cancer written in five “Chapters.”
Rule Makers for Cancer Data Collection

NPCR/NAACCR/FCDS
- Central Registries
- Data Acquisition Manual

ACoS Commission on Cancer
- CoC approved hospital registries
- FORDS

SEER
- SEER Registries
- SEER Program Manual
The cancer dataset (data items on the abstract) and the rules for collecting data in each field are determined by national, state and local users of the data.

Central State registries, like the FCDS, must comply with the rules and definitions specified by NPCR/NAACCR.

The FCDS Data Acquisition Manual includes the NAACCR standards for data collection and provides detailed instructions for uniform collection of cancer data that is to be submitted to the FCDS.

Accredited hospital cancer registries are required to follow the rules and definitions of the American College of Surgeons’ Commission on Cancer as described in the FORDS manual.
SEER registries must follow the rules and definitions as described in the SEER Program Manual.

Although these organizations have cooperated in promoting standardized definitions of data items and rules for data collection, there are some variations among the organizations in terms of scope of the data items collected and in the specific instructions for data collection.

Abstractors should know which set of abstracting standards and rules are followed by the reporting facility to ensure that data will be abstracted consistently within the facility.
Timing of Abstracting

FCDS rule: Abstracts to be completed within six months of first contact with the reporting facility.
Although cancer cases can be identified shortly after diagnosis or even in real time with electronic pathology reporting, the first course of treatment may extend several months following the date of diagnosis.
Abstracting cases too close to the date of diagnosis may result in incomplete reporting of treatment.

Delaying abstracting beyond six months from diagnosis will result in noncompliance with the standard and impact the availability of timely data to funding organizations and researchers who use the data.

A reasonable compromise is to allow enough time following the date of diagnosis to allow at least the development of treatment plans.

This means allowing enough time for a definitive surgical procedure, completion of staging workup, and the opportunity for the patient to be evaluated by medical oncology and/or radiation oncology.
Preparation for abstracting

1. Learn the data set
2. Learn the general content and format of patient health records
3. Assemble necessary manuals and references
4. Know the disease
1. Learn the data set.

Know what to look for as you review the health record.

Organize a search plan.

If you know in advance what data items need to be collected, a single reading of the health record will yield most of the required information, eliminating the need to re-read the record over and over.

This module provides an organized overview of all data items in the FCDS dataset with particular focus on some critical data items.
2. Learn the general content and format of patient health records.

<table>
<thead>
<tr>
<th>Information Needed</th>
<th>Where to find it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographics</td>
<td>Face Sheet, patient registration forms</td>
</tr>
<tr>
<td>Site/Histology/Behavior</td>
<td>Pathology report</td>
</tr>
<tr>
<td>Extent of Disease</td>
<td>History and physical exams, pathology reports, operative reports, imaging reports (CT, MRI, X-ray, nuclear scans), endoscopy reports</td>
</tr>
<tr>
<td>Tumor Markers</td>
<td>Laboratory reports, pathology reports</td>
</tr>
<tr>
<td>Treatment Plan</td>
<td>Consultation reports (surgical, radiation, or medical oncology), physician progress notes, discharge summary</td>
</tr>
<tr>
<td>Treatment</td>
<td>Operative reports, radiation therapy summaries, nuclear medicine reports, chemotherapy flow sheets or medication records, medical oncology consults or notes, discharge summaries</td>
</tr>
</tbody>
</table>
Know which sections and specific documents in the health record are likely to contain the information required on the abstract.

Individual health records can be very long and complex, with paper records sometimes taking up multiple volumes.

The challenges for abstractors are to know what you’re looking for and to develop an efficient approach to screening the health records for the pertinent information.

Many facilities use an electronic medical record (EMR).

Electronic patient records typically include “tabs” for Patient Demographics, Insurance/Financial, Admissions/Encounters, Lab and Pathology, Radiology/Imaging, Medications, and Patient Care Notes (includes physician’s dictated reports such as the history and physical exam, consultations and discharge summary, and/or multidisciplinary patient care notes).
Abstracting Tip:

Beginning abstractors usually find it helpful to take notes while reviewing the record.

By keeping track of pertinent information as it is encountered during record review, the “story” of the tumor begins to take shape in the abstractor’s mind, guiding the search for missing pieces of information.
3. Assemble necessary manuals and references.

“MUST HAVE” References

- FCDS Data Acquisition Manual – Section II, General Abstracting instructions and Appendices: A, B, C, D, E, F,
- International Classification of Diseases for Oncology, Third Edition (ICD-O-3), 2000. (for cases diagnosed on or after 1/1/2001)
- SEER 2007 Multiple Primary and Multiple Histology Rules
- FCDS Reportable List
The FCDS Data Acquisition Manual is the “go to” resource for information and coding instructions for cases submitted to FCDS.

The most current editions of all of these coding manuals and references must be available either in paper form or as electronic references.
WARNING #1

Rules for data collection are periodically revised to reflect new understanding of the disease or to clarify existing coding rules.

Abstractors must be aware of the official implementation dates of all coding references and apply the appropriate coding rules for each case.

Data collected under different rules is different data, i.e. not comparable.

When analyzing data over long periods of time, researchers must take into consideration the fact that the data may have been collected under more than one set of time-specific rules.

Contact FCDS for a summary of “effective dates” for coding references.
Most cancer registry software programs provide “drop down” menus that provide a list of available codes for use in each field.

While these menus help with efficient selection of codes for experienced abstractors, they do not include the complete instructions for use of the individual codes displayed.

Consider the drop down menus to be “helpers”, not the coding manual for field instructions.

A good abstractor relies on the complete coding instructions available in the abstracting manuals to select the correct codes.
4. Know the disease.

Prepare for each new site by reviewing:

- Specific anatomy of the site (helps in determining extent of disease)
- Diagnostic and staging procedures used in the site (imaging, endoscopy, biopsy)
- How the extent of disease is measured (depth of invasion vs. tumor size vs. direct extension, etc.)
- Usual sites of metastasis
- Typical treatment plans for various stages of disease
Review site specific reference material in preparation for abstracting in each primary site.

Cancers in different primary sites are essentially different diseases, with different diagnostic and staging procedures and different combinations of treatment modalities.

The time spent familiarizing yourself with the anatomic site and natural history of malignancy in the site will be more than compensated for by increased efficiency and accuracy of abstracting.

Inexperienced abstractors should focus on abstracting cases from one primary site at a time.
Get comfortable with the site/histology coding, diagnostic procedures and staging requirements, and the typical treatment plans for each site before moving on to another site. (Suggestion: a minimum of 20 cases per site).

The site-specific training modules at the SEER training website are good preparation for abstracting unfamiliar primary sites.

Create your own site specific reference system.

Maintain individual site specific folders to organize additional articles or references that you will accumulate as you continue to expand your abstracting skills.
Registry Information identifies the reporting facility, the case, and the abstracter.

These data items establish responsibility for the abstract and provide the means to locate the source documents at a later date for verification of abstracted data.

• *Asterisked items are FCDS-specific fields (non-standard data items). The source of coding instructions for these fields can be found ONLY in the FCDS Data Acquisition Manual.
1. FCDS Facility Number*

A 2 digit county code followed by the 2 digit facility designation. (See FCDS Data Acquisition Manual – Appendix A).

Each facility must report cases under its unique FCDS Facility Number, regardless of how many other facilities may be involved in the patient’s care.
2. Accession Number

Unique 9 digit number assigned to the patient (not to the tumor).

Represents the year of the patient’s first contact with the reporting facility for diagnosis or treatment of a reportable tumor + the numeric order (00001) in which the case is abstracted.

Example: 200900486 - The 486th tumor to be entered in the registry in 2009.

There is only one accession number per patient per facility per patient lifetime.
If a patient has multiple primaries diagnosed simultaneously or if the patient later presents with subsequent primary cancers, the original accession number is used for all primaries.

Accession numbers are never re-used. If for some reason, an accessioned case is later determined to be non-reportable and is deleted from the database, its accession number must not be re-used.

Many cancer registry software programs automatically assign the Accession number.

Multiple primaries under one accession number are distinguished from one another by the sequence number given to each primary. (See example on next slide.)
### Accession Number for multiple primaries on patient John Jones

<table>
<thead>
<tr>
<th>Accession Number</th>
<th>Seq</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>200312069</td>
<td>01</td>
<td>Adenocarcinoma of the colon diagnosed in 2003.</td>
</tr>
<tr>
<td>200312069</td>
<td>02</td>
<td>Papillary thyroid cancer diagnosed in 2008.</td>
</tr>
<tr>
<td>200312069</td>
<td>03</td>
<td>Chronic lymphocytic leukemia diagnosed in 2009.</td>
</tr>
</tbody>
</table>
## 3. Sequence Number

<table>
<thead>
<tr>
<th>Sequence of Primary – Malignant tumors</th>
<th></th>
<th>Sequence of Primary – Benign and Borderline tumors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>00</strong></td>
<td>One Malignant Primary Only</td>
<td><strong>60</strong></td>
</tr>
<tr>
<td><strong>01</strong></td>
<td>First of two or more malignant primaries</td>
<td><strong>61</strong></td>
</tr>
<tr>
<td><strong>02</strong></td>
<td>Second of two or more malignant primaries</td>
<td><strong>62</strong></td>
</tr>
<tr>
<td><strong>03</strong></td>
<td>Third of three or more malignant primaries</td>
<td></td>
</tr>
</tbody>
</table>
Sequence Number identifies the chronologic order of reportable tumors over the entire life of the patient, regardless of where the tumors were diagnosed or treated.

Sequence numbers reflect the patient’s cancer history (not the facility’s experience with the patient).

Sequence numbers for malignant tumors range from 00 to 35.
Sequence 00 indicates that this is the only reportable primary tumor for this patient.

If the patient ever presents with a second reportable primary tumor, the sequence number 00 is changed to 01 indicating that the original tumor is now the first of multiple tumors.

The new tumor is given sequence number 02.
Benign and borderline tumors of brain and CNS (behavior codes /0 and /1) are sequenced separately from malignant tumors.

Sequence numbers for benign and borderline tumors range from 60 to 88.

A patient’s first benign or borderline tumor is sequenced 60 and subsequent benign/borderline tumors are sequenced 61, 62, etc.

If multiple primaries are diagnosed simultaneously, assign the first sequence number (01) to the cancer with the worst prognosis.
If multiple benign/borderline tumors are diagnosed simultaneously, assign the lowest sequence number (60) to the tumor with the worst prognosis.

Re-evaluate all sequence numbers whenever a new primary is added for a patient.

Note: Be sure to use the Multiple Primaries/Multiple Histologies rules to correctly determine the number of solid tumor primaries for each patient diagnosed after 1/1/2007.

Use the SEER table, “Definitions of Single and Subsequent Primaries for Hematologic Malignancies” to determine the correct number of primaries among multiple hematopoietic malignancies, regardless of the diagnosis date.
4. Date of Admission/First Contact

Year, month and date the patient first came in contact with the reporting facility for diagnosis or treatment of this primary tumor.

Dates of admission are located on the medical record face sheets or patient registration forms.

The intervals between the Date First Contact and the date of diagnosis, date of first course of treatment, or specific treatment dates may be used by hospitals as quality of care indicators.

FCDS issues an error if the interval between the Date of First Contact and the Date of Diagnosis is greater than 30 days.
5. Medical Record Number

The facility’s medical record number (MRN) is the key to relocating the record in the future. Be sure it is entered correctly.

The MRN is found on the face sheet or on patient registration forms.

Justify the field; use leading zeros if necessary to make an 11 digit number.

Special characters (e.g. -, /, #) are not allowed.

Freestanding treatment centers may not use medical record numbers to identify patient records, but may simply file records alphabetically.

When patients are not assigned a medical record number, use any facility-assigned identification number.
6. Date Case Completed/Date Abstracted

Date the case is abstracted.

Cannot be entered as Unknown.

Date abstracted and date of first contact can be used to measure compliance with the 6 month timing standard.
Unique abstractor code assigned by the FCDS.

Must be updated annually by resubmitting the Cancer Abstractor Code Request form to FCDS.
7. Type of Reporting Source

Codes that identify the type of facility that is reporting the case.

The type of reporting facility suggests the potential completeness of the data being submitted from that source and/or the need to seek additional information from other sources.

- Hospital Inpatient; managed health plans with comprehensive, unified medical records
- Radiation Therapy or Medical Oncology Centers (hospital-affiliated or independent)
- Laboratory only (hospital-affiliated or independent)
- Physician’s Office/Private Medical Practitioner (LMD)
- Nursing/Convalescent Home/Hospice
- Autopsy Only
- Death Certificate Only (DCO) - FCDS Use Only
- Other hospital outpatient units/surgery centers

Refer to the FCDS Data Acquisition Manual, page 64-65, for important definitions of terms and a hierarchy of codes when abstracting from multiple sources.
## Patient Demographics

<table>
<thead>
<tr>
<th>Patient Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key identifiers (Sex, DOB, SSN, Race/ethnicity)</td>
</tr>
<tr>
<td>Address at time of diagnosis</td>
</tr>
<tr>
<td>Current address</td>
</tr>
</tbody>
</table>
The data items in Patient Demographics identify the individual *patient*, not the disease. (Name, gender, SSN, DOB, postal code, etc).

Analysis of demographics can illustrate variations in cancer incidence by geographic location and by racial/ethnic populations.

Accurate demographic information is essential for accurate record linkage.

Most Patient Demographic information can be found on the medical record’s face sheet or on patient registration forms.

There are several FCDS-specific fields in the Demographics section.
1. Patient Name –
Last, First, Middle, Maiden, Alias

Truncate names that are longer than the number of characters allowed in the field.

No spaces, hyphens or special characters in any name fields.

- Example:
  - Smith-Carlson = SmithCarlson
  - Mc Donald = McDonald
  - O’Dell = Odell
  - First name of Mary Jo = MaryJo

Maiden names are helpful for record linkage.

Record Maiden Name if given.
2. Key Identifiers - Social Security Number

Use 999999999 for unknown SSN.

SSN and the patient’s Medicare number are the same.

If SSN is not documented, the SSN may be determined from the patient’s Medicare number.

Patient Medicare numbers with the suffix “A” indicate that the Medicare number belongs to the patient, therefore the Medicare Number is the patient’s social security number.

Suffixes of B or D indicate that the number belongs to someone other than the patient (e.g. spouse) and therefore should not be used as the patient’s SSN.
## Birth Date

Registry software uses Birth date and the Date of Diagnosis to automatically calculate the patient’s age at time of diagnosis.

**DOB cannot be left blank.**

**DOB cannot be 999999999.**

If DOB is not documented, estimate the year of birth and use 99 as the month and day of birth if necessary.
# Birthplace Geocode

Use FCDS Data Acquisition Manual Appendix B to look up geocodes.

Use 999 (unknown) if necessary, but use specific codes whenever possible.

For USA residents, use specific state codes rather than 000 (USA) whenever possible.
Be alert for genders other than M and F.
Marital Status may be different for each of multiple primaries.

If younger than 15, assume single.
Race Code

- 01 White
- 02 Black
- 03 American Indian, Aleutian, Alaskan Native or Eskimo (includes all indigenous populations of the Western hemisphere)
- 04 Chinese
- 05 Japanese
- 06 Filipino
- 07 Hawaiian
- 08 Korean
- 09 Asian Indian, Pakistani
- 10 Vietnamese
- 11 Laotian
- 12 Hmong
- 13 Kampuchean
- 14 Thai
- 20 MicronesIan, NOS
- 21 Chamorran
- 22 Guamanian, NOS
- 25 Polynesian, NOS
- 26 Tahitian
- 27 Samoan
- 28 Tongan
- 30 Melanesian, NOS
- 31 Fiji Islanders
- 32 New Guinean
- 96 Other Asian, including Asian, NOS and Oriental, NOS
- 97 Pacific Islander, NOS
- 98 Other
- 99 Unknown
Up to 5 distinct race codes may be recorded for mixed race patients.

If the patient’s race is any combination of Caucasian and other race, code the other race as RACE 1, Caucasian as RACE 2.

Any combination of Hawaiian and other races, code RACE 1 as Hawaiian. (A Hawaiian address does not equate to Hawaiian race).
When race is not stated, but there is other descriptive information in the medical record, refer to FCDS Data Acquisition Manual Appendix D – Race and Nationality Descriptions from the 2000 Census and the Bureau of Vital Statistics.

- Example: French-Croatian patient. Both French and Croatian are nationalities that are presumed white and race should be coded as 01.

Do not code race from name alone.

Spanish/Hispanic origin may be of any race. See further specific instructions in FCDS Data Acquisition Manual Section II, Supplement C, “Race Coding Instructions.”
Spanish/Hispanic Origin

**Code Definition**

- **0** Non-Spanish; non-Hispanic (including Portuguese and Brazilian)
- **1** Mexican (includes Chicano)
- **2** Puerto Rican
- **3** Cuban
- **4** South or Central American (except Brazil)
- **5** Other specified Spanish/Hispanic origin (includes European; excludes Dominican Republic)
- **6** Spanish, NOS; Hispanic, NOS; Latino, NOS (There is evidence other than surname or maiden name that the person is Hispanic, but he/she cannot be assigned to any category of 1-5.)
- **7** Spanish surname only (The only evidence of the person’s Hispanic origin is surname or maiden name and there is no contrary evidence that the person is not Hispanic.)
- **8** Dominican Republic
- **9** Unknown whether Spanish or not
Spanish/Hispanic Origin

Hispanic populations have different patterns of occurrence of cancer from other populations that are included in the White (01) category of Race.

Accurate reporting of ethnicity is important for calculating accurate rates of cancer incidence for Hispanic populations.


If Hispanic ethnicity is not stated in the medical record, and the patient’s last name is not on the list of Spanish names in Appendix E, code as Non-Hispanic.
Assume the following patients are newly diagnosed and/or receiving first course treatment at your facility.

Provide the appropriate Race codes and Spanish Origin for each.
3. Address at Diagnosis

Establishes reportability of the case.

Used in epidemiologic research.

May be different for each of multiple primary tumors.

Must not be changed, even if the patient changes residences.

Not necessarily the same as current address.
Cancer cases in non-Florida residents are not reportable to the FCDS.

A patient’s residence at time of diagnosis may be different for each of multiple primary tumors.

The address at diagnosis is used in epidemiologic research.

The Address at DX should not be changed, even if the patient changes residences.

A second set of address fields is provided elsewhere on the abstract to record the patient’s current address for potential follow-up contact.
For analytic cases (diagnosis and/or First Course of Treatment given at the reporting facility), the address at diagnosis is likely to be the same as the patient’s current address.

For non-analytic cases (the patient was diagnosed and treated elsewhere prior to being treated at the reporting facility), the address at diagnosis may not be the same as the patient’s current address.

Do not assume that the address on the face sheet of the current admission is the address at diagnosis.

Review the medical record for clues to the patient’s address at the time the patient was diagnosed.

Review complete residency guidelines in FCDS Data Acquisition Manual for special residency issues like homelessness, multiple residences, and military personnel.
Address at Dx – Number & Street

- Includes apartment number.
- Enter “Unknown” for unknown street address.
- “RR” and “PO Box” are acceptable only if no street address is given.

Address at Dx – Supplemental

- Provides a place to record the name of a place, not an address.
- For example: “Diamond Willow Care Center”
- Also may be used as a text field to indicate homeless, transient or foreign resident.

Address at Dx – City

- Do not use abbreviations.
- Enter “Unknown” for unknown city.
FCDS Addr at DX – State

- FCDS – Specific field. Instructions for FCDS – Specific fields must be obtained from the FCDS Data Acquisition Manual ONLY.
- Because of large numbers of out-of-country referrals to Florida facilities, FCDS uses the 3 digit SEER geocode instead of the 2 character alphabetic state abbreviations (See DAM Appendix B). (If your software vendor allows only entry of the 2 character state abbreviation, the abbreviations must be converted to geocodes at the time cases are exported to FCDS).
- Florida’s geocode is 035.
Address at DX – Postal Code

- Zip codes are an important epidemiologic and administrative tool for analyzing patterns of cancer incidence and assessing the need for cancer services within specific geographic areas.
- 5 digit zip code or 9 digit zip code.
- Use 999999999 for Canadian residents.
- Use 888888888 for non-USA residents.
- Use the US Postal Service website, [www.usps.com](http://www.usps.com), to find missing zip codes. Enter 999999999 for unknown zip code if necessary.
FCDS Addr at DX – County

• FCDS - Specific field. Instructions for FCDS – Specific fields must be obtained from the FCDS Data Acquisition Manual ONLY.
• 2 digit FCDS County Code (See DAM Appendix B).
• FCDS County Codes are NOT the same as FIPS codes.
4. Current Address Fields

The Current Address = the patient’s last known address.

Revised each time the patient changes residences.
Includes FCDS-Specific fields for Current State and County Current. Instructions for FCDS – Specific fields must be obtained from the FCDS Data Acquisition Manual ONLY.

The Current Address is maintained so that the patient can be contacted if necessary.

The Census Bureau definition of residence is “the place where he or she lives and sleeps most of the time or the place the person considers to be his or her usual home.”

The rules for data entry in the Current Address fields are the same as for the Address at Diagnosis fields, i.e. use of abbreviations, codes for unknown address elements, use of geocodes, etc.
Enter the patient’s current telephone number with area code.
FCDS – Primary Payer - DX

FCDS – Specific field. Instructions for FCDS – Specific fields must be obtained from the FCDS Data Acquisition Manual ONLY.

Record the primary medical insurance provider or method of payment at the time of diagnosis.

If multiple payers are listed in the medical record, record the first listed as the primary payer.

Be alert for combination codes for Medicare and state funded programs in combination with other methods of payment, e.g. Medicare + supplemental insurance.
The managing physician is the physician coordinator of the patient’s care at the reporting facility.

Often the managing physician is the medical oncologist who determines the need for adjuvant therapy and establishes a plan for long term surveillance.

The managing physician may be contacted for additional information if the hospital medical record does not provide enough information to complete the abstract.
If the patient is treated at multiple facilities, each facility reports its own managing physician.

Use the facility-assigned physician code to identify the managing physician.

Use leading zeros to fill the field.

If the physician is no longer on staff, enter the FCDS facility number or enter the physician’s last name.
Use brief text to describe the type of work the patient has done most of his/her life.

This information may indicate potential exposure to environmental health hazards known or suspected to increase the risk of cancer.

- Examples: Plumber, accountant, housewife/househusband, data entry, nurse, mechanic, clergy, laborer.

Don’t use “Retired” – it adds nothing.

If no information is available, type “Unknown.”
Broader in scope than “occupation”, Usual Industry describes the environment in which the work was performed.

- For example: Education, manufacturing, tourism, mining, forestry, health care.

If the industry is not known or documented, but the patient’s employer is listed in the medical record, record the name of the employer in this field.
FCDS – Tobacco Use

FCDS – Specific field.

Be aware: FCDS codes are different from CoC codes.

As in all FCDS-specific fields, the FCDS Data Acquisition Manual is the ONLY source of coding instructions for the field.

Record the patient’s average tobacco use at the time of first contact with the reporting facility.
# Tumor Information

## Administrative Items
- Class of case
- Diagnostic Confirmation
- Date and place of diagnosis

## Clinical Items
- Primary Site and Histology
- Collaborative Stage elements
- Text – Dx Procedures
Tumor information data items describe the tumor itself, in contrast to Patient Demographic items which describe the personal identity of the patient.

Tumor information, obviously, is different for each of a patient’s tumors.

Much of the information needed for abstracting the Tumor Information items will be on the pathology reports from biopsies and surgical procedures.

Collaborative Stage, however, requires additional review of imaging and lab reports, history and physical exam, and other physicians’ documentation to completely abstract the CS data elements.

Text – Dx Procedures fields must include enough natural language information to justify the coded Tumor Information data items.
Date of Initial Diagnosis

Date of first diagnosis of this cancer by any recognized medical practitioner.

Date of first diagnosis may be a date of clinical diagnosis.

Date of Initial Diagnosis is the date of the first diagnosis of this cancer by any recognized medical practitioner.

The Date of Initial Diagnosis is often the date of a clinical diagnosis (positive findings on a CT scan, endoscopic procedure, cytology report, etc).

Don’t confuse the Date of Initial Diagnosis with the date of histologic confirmation.

Some tumors never have histologic confirmation.

Use the first date of diagnosis whether clinically or histologically confirmed.
Date of diagnosis, along with date of last contact and DOB, are critical dates because they are used to calculate significant time intervals.

For example:
- Date of diagnosis minus the date of birth = age at diagnosis
- Date of last contact minus the date of diagnosis = length of survival

Unknown date of initial diagnosis is not allowed.

If necessary, approximate the actual date of diagnosis as closely as possible.
Do not use 9’s for any part of the diagnosis date.

If only the year of diagnosis is known, use 6/15/YYYY.

If only the year and month of diagnosis are known, use MM/15/YYYY.

Refer to the FCDS Data Acquisition Manual guidelines for more specific information on approximating the date.
For cases diagnosed at autopsy, the Date of Initial Diagnosis = Date of Death.

The FCDS guidelines for ambiguous terms apply to the date of diagnosis.

- Example: The date of a mammogram with a radiologist’s diagnosis of a mass suspicious for malignancy becomes the date of diagnosis.
- Refer to the FCDS list of ambiguous terms that constitute a diagnosis of cancer.
Type the name of the facility where the initial diagnosis was made.

This text is the only documentation in the abstract of the place of diagnosis – it is not coded elsewhere.

Do not leave it blank.
FCDS – County at Diagnosis

FCDS – Specific field.

Instructions for FCDS – Specific fields must be obtained from the FCDS Data Acquisition ONLY.

County where the diagnosis facility is located. Correlate with Place of Diagnosis text.

NOT the patient’s County at Diagnosis.

Use the 2 digit FCDS County codes from FCDS DAM, Appendix B.
Class of Case

Analytic Cases

- **0** Diagnosis at the accessioning facility and the entire first course of treatment was performed elsewhere or the decision not to treat was made at another facility.

- **1** Diagnosis at the accessioning facility, and all or part of the first course of treatment was performed at the accessioning facility.

- **2** Diagnosis elsewhere, and all or part of the first course of treatment was performed at the accessioning facility.
Class of Case

Nonanalytic Cases

- 3 Diagnosis and the entire first course of treatment were performed elsewhere. Presents at your facility with recurrence or persistent disease.
- 4 Diagnosis and/or first course of treatment were performed at the accessioning facility prior to the reference date of the registry.
- 5 Diagnosed at autopsy. Prior to autopsy, there was no suspicion or diagnosis of cancer.
- 6 Diagnosis and the entire first course of treatment were completed by the same staff physician in an office setting. “Staff physician” is any medical staff with admitting privileges at the reporting facility.
Nonanalytic Cases

• NOTE: COC no longer recommends this code for use on or after January 1, 2000. However, these cases are very important to FCDS. Therefore, FCDS will continue to accept these cases coded as class 6.

• 8* Diagnosis was established by death certificate only. Used by central registries only.

• 9* Unknown Sufficient detail for determining Class of Case is not stated in patient record. Class Used by central registries only.

• * All classes of case are reportable to the FCDS except Class 8 and 9.
Class of Case

Refer to the complete Class of Case table in FCDS DAM Manual and review complete definitions of all classes.

Class of case codes describe the reporting facility’s role in the initial diagnosis and first course of treatment of the reported primary tumor.

Class of Case categorizes cases for administrative analysis purposes such as planning and evaluation of services.
The casefinding procedure may have identified a case as being reportable based on site and histology, but the abstractor’s assignment of class of case actually confirms that the case is truly reportable to FCDS and determines the extent of data collection that is required for the case.

Classes of Case 0, 1, 2, 3, 4, 5 are reportable to FCDS. (See Section I of the Data Acquisition Manual for complete information on case reportability.)

Class of Case codes are divided into analytic and non-analytic categories.
Analytic cases (Class of Case 0, 1, and 2) are cases in which the reporting facility has played a major role in the initial diagnosis and/or first course of treatment of the tumor.

Analysis of treatment outcomes and survival data are based on analytic cases.

CoC approved cancer programs are required to accession and abstract analytic cases.
Non-analytic cases

In contrast, **non-analytic cases** (Class of Case 3 – 9) are cases in which the reporting facility has had no role in the initial diagnosis or first course of treatment of the tumor.

Non-analytic cases are excluded from outcomes analysis and survival statistics.

CoC Hospitals are **NOT** required to accession or abstract nonanalytic cases.

However, classes 3, 4, and 5 are reportable to the FCDS.

Non-analytic cases and historical cases may contain only sketchy information about the original diagnosis, staging and first course of treatment.

Abstract as much information as is available from the record.
Cases that, after review, prove NOT to be reportable should be recorded on an FCDS Not Reportable Form.

Cancer diagnoses that are not reported show up as “missed cases” in FCDS casefinding audits.

Failure to keep a list of not-reported cases will result in facilities having to re-examine the medical records on those “missed cases” to justify their non-submission to the FCDS.
Diagnostic Confirmation identifies the method that was used to diagnose the tumor.

Tumors may be evident on the results of multiple diagnostic procedures, i.e. demonstrated on a CT scan (imaging) and positive by analysis of fluid aspirate (cytology), as well as positive on tissue biopsy or resection (histology).

Select the Diagnostic Confirmation code that represents the greatest level of diagnostic certainty.

The codes for Diagnostic Confirmation are hierarchical.

Use the lowest numeric code that applies.
Code 1 (Histology) takes precedence over all other codes because it provides the greatest level of diagnostic certainty.

Code 1 includes positive hematologic findings and bone marrow specimens for leukemia, including peripheral blood smears and aspiration biopsies.
Diagnostic Confirmation is one of the few codes that can and should be changed as more certain diagnostic information is gained throughout the course of the patient’s disease.

- For example: A case that is confirmed by endoscopy (without biopsy) at initial diagnosis, receives chemotherapy as first course of treatment, and develops metastatic disease that is confirmed by biopsy 3 years later would be initially abstracted with Dx Confirmation code of 6 (Direct visualization without biopsy), but updated to code 1 (Positive Histology) following the biopsy of metastasis.
Primary site is synonymous with Topography.

Histology is synonymous with Morphology, Pathology and Cell type.

Use ICD-O-3 for cases diagnosed on or after 1/1/2001.

Use ICD-O-2 for cases diagnosed prior to 1/1/2001.

*Site, Histology and Behavior absolutely MUST be correct!*
The ICD-O-3/ICD-O-2 primary site code is the key identifier of a tumor and determines the coding schema for many of the data items that follow in the abstract.

If the primary site is coded incorrectly, by association, much of the rest of the abstract’s tumor and treatment information may also be incorrect.

Refer to the introductions to ICD-O-2 and ICD-O-3 for complete coding instructions for site and histology.
For cases diagnosed on or after 1/1/2007, use of The Multiple Primary/Histology rules is required for accurate assignment of histology codes when multiple histologies are present.

- For cases diagnosed prior to 1/1/07, follow the ICD-O-2/ICD-O-3 histology coding rules as presented in the FCDS Data Acquisition Manual (page 93), which are based on the Introductions to ICD-O-2 and ICD-O-3.
FCDS Data Acquisition Manual sections on Primary Site and Histology offer specific information for confirming the accuracy of site and histology codes.

Note these helpful FCDS guides for site coding:

- Coding instructions for selecting primary site codes for specific histologic types (e.g. lymphoma, mesothelioma, melanoma, leukemia, sarcoma, meningioma).
- Impossible site/histology combinations (e.g. melanoma of bone, carcinoma of brain).
- Preferred site codes for ill-defined primaries (the histology often suggests a better primary site code than the ill-defined codes).
Type the name of the specific primary site and the laterality, if applicable. The text must justify the primary site code and the laterality code.

- Example:
  - Upper outer quadrant, right breast
  - Tail of pancreas
  - Overlapping mid-distal esophagus
Type the name of the specific histologic type, the behavior, and the tumor grade.

The text must justify the coded histology, behavior and grade.

- Example:
  - Infiltrating duct carcinoma Grade 3
  - Non-invasive urothelial carcinoma
  - Large B-Cell lymphoma
### Laterality

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not a paired site</td>
</tr>
<tr>
<td>1</td>
<td>Right: origin of primary</td>
</tr>
<tr>
<td>2</td>
<td>Left: origin of primary</td>
</tr>
<tr>
<td>3</td>
<td>Only one side involved, right or left origin unspecified</td>
</tr>
<tr>
<td>3</td>
<td><em>For in-situ cases, if the laterality is unknown or midline, use code ‘3’.</em>**</td>
</tr>
<tr>
<td>4</td>
<td>Bilateral involvement, lateral origin unknown, stated to be a single primary</td>
</tr>
<tr>
<td>9</td>
<td>Paired site, but lateral origin unknown; midline tumor</td>
</tr>
</tbody>
</table>
Tumors that occur simultaneously in paired organs are usually (but not always) considered to be separate primary sites requiring separate abstracts.

The abstracts on bilateral cancers are distinguished from one another by the sequence of primary number and the laterality code.

Refer to the MP/H site specific rules for determining the number of primary sites when there is bilateral tumor involvement.
Enter the laterality code that corresponds to the location of the primary site of the tumor being abstracted.

The presence of metastatic disease in a contralateral organ should not be considered when determining laterality.

- See FCDS Data Acquisition Manual for a table of primary sites for which laterality must be recorded.
- Sites not listed in the table must have laterality coded as O, None, not a paired site.
- Don’t confuse bilateral involvement of paired organs (a laterality issue) with bilateral involvement of paired structures within a single (non-paired) organ (a staging issue).
- For example: Bilateral involvement of the right and left lobes of the thyroid does not change the fact the thyroid is a non-paired organ; the laterality code is O – none.
Special circumstances:

- Retinoblastoma – Code 4
- Wilms tumor – Code 4
- Bilateral ovarian involvement of the same histologic type of cancer, origin not able to be determined is considered a single primary – Code 4
The grade or differentiation of the tumor describes the resemblance of the tumor to normal tissue.

Well differentiated (Grade I) is the most normal tissue, and undifferentiated (Grade IV) is the least normal tissue.

The terms “grade” and “differentiation” are used synonymously in most cases.

Grade is an indicator of the aggressiveness of a tumor and plays a role in determining appropriate treatment.
Consistent coding of grade is complicated by the fact that there are multiple grading systems in use for different sites and histologies.

It’s imperative that the abstractor know which system(s) the pathologists are using at the reporting facility.

In addition, the language used to describe grade varies widely among pathologists.

The FCDS Data Acquisition Manual table of Grade/Differentiation codes and definitions has been expanded from the standard Grade table to include many of the variations in grade expressions used by pathologists.
Basic Rules for Coding Tumor Grade

Code grade from the FINAL pathologic diagnosis.

Assign grade based only on tissue from the primary site.

Code the highest grade documented for the primary site.

If the tumor is both invasive and in situ, only code the grade from the invasive component.

Grade written as “2/3” means “grade 2 of a 3 point grade system.”

Grade/Differentiation can be site-specific and histology-specific.
Grade has many coding rules:

- If no grade is given in the final diagnosis, but a grade is documented in the microscopic description, use the grade described in the microscopic description.

- Example: A tumor grade is stated on pathology report from an incisional biopsy of the breast.
  - On re-excision, there is no residual tumor.
  - Code grade from the biopsy.

Code grade from the FINAL pathologic diagnosis.

If a needle biopsy or incisional biopsy of the primary site has a grade given and the excision or resection does not, code the information from the needle/incisional biopsy.
Assign grade based only on tissue from the primary site.

If there is no examination of tissue from the primary site, code grade as 9 – Unknown, even if grade is reported on path exam of a metastatic site.

Don’t code grade from a metastatic site.

- Example: Pathology report from a needle biopsy of the liver showed metastatic poorly differentiated adenocarcinoma consistent with colon primary.
- Code grade 9.
If a diagnosis includes more than one grade, code the highest grade documented for the primary site, even if it does not represent the majority of the lesion.

- Example: Grade 2-3/3. Translates to “Grade 2 to Grade 3 on a scale of 3” or “Moderately undifferentiated to poorly differentiated on a 3 point scale.”
- Document the highest grade – poorly differentiated.
If the tumor is both invasive and in situ, only code the grade from the invasive component.

If the invasive component grade is unknown, then code 9.

Occasionally a grade is written as “2/3” meaning this is grade 2 of a 3 point grade system.

To code in a three-grade system, refer to the terms “low grade”, “medium grade”, and “high grade.”
Grade/Differentiation is somewhat site-specific and histology-specific.

For sites other than breast, prostate and kidney, code the tumor grade using the following priority order:

1) terminology (e.g. “well differentiated”)
2) histologic grade (e.g. Grade 1/3)
3) nuclear grade (e.g. Nuclear grade 2).
Specific rules for:

- Astrocytoma (Use ICD-O-3 rules, don’t use the WHO grade)
- Glioblastoma multiforme (Don’t assume grade IV)
- CNS tumors (Don’t use the WHO grade)
- Lymphoma/Leukemia (T-, B-, Null-, NK-cell)
- Prostate (Translate from Gleason pattern/score)
- Breast (Translation from Bloom-Richardson)
- Kidney (Use Fuhrman grade)
The scope of this presentation is too limited to explore all of the site specific grading rules.

It’s important to carefully review all grading rules on your own. Refer to ICD-O-3, the FCDS Data Acquisition Manual, and the FORDS manual for complete information on tumor grade.

The Grade table presented in the FCDS Data Acquisition Manual combines the language from multiple grading systems and should be used a primary guide for tumor grading.

The Gleason’s score for prostate cancer and Bloom-Richardson score for breast cancer are reviewed simply because of the high volume of breast and prostate cases you will be abstracting.
Prostate cancer shows two main histologic patterns; a primary pattern (occupying >50% of the cancer) and a secondary pattern.

Each pattern is “graded” from 1 to 5. The two patterns are usually expressed as (for example):

- “Gleason pattern 3, 4” with 3 being the primary pattern and 4 being the secondary pattern.
An overall grade is obtained by adding the two patterns to form a Gleason Score.

<table>
<thead>
<tr>
<th>Primary pattern (1-5)</th>
<th>Secondary pattern (1-5)</th>
<th>Gleason Score (2-10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>
The abstractor’s task is to convert Gleason’s score to a standard histologic grade. See conversion table below.

If Gleason’s score (2-10) is given, code as follows:

<table>
<thead>
<tr>
<th>Gleason’s Score</th>
<th>Grading</th>
<th>Grade Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>2, 3, 4</td>
<td>I Well Differentiated</td>
<td>1</td>
</tr>
<tr>
<td>5, 6</td>
<td>II Moderately Differentiated</td>
<td>2</td>
</tr>
<tr>
<td>7, 8, 9, 10</td>
<td>III Poorly Differentiated</td>
<td>3</td>
</tr>
</tbody>
</table>
If a single Gleason’s pattern (1-5) is given, double the value and code as follows:

*Complete rules for recording Gleason Score are provided in the Data Acquisition Manual, Page 98.*

<table>
<thead>
<tr>
<th>Gleason’s pattern</th>
<th>Grading</th>
<th>Grade Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>1, 2</td>
<td>I Well Differentiated</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>II Moderately Differentiated</td>
<td>2</td>
</tr>
<tr>
<td>4, 5</td>
<td>III Poorly Differentiated</td>
<td>3</td>
</tr>
</tbody>
</table>
Bloom-Richardson Score and Grade

Much like Gleason’s pattern and score, Bloom-Richardson score for breast cancer evaluates three distinct histologic features:

- tubule formation,
- nuclear pleomorphism,
- and mitotic rate.

Each feature is assigned a value of slight (1), moderate (2) or marked (3).

These three values are added to produce a BR combined score.

As with Gleason’s score, the abstractor’s task is to convert the BR score into a histologic grade.
<table>
<thead>
<tr>
<th>BR COMBINED SCORE</th>
<th>DIFFERENTIATION/ BR GRADE</th>
<th>GRADE CODE</th>
</tr>
</thead>
<tbody>
<tr>
<td>3, 4, 5</td>
<td>Well-differentiated (BR Low grade)</td>
<td>1</td>
</tr>
<tr>
<td>6, 7</td>
<td>Moderately differentiated (BR intermediate grade)</td>
<td>2</td>
</tr>
<tr>
<td>8, 9</td>
<td>Poorly differentiated (BR high grade)</td>
<td>3</td>
</tr>
</tbody>
</table>
Collaborative Stage Elements

- CS Tumor Size
- CS Extension and CS Tumor Size/Ext Eval
- CS Lymph Nodes and CS Lymph Nodes Eval
- Reg Nodes Examined/ Reg Nodes Positive
- CS Mets Dx and CS Mets Eval
- CS Site-Specific Factors 1 - 6
The general rules for assigning Collaborative Staging (CS) are documented in the Collaborative Stage Manual, Part I.

Beginning abstractors must carefully review the CS site-specific staging rules (Collaborative Stage Manual, Part II) before abstracting unfamiliar sites.

Know what you are looking for as you review the medical record.

- CS is to be used for all cases, regardless of date of diagnosis.
- Do not leave any CS fields blank.
CS describes the extent of disease, lymph node status and presence of metastasis at the time of initial diagnosis and treatment.

Use all information gathered through completion of surgery(ies) in first course of treatment or all information available within four months of the date of diagnosis in the absence of disease progression, whichever is longer.

- For CS staging purposes, disease progression is defined as further direct extension or distant metastasis known to have developed after the diagnosis was established.
- Information about tumor extension, lymph node involvement, or distant metastasis obtained after documented disease progression should be excluded from the CS coding.
- For example: Information about brain metastasis diagnosed 6 weeks after completion of the first course of treatment (chemotherapy) for lung cancer would be disregarded in assigning the CS stage at diagnosis.
Always refer to the complete coding schema in the CS Manual.

Don’t rely solely on the software’s drop-down menus.

Pay attention to all the site specific notes in each chapter.
For the complete coding rules of Collaborative Staging, go to the Collaborative Staging Educational Module.
Text justifies the coded information.
The purpose of text is to substantiate the coded information.

Text is used for data quality assessment and in special studies.

Accurate text alleviates the need to go back to source documents for justification of coded data.

Text is also the “face” of the cancer registry.

Printed abstracts usually include the text fields, exposing the content and accuracy of the abstract to the scrutiny of the reader.

Good text builds confidence in the content and accuracy of the entire abstract.
Record information that supports the site, histology, grade and stage of the disease at the time of diagnosis.

Text fields are limited to 200 – 250 characters.

Use only standard abbreviations.

Be sure the text will make sense to another reader.
Abstracting tip:

If software allows, record text first and then assign codes based on the text.

If you’re not able to assign codes based on the text, go back and enter appropriate text.

For treatment text fields, record only information from the first course of treatment.

Enter text information from history and physical exams.

Document only the clinical history that relates to the cancer diagnosis.

Examples:
- (Lymphoma) - “c/o fever and night sweats, adm for w/u”
- (Prostate) - “DRE: Palpable nodule lt prostatic apex”
- (Breast) - “1.5 cm palpable mass 6:00 rt breast, no palpable axillary lymphadenopathy”
Enter text information from diagnostic imaging reports, including x-rays, MRI, and PET scans, ultrasound and other imaging studies. Include the date, the site or procedure name, both positive and significant negative clinical results (Space is limited - record positive before negative).

Examples:

- (Lymphoma) 2/24/09 staging PET: “Abn FDG uptake in retroperitoneal and inguinal node regions.”
- (Prostate) 3/1/09 prostatic ultrasound: 0.5 cm hypoechoic region, apex lt lobe, right lobe normal.
- (Breast) 4/12/09 Mammo: 1.5 cm spiculated mass at 6:00 rt breast c/w malignancy. Enl ax ln identified.
Enter text information from endoscopic examinations. Record the procedure date, the site or procedure name, positive and significant negative results of clinical findings (record positive results first).

Examples:

- (Stomach) 2/12/09 EGD: Gastric mucosa showed large tumor occupying half of the stomach. Numerous satellite tumors seen on opposite wall of the stomach.
- (Lung) 10/1/09 Mediastinoscopy: Several enlarged firm 4R peritracheal lymph nodes.
- (Larynx) 7/27/09 Laryngoscopy: Lg mass obstructing 60% of airway. Lt vocal cord paralysis. Base of tongue, fl of mouth, hypopharynx, pyriform sinuses, and epiglottis all normal.
Enter text information from laboratory examination other than cytology or histopathology.

Include site-specific tumor markers. Record the date, type of test, test results.

Examples:
- (Breast)  ER +, PR -
- (Prostate) PSA 5.2
- (Melanoma) LDH normal
Enter text information from operative reports including observations at surgery, tumor size, the extent of involvement of primary or metastatic sites NOT surgically excised or biopsies and other information that may not be documented elsewhere.

Record the date, procedure, documentation of gross residual tumor or gross evidence of invasion of surrounding areas.

Any surgical observation of extent of disease that is not included on the pathology report should be included here.

Examples:
- 5/4/09 Prostatectomy: Extensive disease found in the pelvis (carcinomatosis), surgery was aborted.
- 8/14/09 Hemicolecotomy: 4.0 cm mass noted at rectosigmoid junction.
- 6/12/09 Craniotomy: Gross tumor completely excised.
Enter text information from cytology and histopathology reports.

In general, record the date of the pathology report, specimen (site), morphology, tumor extension, lymph node status (if removed or biopsied), and margin status.

Pathology text is somewhat site-specific, in that different sites require different information to substantiate the CS staging elements.

Examples:

- 4/12/09 sigmoid colon: Mod diff adenoca, 2.5 cm, exten into the pericolic fat. 00/22 ln, margins negative.
- 7/21/09 rt lumpectomy: Infiltrating duct ca, Grade 2/3, 1.1 cm invasive component, DCIS present - not extensive, margins negative, 1/2 sentinel LN positive for ITCs.
Enter additional staging information *not already entered in other text areas*.

Include organs involved by direct extension, size of tumor, status of margins, sites of distant metastasis, special site-specific considerations for staging.

No need to repeat staging information documented in other text fields.
Treatment

- Surgery
- Radiation
- Systemic Therapy
  - Chemotherapy
  - Hormone Therapy
  - BRM (Immunotherapy)
- Other
Abstracting of treatment is based on two critical concepts:

- First course of treatment and
- Cancer Directed Therapy

FCDS collects treatment data ONLY from the first course of treatment.
First course of treatment includes all methods of treatment recorded in the treatment plan and administered to the patient before disease progression or recurrence.

Familiarity with standard treatment plans for different stages of disease in each site helps in gathering complete treatment information for the abstract.
Cancer directed therapy

Cancer directed treatment is any treatment that is given to modify, control, remove or destroy primary or metastatic cancer tissue.

The goal of cancer directed treatment is to remove a tumor, minimize the size of a tumor, or delay the spread of disease.
Time frame for first course of treatment (in order of precedence):

If there is a documented, planned first course of treatment, first course ends at the completion of the planned treatment, regardless of the duration of the treatment.

If the patient is treated according to a facility's standard of practice, first course ends at the completion of the treatment.

If there is no documentation of a planned first course of treatment or standard of practice, first course of treatment includes all treatment received before disease progression or treatment failure. If it is not documented whether there is disease progression/treatment failure and the treatment in question begins more than one year after diagnosis, assume that the treatment is not part of first course.
If a patient refuses all treatment modalities and does not change his/her mind within a reasonable time frame, or if the physician opts not to treat the patient, record in the text that there was no treatment in the first course and document the reason for no treatment.
Surgical Procedure Coding is Site Specific

Refer to FORDS Appendix F for complete site specific surgery codes.

Non-Cancer directed surgical codes (01 – 09) need not be recorded in the abstract.
Related Surgical Data Items

Understanding the relationship among the surgical data items will help you avoid the frustration of edit errors in surgery coding.

These data items are all considered to be “surgical procedure” fields:

- RX Summ-Surg Primary Site
- RX Summ- Surg Other Reg/Distant
- RX Summ-Scope Reg LN Surg
Therefore all three must be considered when determining correct responses for:

- RX Date – Surgery
- RX Summ- Systemic/Surg Sequence
- RX Summ- Surg/Rad Sequence

For example:

- If Surgery of Primary Site and Surgery of Other Regional/Distant Sites are both coded 00 (None), but Scope of Regional LN Surgery is coded 1 (Biopsy of regional LN), then RX Date-Surg is the date of the node biopsy; if chemotherapy and radiation are also given in first course, RX Summ-Systemic/Surg Sequence and RX Summ-Surg/Rad Sequence cannot be zero.
Treatment modalities in the first course of treatment may be delivered at multiple facilities.

RX Summ fields are summary fields.
• Surgical RX Summ data items (*RX Summ-Surg Primary Site*, *RX Summ-Surg Other Reg/Distant*, and *RX Summ-Scope Reg LN Surg*), should reflect the most definitive surgical procedure performed, regardless of where the procedure was performed.

• RX Summ-Radiation should combine and summarize all radiation modalities delivered during the first course of treatment, without regard to where the radiation was delivered. (This is in contrast to Rad – Regional RX Modality which describes the single dominant radiation modality used to deliver the most clinically significant regional dose of radiation, also without regard for where the modality was delivered.)

• RX Summ fields for systemic therapy (Chemo, Hormone, BRM) should be coded to reflect the administration of all systemic treatment, regardless of where the therapy was given.
Use the interactive database, SEER*RX, as a guide for coding antineoplastic drugs and drug regimens.

Drug regimens may include a combination of chemotherapy and hormonal agents, for example: CHOP ( Cyclophosphamide, Adriamycin, Oncovin and Prednisone).

Enter the appropriate code in both the RXSUMM-Chemo and RXSUMM-Hormone fields to document the administration of both drug types.

All RX Date fields represent the date the treatment modality was initiated.
Treatment text should corroborate the coded responses in all of the treatment fields and the treatment date fields.

If the patient did not receive treatment in the first course, document the reason for no treatment, i.e. patient or family refusal, treatment contraindicated due to comorbidity, patient expired prior to treatment, etc.
Enter text describing the surgical procedure(s) performed as part of first course treatment.

Record the date(s), type of procedure, treatment facility.

- Example:
  - 2/15/09 (Facility) exc bx rt breast w/ sentinel LN bx.
  - 2/21 (Facility) rt mrn w/ rt ax node dissection and TRAM reconst.
Enter the radiation start date, treatment facility, targeted volume, and specific treatment modality of external beam radiation delivered during first course of treatment.

Examples:

- 4/21/09 (Facility) Stereotactic radiosurgery, left parietal lobe
- 7/11/09 (Facility) 10 MV photon EBRT, left chest wall
- 2/28/09 (Facility) IMRT, rt breast
Enter the radiation start date, treatment facility, and specific treatment modality of nonbeam radiation delivered during first course of treatment.

Examples:

- 10/13/09 (Facility) I-125 seed implants, prostate
- 6/18/09 (Facility) Combined brachytherapy and EBRT, prostate and pelvis
- 12/22/09 (Facility) Systemic I-131
Enter the start date, treatment facility, and the names of chemotherapy agents or the names of chemotherapy regimens used in the first course of treatment for the tumor being reported.

Examples:

- 4/30/09 (Facility) AC + Taxol
- 11/30/09 (Facility) CHOP + Rituxan
- 7/18/09 (Facility) Carboplatin + Taxol
Enter the start date, treatment facility, and the names of hormonal agents or endocrine procedures used in the first course of treatment for the tumor being reported.

Examples:

- 5/1/09 (Facility) Tamoxifen
- 1/17/09 (Facility) Bilateral orchiectomy
Enter the start date, treatment facility, and the names of biological response modifiers (immunotherapy agents) or immunotherapeutic procedures used in the first course of treatment for the tumor being reported.

Examples:

- 8/21/09 (Facility) BCG
- 1/6/09 (Facility) Autologous bone marrow transplant
Enter information regarding treatment that cannot be defined as surgery, radiation, or systemic therapy.

Document any alternative therapies that are administered to a patient who declines standard treatment modalities.

Examples:
- 4/11/09 (Facility) Protocol 45-0312, double blind study
- 11/02/09 (Facility) Phlebotomy (for diagnosis of polycythemia vera)
Enter information not recorded elsewhere that may have impact on the diagnosis, treatment decisions or outcome of tumor being reported.

Document personal history of cancer.

Example:

- Personal history of breast and bladder cancer.
## Follow-up Information

<table>
<thead>
<tr>
<th>Date of Last Contact</th>
<th>Cancer Status</th>
<th>Vital Status</th>
</tr>
</thead>
</table>

*FLORIDA CANCER DATA SYSTEM*
Think of Follow-up information as “Outcome Information.”

- What happened to this patient after receiving the 1\textsuperscript{st} course of treatment?
- How successful was the treatment?

These are possible outcomes:

- As of the date of last contact, this patient was alive and free of this cancer.
- As of the date of last contact, this patient was alive with evidence that this cancer is still active.
- On the date of last contact, this patient expired with evidence that this cancer was still present.
- On date of last contact, this patient expired and it’s unknown whether this cancer was present or not.

Follow-up information is critical for calculation of survival rates.
Date of Last Contact

Enter the date the patient was last known to be alive. This is usually the date of the reporting facility’s last encounter or contact with the patient.

If the patient is known to be dead, the date of death will be the Date of Last Contact.

- **If the exact date of death is unknown, approximate a date of death.**

The date of Last Contact applies to the patient (not to the primary tumor).

Therefore, if the patient has multiple primaries, the date of last contact will be the same for all primaries.

This field cannot be left blank.

Unknown (99999999) is not allowed.
Vital Status

0  Dead

1  Alive
   (If not known to be dead, the patient is assumed to be alive).
Cancer Status

Enter the cancer status that corresponds to the date of last contact.

Cancer status is the *clinical* absence or presence of cancer.

- If a patient has had surgical removal of the primary cancer and there is no documentation of the presence of residual disease, progression of disease, or recurrent disease, Cancer Status may be recorded as 1 (NED - No evidence of this cancer).

Cancer Status is coded independently for each primary.

If a patient has multiple primaries, each abstract could have a different cancer status.
Accuracy and consistency are the most important abstracting goals. Apply abstracting rules consistently.

Even if data are abstracted incorrectly, if abstracted *consistently* incorrectly, corrections will be easier later.

Check your work by visual editing.
Know where to go for help with abstracting dilemmas.

- Check all available references and manuals.
- Use online interactive resources for help with specific abstracting questions.
  - CoC Inquiry and Response System [www.facs.org](http://www.facs.org)
  - Contact FCDS
  - Use a designated abstracting mentor
Keep learning. The more you know about cancer, the better abstractor you will be. It takes a long time to develop sharp abstracting skills.

- Participate in cancer registry continuing education events and webinars.
- Attend tumor conferences at your facility.
- **ASK QUESTIONS.**
The current edition of the FCDS Data Acquisition Manual is the primary source for abstracting instructions.

The manual is available online at http://fcds.med.miami.edu/downloads/dam2008

Use essential source manuals for complete information and coding instructions; don’t rely on memory or software drop-down menus.

Be sure you are working with the most current editions of all coding manuals, including the most current published errata.

Use a consistent routine of chart review and data entry to avoid overlooking significant information.

A haphazard approach to abstracting leads to inconsistency and inefficiency.