

## SECTION I: GUIDELINES FOR CANCER DATA REPORTING

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The Florida Cancer Data System (FCDS) is charged with maintaining a high quality database of useable, timely, complete and accurate cancer data for every reportable case of cancer diagnosed or treated in the state of Florida. The FCDS Data Acquisition Manual (FCDS DAM) includes guidelines and instructions for case identification, case eligibility (which cases must be reported to FCDS), abstracting and coding, and multiple appendices that are referenced throughout the manual. The manual only addresses data items that are required by FCDS and the Florida Department of Health to support Florida's statewide, population-based cancer registry. These guidelines have been established as a means to achieve and maintain this objective.

All reporting facilities, regardless of affiliation, **MUST** adhere to the following guidelines for cancer data reporting. The instructions and codes in this manual take precedence over all previous instructions/manuals.

It is the responsibility of both the reporting facility and the facility abstractor (contractor) to be familiar with and understand the content of the most current version of the FCDS Data Acquisition Manual and to update it upon receipt of any changes from FCDS. This responsibility exists without regard to whether or not case abstracting and reporting is being performed by an employee of the reporting facility or through some contractual arrangement with an independent abstracting agency or individual within or outside the state of Florida.

**CONFIDENTIALITY - Patient information, personal health information, medical records and healthcare facility data are all confidential and continue to be a concern with regard to cancer and other disease reporting. Please do not fax or email patient information to FCDS. Also, please take care when discussing cases over the phone with FCDS staff.**

**DO NOT E-MAIL, FAX OR MAIL PATIENT INFORMATION (PHI) TO FCDS UNDER ANY CIRCUMSTANCES unless you are provided specific instructions for using our Secure Fax Service.**

### A. CASE ELIGIBILITY

Florida facilities are legislatively mandated to report any case of cancer meeting the Florida "cancer" definition, regardless of facility or network affiliation or Class of Case. FCDS requires complete abstracting of cancer cases that the Commission on Cancer/American College of Surgeons may not require.

If your facility participates in the diagnosis, staging, treatment, or continuing care of a patient during the first course of treatment, progression of disease or disease recurrence the case must be reported to FCDS. If any diagnostic, staging, or other evaluative studies are conducted at your facility (diagnostic imaging, re-biopsy, sentinel node biopsy, surgical resection or other staging or treatment, etc.) your facility must report the case regardless of the Class of Case.

Patients whose First Course of Therapy is "Active Surveillance" or "Watchful Waiting" must be reported as their cancer has not been treated by any means...it is only being followed. However, "NO TREATMENT" is a different treatment decision than "Watchful Waiting". Please be cautious when distinguishing the two cases.

"Consult-Only" cases *MAY* be an exception to reporting.

A "consult only" case is any case where the facility provides a second opinion or review of earlier studies **without additional testing at your facility**. A second opinion may include re-reading pathology slides or re-reading diagnostic imaging studies. If your facility does not perform any additional testing, the case may not be reportable to FCDS. However, if you facility does any additional testing for this or any other cancer and they have evidence of disease or are undergoing treatment for cancer, the case is reportable.

**Exception 1:** Patients undergoing planned first course or later course hormonal treatment for breast or prostate cancer that continue to demonstrate no active neoplasm should not be reported. Any patient with active malignancy (any evidence of disease) must be reported.

**Exception 2:** Patients seen in an ambulatory care setting for “port-a-cath” placement where no chemotherapeutic or anti-neoplastic agent(s) is injected into the port do not need to be reported. However, many Florida healthcare facilities including Commission on Cancer/American College of Surgeons accredited cancer programs continue to report these cases as part of monitoring the full continuum of patient care.

Please note that many types of drugs may be administered through a “port-a-cath” delivery system. The medical record and medication flow sheets **MUST** be reviewed and cannot include administration of any anti-neoplastic agent(s) through the port-a-cath for the case to meet this exclusion criterion. If any anti-neoplastic agent is administered at the reporting facility, either as an outpatient or inpatient, the case must be reported.

Note: Facilities may opt to abstract and report “port-a-cath” placement cases at their discretion.

### 1. Reportable Patients

All patients first seen at the reporting facility on or after January 1, 1981 (July 1, 1997 for free-standing/ambulatory surgery centers and freestanding radiation therapy centers), whether as an inpatient, outpatient or in an ambulatory care setting, who meet one or more of the following criteria must be reported:

- a) .....all patients with an active, malignant neoplasm (in-situ or invasive), whether being treated or not (includes active surveillance),
- b) .....all patients with an active, benign or borderline brain or central nervous system (CNS) tumor, diagnosed on or after 01/01/2004, whether being treated or not (includes active surveillance)
- c) ..... all patients undergoing prophylactic, neoadjuvant, or adjuvant therapy for malignancy,
- d) .....all patients diagnosed at autopsy,
- e) .....all historical cases that meet FCDS reportability guidelines.

### 2. Not Reportable Patients

- a) .....patients seen only in consultation to provide a second opinion to confirm a diagnosis or a treatment plan (no additional testing can be performed at your facility or the case is reportable),
- b) .....patients in remission (NED) and not receiving prophylactic or adjuvant therapy,
- c) .....patients first seen at the reporting facility prior to January 1, 1981 (July 1, 1997 for free-standing centers) and returning after that date for the same primary malignant neoplasm,
- d) .....patients who receive transient care to avoid interrupting a course of therapy started elsewhere.

### 3. Reportable Neoplasms

Determination of whether or not a given primary neoplasm is reportable is made by reference to the morphology and behavior codes of the *International Classification of Diseases for Oncology* including any approved updates or errata published by WHO and approved by NAACCR for ICD-O-3. Three newly reportable conditions were introduced with the *2010 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual*. Please refer to the most current version of the Hematopoietic Database and Manual for complete reporting instructions.

**NEW FOR 2015:** Two newly reportable conditions have been introduced for cancer reporting in 2015. **The new reporting requirement does not affect any case diagnosed prior to 1/1/2015.** This is in accordance with the nationwide phased-in implementation of the WHO 2011 Updates to ICD-O-3. The two newly reportable conditions are “**carcinoid tumor of the appendix**” AND “**malignant enteroglucagonoma of pancreas**.” Neither are new conditions. However, both are now treated as any other reportable malignancy and abstracted/reported to both the CoC and to FCDS. Cases should be included in 2015 casefinding and reporting. Additional WHO ICD-O-3 Updates from 2011 will be implemented nationwide on 1/1/2016 and will affect additional types of neoplasms and behavior.

An online version of ICD-O-3 is available on the WHO International Agency for Research on Cancer (IARC) website: <http://codes.iarc.fr/>. This useful online tool should be used with the following notes:

- The online version of ICD-O-3 is referred to as ICD-O-3.1 as it includes the 2011 updates and any previous errata to ICD-O-3 that have been published since 2000.
  - For solid tumors – DO USE the original publication, ICD-O-3 (2000), only.
  - For solid tumors – DO NOT USE the ICD-O-3.1 (2011) codes for solid tumors (non-hematopoietic, non-lymphoid), as the new codes have not been approved for implementation in the United States and/or Canada as yet.
  - For non-solid tumors, use the histology rules in the Hematopoietic and Lymphoid Database. The database already includes the 2011 Heme/Lymph Histology Code Updates.
  - Please refer the Appendix R (NAACCR Guidelines for ICD-O-3 Update Implementation) for the complete list of ICD-O-3 code changes effective 1/1/2015 and the complete 2011 Updates.
- a) **In Situ and Invasive Cancers** - FCDS includes primary malignancies which are in situ and/or invasive. Therefore, any cancer with an ICD-O behavior code of /2 (in situ) or /3 (malignant) is reportable to FCDS (**except** carcinoma in situ of the cervix, carcinoma in situ of the prostate, CIN III, and PIN III). Cancers with benign or borderline behavior are discussed elsewhere in this section.

If a tumor with an ICD-O behavior code of /0 or /1 is determined to be in-situ or invasive by the manner in which it is behaving (in malignant fashion), or by a pathologist, the case is reportable.

- i. **Anal Intraepithelial Neoplasia (AIN III)** is reportable to FCDS and should be included in casefinding activities. This non-invasive neoplasm of the anus or anal canal (C21.0-C21.1) is not the same as SCC of perianal skin (C44.5). It is important to distinguish between true anal cancers and skin of anus neoplasms. Neoplasms of the skin of anus (perianal skin) are not reportable, even if they extend into the anal canal. **AIN III** of the perianal skin is not reportable to FCDS.
- ii. **Laryngeal Intraepithelial Neoplasia (LIN III)** is reportable to FCDS and should be included in casefinding activities.
- iii. **Vaginal Intraepithelial Neoplasia (VAIN III)** is reportable to FCDS and should be included in casefinding activities.
- iv. **Vulvar Intraepithelial Neoplasia (VIN III)** is reportable to FCDS and should be included in casefinding activities.
- v. **Pancreatic Intraepithelial Neoplasia (PAIN III)** is reportable to FCDS (histology 8148/2) and should be included in casefinding activities.
- vi. **\*Glandular Intraepithelial Neoplasia, Grade III/High Grade Glandular Dysplasia** is reportable as adenocarcinoma in situ of the esophagus with histology code 8148/2.
- vii. **In Utero Diagnosis and Treatment** – beginning in 2009, diagnosis and treatment dates for a fetus prior to birth are to be assigned the actual date of the event. In the past, those dates were set by rule to the date the baby was born. The exact date may be used for cases diagnosed prior to 2009 and must be used for cases diagnosed 1/1/2009 and later.
- viii. **New terminology may be used by your local pathologist** to describe malignant or in situ neoplasms (i.e. well differentiated neuroendocrine neoplasm). When this occurs the neoplasm is reportable to FCDS.

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**\*Note 1:** AJCC TNM Manual, 7<sup>th</sup> edition states for Esophageal Cancers: “High grade dysplasia includes all non-invasive neoplastic epithelia that was formerly called carcinoma in situ, a diagnosis that is no longer used for columnar mucosae anywhere in the gastrointestinal tract.” Therefore, all high grade/severe dysplasia of esophagus are reportable as carcinoma in situ.

**\*Note 2:** AJCC TNM Manual, 7<sup>th</sup> edition states for Colon Cancers: “The terms ‘high grade dysplasia’ and ‘severe dysplasia’ may be used as synonymous for in situ adenocarcinoma and in situ carcinoma. These cases should be assigned a pTis.” It is necessary to contact your pathologist and/or cancer committee to determine if s/he applies this definition to all colon cancers. If so, high grade/severe dysplasia of any colon site is reportable as adenocarcinoma in situ (8140/2).

- b) **Specified malignant neoplasms of the skin;** dermatofibrosarcoma protuberans, Kaposi sarcoma, malignant melanoma, Merkel cell carcinoma, mycosis fungoides, sebaceous adenocarcinoma, and sweat gland adenocarcinoma **are reportable conditions.**
- c) **Gastro-intestinal stromal tumor (GIST) and thymoma** are often non-malignant. However, they must be abstracted and assigned a Behavior Code of /3 if they are noted to have multiple foci, metastasis, or positive lymph nodes or there is other evidence of malignancy noted by surgeon, pathologist, or during clinical workup following initial diagnosis.
- d) **Chronic Lymphocytic Leukemia** patients may exhibit clinical remission (no symptoms) but are never totally free of disease. Physicians may even state these patients are “in remission”. However, these cases should be reported to FCDS, regardless of physician-stated remission status.
- e) **Basal and squamous skin cancers in genital sites (histology codes 8000-8110) are reportable.**

“Genital Sites” include the following anatomic locations:

**C51.0 - C51.1 – Labia**

**C51.2 - Clitoris**

**C51.8 - C51.9 - Vulva**

**C52.9 - Vagina**

**C60.0 - Prepuce**

**C60.9 - Penis**

**C63.2 - Scrotum**

- d) **Benign and Borderline Cancers - Benign and borderline primary intracranial and central nervous system (CNS) tumors with a behavior code of /0 or /1 in ICD-O-3** are reportable as of 01/01/2004. This includes benign and borderline tumors of intracranial glands (pituitary gland, pineal gland, and tumors of the craniopharyngeal duct), meningioma, and tumors of cranial nerves. If the patient has a history of benign and/or borderline intracranial and/or central nervous system (CNS) tumor that was diagnosed prior to 1/1/2004 the case should not be reported to FCDS as a “history of cancer” and should not be sequenced.

CDC published a reference manual in 2004 entitled, “Data Collection of Primary Central Nervous System Tumors.” The manual is available free of charge in PDF format on the CDC NPCR Website at <http://www.cdc.gov/npcr/pdf/btr/braintumorguide.pdf>. This document and ICD-O-3 are the primary references when determining case reportability for primary brain and CNS tumors.

**If the diagnoses date of a benign or borderline brain and CNS tumor is unknown and the admission date is 01/01/2004 or later, the case is reportable.**

**Benign and borderline brain and CNS tumors diagnosed prior to 01/01/2004 are reportable as historical cases when accompanied by another reportable primary on or after 01/01/2004.**

**Benign and borderline neoplasms of the cranial bones (C41.0) are not reportable.**

- e) **Pilocytic/Juvenile astrocytoma is reportable; code the histology and behavior code 9421/3.**
- f) **Table of Anatomic (Primary) Sites for Reportable Benign and Borderline Tumors of Intra-cranial and other central nervous system tumors.**

<b>Anatomic Intracranial and CNS Sites for Reportable Benign / Borderline Tumors</b>		
<b>General Term</b>	<b>Anatomic Site</b>	<b>ICD-O-3 Code</b>
<b>Meninges</b>	Cerebral meninges	C700
	Spinal meninges	C701
	Meninges, NOS	C709
<b>Brain</b>	Cerebrum	C710
	Frontal lobe	C711
	Temporal lobe	C712
	Parietal lobe	C713
	Occipital lobe	C714
	Ventricle, NOS	C715
	Cerebellum, NOS	C716
	Brain stem	C717
	Overlapping lesion of brain	C718
	Brain, NOS	C719
<b>Spinal cord, cranial nerves, and other parts of the central nervous system</b>	Spinal cord	C720
	Cauda equine	C721
	Olfactory nerve	C722
	Optic nerve	C723
	Acoustic nerve	C724
	Cranial nerve, NOS	C725
	Overlapping lesion of brain and central nervous system	C728
	Nervous system, NOS	C729
<b>Pituitary gland, craniopharyngeal duct and pineal gland</b>	Pituitary gland	C751
	Craniopharyngeal duct	C752
	Pineal gland	C753

#### **4. Not Reportable Neoplasms**

- a) **Primary skin tumors (C44.\_) with histology codes 8000-8110**

Skin Cancers - Basal cell carcinoma and squamous cell carcinoma of non-genital skin sites are common malignancies. These tumors are not to be reported to FCDS, regardless of stage. All other malignant tumors of the skin must be reported including but not limited to malignant melanoma, Merkel cell carcinoma, lymphoma of skin, and other non-squamous and non-basal cell skin cancers. Only the following malignant neoplasms of the skin (C44.0-C44.9) are not reportable:

M 8000 – M 8005	Neoplasm, malignant, NOS of the skin
M 8010 – M 8046	Epithelial carcinoma, NOS of the skin
M 8050 – M 8084	Papillary and squamous cell neoplasm of the skin
M 8090 – M 8110	Basal cell carcinoma of the skin

- b) **AIN III (8077/2) of the Perianal Skin (C44.5) is not reportable. AIN III of anus or anal canal (C21.0- C21.1) is reportable to FCDS.**
- c) **BIRADS 4 or BIRADS 5 on Mammography without biopsy to confirm cancer is not reportable to FCDS.** BIRADS 4 and BIRADS 5 are diagnostic imaging designations for highly suspicious for malignancy and malignancy on imaging. If only the mammography report is available stating BIRADS 4 or BIRADS 5, this is not enough information to abstract and report the case to FCDS.

### 5) Reporting Multiple Primary Tumors - Single versus Multiple Primaries

Operational rules are needed to ensure consistency in reporting multiple primary neoplasms. Basic factors include the anatomic site of origin of the neoplasm, the date of diagnosis, the histologic type of each neoplasm, the behavior of the neoplasm, and laterality. Please consult the attending physician if questions arise regarding the number of primary tumors.

In general, if there is a difference in the primary site where the neoplasm originates, it is fairly easy to determine whether it is a single or multiple primaries, regardless of dates of detection or differences in histology. Likewise, if there is a clear-cut difference in histology, other data such as the primary site and the date of detection are not essential to make this determination. Standardized rules have been developed and published to assist the registrar in making single versus multiple primary decisions.

#### ***2007 Multiple Primary and Histology Coding Rules for Solid Tumors***

The *2007 Multiple Primary and Histology Coding Rules* for solid tumors contain site-specific rules for lung, breast, colon, melanoma of the skin, head and neck, kidney, renal pelvis/ureter/bladder, and malignant and nonmalignant brain primaries. A separate set of rules addresses the specific and general rules for all other solid tumor sites. And, a special set of rules has been written for hematopoietic and lymphoid neoplasms. The multiple primary rules guide and standardize the process of determining the number of primary tumors or abstracts to be created. The histology rules contain detailed histology coding instructions. Registrars must refer to the *2007 Multiple Primary and Histology Coding Rules* for general and cancer site-specific instructions. More information on these rules can be found on the NCI SEER website at <http://seer.cancer.gov/tools/mphrules/index.html>

#### ***2015 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Rules and Heme DB***

The *Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual* and the accompanying Hematopoietic Database replaced the February 2001 Single Versus Subsequent Primaries of Lymphatic and Hematopoietic Disease rules and foldout table. An on-line version of the new rules and database is available at: <http://seer.cancer.gov/seertools/hemelymph>. A desktop version is available for download at <http://seer.cancer.gov/tools/heme/>. Please be sure to use the most current version as these rules and codes replace all previous versions.

**DO NOT USE ICD-O-3 to code any histology 9590-9992. Use the Heme Manual and Database.**

### 6) Clarification of Reporting Requirements

#### **a) Malignant Neoplasms/Benign tumors**

A patient is considered to have a benign, borderline, or malignant neoplasm when so indicated by a recognized medical practitioner. In determining a diagnosis of cancer, a positive pathology report takes precedence over all other reports or statements. Many benign and borderline neoplasms of the brain and central nervous system are diagnosed based upon diagnostic imaging, only (CT, PET, MRI, etc.). Other cancers may be diagnosed by alternate means such as direct visualization (without biopsy) or a diagnosis may be based upon clinical evidence, alone. The data item "Diagnostic Confirmation" is used to identify the method of diagnosis for each case. The codes are to be used in a hierarchical order in most cases. In the absence of a positive pathology report, all information in the record must be assessed to determine whether or not the case is reportable and to identify the method used to establish (confirm) the diagnosis.

#### **b) Clinically Diagnosed Cases Are Reportable**

In the absence of a histologic or cytologic confirmation of a reportable cancer, accession a case based on the **clinical diagnosis** (when a recognized medical practitioner says the patient has a cancer or carcinoma or when the patient is undergoing treatment for cancer that may not have been histologically or otherwise confirmed). A clinical diagnosis may be recorded as part of the final diagnosis on the face sheet or other parts of the medical record. See Note and Exceptions below.

**Note:** A pathology report normally takes precedence over a clinical diagnosis. If the patient has a negative biopsy, the case would not be reported.

**Exception 1:** If the physician treats a patient for cancer in spite of the negative biopsy, abstract and report the case.

**Exception 2:** If enough time has passed that it is reasonable to assume that the physician has seen the negative pathology, but the clinician continues to call this a reportable disease, accession the case. A reasonable amount of time would be equal to or greater than 6 months.

### c) Ambiguous Terminology

As part of the registry case-finding activities, all diagnostic reports should be reviewed to confirm whether a case is reportable. This includes pathology reports, bone marrow biopsy reports, autopsy reports, diagnostic imaging reports, and results from medical testing. If the terminology describing the diagnostic assessment is ambiguous, use the following guidelines to determine whether a particular case should be abstracted and reported to FCDS. Words or phrases that appear to be synonyms of these terms do not constitute a diagnosis. For example, “likely” alone does not constitute a diagnosis.

In the absence of more definitive evidence, the following modifying terms, when applied to a neoplasm, should be interpreted as diagnostic of cancer:

Apparent(lee)	consistent with	neoplasm*	suspicious (for)
Appears	favor(s)	presumed	tumor *
comparable with	malignant appearing	probable	typical of
compatible with	most likely	suspect(ed)	

\* use of the terms “neoplasm” and “tumor” begin with cases diagnosed 1/1/2004 and later and are to be used in conjunction with nonmalignant (benign or borderline ICD-O-3 behavior codes /0 or /1) primary intracranial and central nervous systems, only (C70.0-C72.9, C75.1-C75.3).

“While ‘consistent with’ can indicate involvement, ‘neoplasm’ without specification of malignancy is not diagnostic except for non-malignant primary intracranial and central nervous system tumors.”

**Exception:** If cytology is reported as “suspicious,” abstract the case only if a positive biopsy or a physician’s clinical impression of cancer supports the cytology findings.

### Examples of Diagnostic Terms:

**Example 1:** The inpatient discharge summary documents a chest x-ray *consistent with carcinoma* of the right upper lobe. The patient refused further work-up or treatment. *Consistent with carcinoma* is indicative of cancer.

**Example 2:** The mammogram report states *suspicious for malignancy*. *Suspicious for malignancy* is indicative of cancer.

### Ambiguous Terms That Do Not Constitute a Diagnosis *without additional information*

The following modifying terms, when applied to a malignancy, should NOT be considered diagnostic of cancer without additional information such as treatment for cancer.

Cannot be ruled out possible	questionable suggests	equivocal potentially malignant	rule out worrisome
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Positive molecular marker or cytogenetic testing in the absence of pathologic or clinical evidence of reportable disease are indicative of risk only and do not constitute a diagnosis.

**In Situ and Invasive** (Behavior codes /2 and /3)

- If an **ambiguous term(s) precede** a word that is **synonymous** with an in situ or invasive tumor (e.g.: cancer, carcinoma, malignant neoplasm, non-invasive cancer, etc.) the case is reportable. Abstract and report the case

*Example:* The pathology report says: Prostate biopsy with markedly abnormal cells that are typical of adenocarcinoma.” Abstract and report the case.

*Negative Example:* The final diagnosis on the outpatient report reads: Rule out leukemia. Do not abstract or report the case. **Do** track that you reviewed the record and deemed the case not reportable. Be sure to include the reason the case is not reportable to FCDS so you do not have to re-review the case during the annual AHCA casefinding audit.

- **Discrepancies:** If one section of the medical record(s) uses a reportable term such as “apparently” and another section of the medical record(s) uses a term that is not on the reportable list, accept the reportable term and abstract the case.

*Exception:* Do not abstract a case based on *suspicious* cytology, alone. The case is to be abstracted only if proven by *positive cytology or other diagnostic method* including a physician’s clinical diagnosis. See the data item Diagnostic Confirmation for methods of diagnosis.

*Note:* If the **word or an equivalent term does not appear** on the reportable list or is not a form of a word on the reportable list, the term is not diagnostic of cancer. Do not report the case. Forms of the word are such as: “Favored” rather than Favor(s); “appeared to be” rather than appears. Do not substitute synonyms such as “supposed” for presumed or “equal” for comparable.

- Use these terms when **screening** diagnoses on pathology reports, operative reports, imaging/scans, mammograms and other diagnostic testing other than tumor markers.

*Note:* If the ambiguous diagnosis is **proven to be not reportable** by biopsy, cytology, or physician’s statement (cancer was ruled out as diagnosis), **do not report** the case.

*Example:* Mammogram shows calcifications suspicious for intraductal carcinoma. The biopsy of the area surrounding the calcifications is negative for malignancy. Do not report the case.

**Benign and borderline primary intracranial and CNS tumors**

- Use the “Ambiguous Terms that are Reportable” list to identify benign and borderline primary intracranial and CNS tumors that are reportable.
- If any of the reportable **ambiguous terms precede** either the word **“tumor”** or the word **“neoplasm,”** the case is reportable. Abstract and report the case.

*Example:* The mass on the CT scan is consistent with pituitary tumor. Abstract and report the case.

- **Discrepancies:** If one section of the medical record(s) uses a reportable term such as “apparently” and another section of the medical record(s) uses a term that is not on the reportable list, accept the reportable term, abstract and report the case.

**Exception:** Do not abstract a case based only on suspicious cytology without additional confirmation of the presence of disease. The case is abstracted and reported if proven by positive cytology or other diagnostic methods including a physician's clinical diagnosis. See the data item Diagnostic Confirmation for methods of diagnosis.

**Note:** If the **word or an equivalent term does not appear** on the reportable list or is not a form of a word on the reportable list, the term is not diagnostic of cancer. Do not abstract the case. Forms of the word are such as: "Favored" rather than Favor(s); "appeared to be" rather than appears. Do not substitute synonyms such as "supposed" for presumed or "equal" for comparable.

- Use these terms when **screening** diagnoses on pathology reports, scans, ultrasounds, and other diagnostic testing other than tumor markers.

**Note:** If the **ambiguous** diagnosis is proven to be **not reportable** by biopsy, cytology, or physician's statement, **do not abstract or report** the case.

**d) Outpatient/Ambulatory Care Only Cases**

There must be sufficient documentation in the medical chart (positive radiology report, positive pathology report, physician statement, etc.) that definitively establishes that the patient either has active malignancy and/or is currently undergoing therapy for malignancy. If insufficient documentation exists in the medical chart, do not abstract the case.

**e) Non-Analytic Cases**

The American College of Surgeons/Commission on Cancer does not require accredited facilities to abstract non-analytic cases. However, FCDS does require the collection and reporting of ALL cases that meet the FCDS reporting requirements, regardless of Class of Case.

**f) Historical Cases**

The American College of Surgeons/Commission on Cancer does not require accredited facilities to abstract historical cases. However, FCDS does require the collection and reporting of certain historical cancers even when the patient has no evidence the historical cancer is "active".

Patients diagnosed with any cancer during their lifetime are many times more likely to develop new cancers. It is important for researchers to know the number and types of any and all cancers each patient has had during his/her lifetime in order to effectively research and evaluate cancer incidence.

If a patient has had at least one primary reportable neoplasm that is currently active or under treatment, all other primary reportable neoplasms the patient has ever had (active or inactive), regardless of the date of diagnosis, must be reported. Each case of cancer must be abstracted and reported separately.

Information about the previous (historical) primary(s) may be sketchy. The abstractor should attempt to complete an abstract with as much information as is available in the medical record.

If the patient does not have any reportable neoplasms, active or under treatment, no other primary neoplasms the patient has ever had need to be reported.

See Section I-C Abstracting Historical Cases Optional Minimal Dataset for guidelines regarding the abstracting of historical cases in an abbreviated format. **NOTE: DO NOT INCLUDE OBSOLETE CODES** of any kind when reporting historical cases regardless of method for reporting these cases (Minimal Historical Grid or Full Abstract). This includes obsolete histology codes (do not include), obsolete treatment codes (do not include), obsolete staging system or stage code(s), etc. Abstract these cases according to current standards.

**g) Multi-Facility Reporting (shared cases)**

FCDS requires that any cancer case that meets FCDS case reporting requirements must be submitted by every facility providing services to the patient. Therefore, facilities that are members of shared, combined or joint cancer registries and/or cancer programs must report each cancer case seen in each facility separately unless approved to do so by the Florida Department of Health and FCDS.

**h) Responsibility for Reporting**

It is the responsibility of the custodian of the medical record or the facility that is administering care to report the case to FCDS. FCDS reviews the Agency for Health Care Administration (AHCA) cancer patient data annually as a retrospective quality control completeness audit. The AHCA database provides an after-the-fact case finding mechanism; ensuring cancer cases that have been reported to AHCA are also included in the FCDS database.

**i) Annual Reporting Deadline – June 30<sup>th</sup>**

The June 30<sup>th</sup> Deadline is an annual milestone for cancer reporting in Florida. Florida law requires that all cancer cases diagnosed/treated for cancer, having a cancer-related health visit while undergoing cancer treatment, or having any evidence of disease at the time of encounter must be abstracted and transmitted to FCDS within 6 months of the date of first encounter for cancer.

FCDS reinforces the 6-month reporting standard with a June 30<sup>th</sup> Deadline each year.

Reporting Compliance and Data Quality Reports are run following the annual June 30<sup>th</sup> Deadline.

Facilities not in compliance with the 6-month reporting rule will be notified by FCDS of the delinquency. Each facility will be asked to develop a remedial plan to bring the facility back into compliance with state statutes. The plan must also include a statement indicating how the facility plans to stay in compliance once the current reporting year has been completed and compliance has been reached for the year in question.

If no action is taken or delinquency continues, FCDS will notify the Florida Department of Health that the facility is non-compliant and further action will be taken. Any remediation or other action plan must be approved by the Florida Department of Health and FCDS. FCDS will monitor the plan.

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**Table A: NAACCR Layout Version 15: Comparison of Reportable Cancers: FCDS, CoC, and NPCR.**

	<b>FCDS</b>	<b>CoC</b>	<b>NPCR</b>
<b>Reportable Diagnoses</b>	1. Behavior code of 2 or 3 in ICD-O-3 (includes LIN III, VIN III, VAIN III, AIN III). 2. Non-malignant (behavior codes 0 and 1) primary intracranial and central nervous system tumors, including juvenile astrocytoma (M9421/3)* for primary sites as defined in the Table: Primary Site Codes for Non-Malignant Primary Intracranial and Central Nervous System Tumors.	1. Behavior code of 2 or 3 in ICD-O-3; or, for 2010 and later diagnoses, behavior code 3 according to the <i>WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues</i> (2008). 2. Non-malignant (behavior codes 0 and 1) primary intracranial and central nervous system tumors, including juvenile astrocytoma (M9421/3)* for primary sites as defined in the Table: Primary Site Codes for Non-Malignant Primary Intracranial and Central Nervous System Tumors.	1. Behavior code of 2 or 3 in ICD-O-3 (includes VIN III, VAIN III, AIN III); or, for 2010 and later diagnoses, behavior code 3 according to the <i>WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues</i> (2008). 2. Non-malignant (behavior codes 0 and 1) primary intracranial and central nervous system tumors, including juvenile astrocytoma (M9421/3)* for primary sites as defined in the Table: Primary Site Codes for Non-Malignant Primary Intracranial and Central Nervous System Tumors.
<b>Exceptions (not reportable)</b>	1. Skin cancers (C44._) with histologies 8000-8110. 2. CIS of the cervix and CIN III 3. PIN III (after 1/1/2001).	1. Skin cancers (C44._) with histology 8000-8110 (after 1/1/2003); prior to that date, AJCC stage groups 2-4 in this group were reportable. 2. CIS of the cervix and CIN III (after 1/1/96). 3. PIN III (after 1/1/96). 4. VIN III (after 1/1/96). 5. VAIN III (after 1/1/96). 6. AIN (after 1/1/96).	1. Skin cancers (C44._) with histologies 8000-8005, 8010-8046, 8050-8084, 8090-8110. 2. CIS of the cervix and CIN III. 3. PIN III (after 1/1/2001).
<b>Historical Neoplasm</b>	If a patient has at least one primary reportable neoplasm which is active or under treatment, all other primary reportable neoplasms the patient has ever had (active or inactive), regardless of the date of diagnosis, must be reported to FCDS.	Not included unless patient has evidence of this neoplasm (active disease).	Not included unless patient has evidence of this neoplasm (active disease).
<b>Multiple Primary Rules</b>	2007 Multiple Primary and Histology Coding Rules	2007 Multiple Primary and Histology Coding Rules.	2007 Multiple Primary and Histology Coding Rules
<b>Hematopoietic and Lymphoid Neoplasm Rules</b>	2014 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the 2014 Hematopoietic Database	2014 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the 2014 Hematopoietic Database	2014 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the 2014 Hematopoietic Database
<b>Ambiguous Terminology Considered as Diagnostic of Cancer</b>	apparent(ly) appears comparable with compatible with consistent with favors malignant appearing most likely presumed probable suspect(ed) suspicious (for) typical of Exception: if the cytology is reported as "suspicious" and neither a positive biopsy nor a physician's clinical impression supports the cytology findings, do not consider as diagnosis of cancer.	apparent(ly) appears comparable with compatible with consistent with favors malignant appearing most likely presumed probable suspect(ed) suspicious (for) typical of Exception: if the cytology is reported as "suspicious" and neither a positive biopsy nor a physician's clinical impression supports the cytology findings, do not consider as diagnosis of cancer.	apparent(ly) appears comparable with compatible with consistent with favors malignant appearing most likely presumed probable suspect(ed) suspicious (for) typical of Exception: if the cytology is reported as "suspicious" and neither a positive biopsy nor a physician's clinical impression supports the cytology findings, do not consider as diagnosis of cancer.
<b>Ambiguous Terminology NOT Considered as Diagnostic of Cancer</b>	cannot be ruled out equivocal possible potentially malignant questionable rule out suggests	cannot be ruled out equivocal possible potentially malignant questionable rule out suggests	cannot be ruled out equivocal possible potentially malignant questionable rule out suggests

**SECTION I: GUIDELINES FOR CANCER DATA REPORTING**

	worrisome	worrisome	worrisome
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\* Juvenile astrocytoma is reported as 9421/3.

\*\* Do not substitute synonyms such as “supposed” for “presumed” or “equal” for “comparable.” Do not substitute “likely” for “most likely.” Use only the exact words on the list.

**Table 3. Primary Site Codes for Non-Malignant Primary Intracranial and Central Nervous System Tumors (non-malignant primary intracranial and central nervous system tumors with a behavior code of 0 or 1 [benign/borderline] are reportable regardless of histologic type for these topography codes).**

The CDC Brain Tumor Guide entitled, “*Data Collection of Primary Central Nervous System Tumors*” is available for reference @ <http://www.cdc.gov/cancer/npcr/pdf/btr/braintumorguide.pdf>

*Reference Standards for Cancer Registries, Volume II: Data Standards and Data Dictionary, Sixteenth Edition Version 15 – Chapter III: Standards for Tumor Inclusion and Reportability*

Topography	
Codes	Description
C70.0 C70.1 C70.9	Meninges Cerebral Meninges Spinal meninges Meninges, NOS
C71.0 C71.1 C71.2 C71.3 C71.4 C71.5 C71.6 C71.7 C71.8 C71.9	Brain Cerebrum Frontal lobe Temporal lobe Parietal lobe Occipital lobe Ventricle, NOS Cerebellum, NOS Brain stem Overlapping lesion of brain Brain, NOS
C72.0 C72.1 C72.2 C72.3 C72.4 C72.5 C72.8 C72.9	Spinal Cord, Cranial Nerves, and Other Parts of the Central Nervous System Spinal cord Cauda equina Olfactory nerve Optic nerve Acoustic nerve Cranial nerve, NOS Overlapping lesion of brain and central nervous system Nervous system, NOS
C75.1 C75.2 C75.3	Other Endocrine Glands and Related Structures Pituitary gland Craniopharyngeal duct Pineal gland

**B. CASEFINDING**

Casefinding is the method used to identify new cancer cases, inpatient or outpatient. All facilities are responsible for complete casefinding for all patients seen at your facility regardless of type of service. It is important that the following multiple sources in the hospital be searched to keep missed reportable cases to a minimum. The procedure outlined below should be adapted to each individual facility:

1. **HIM/Medical Record Disease Indices** or Unified Billing System Report (Inpatient and outpatient, including inpatient hospice)
2. **Pathology Reports** (biopsy specimen reports, surgical specimen reports, bone marrow biopsy, needle biopsy, cytology, autopsy, addenda, consultation reports, etc.)
3. **Radiation Therapy** Department (patient logs and/or billing reports)
4. **Infusion Center** (patient logs and/or billing reports)
5. **Outpatient Departments** (including cancer specialty clinics, chemotherapy clinics, infusion centers, day surgery, emergency room, medical oncology logs, etc.)
6. **Diagnostic Imaging** (Radiology) Department (MRI, CT scan, PET scan, x-ray, mammogram, etc.)

**1. HIM/Medical Record Disease Index/Unified Billing System Report**

Every patient record with a reportable ICD-9-CM or ICD-10-CM code (see Current Casefinding List) must be reviewed to determine whether or not the case meets FCDS criteria for case reporting. It is essential that all patient service areas be included in these reports. The FCDS Casefinding Lists have been pared down to only include diagnoses of active disease. Therefore, most cases on your list will need to be abstracted and reported.

ICD-10-CM and ICD-10-PCS will be adopted as a new standard on 10/1/2015. ICD-10-CM Casefinding List is included in this and previous FCDS DAM documents. Please ensure your facility IT staff has been given a copy of the ICD-10-CM list to avoid interruption in casefinding for the last quarter of calendar year 2015.

Upon review, if a patient is found not to have a malignancy as coded by the HIM/Medical Record or Billing Department or does not meet FCDS criteria for case reporting, the name should be added to the facility's "Not Reportable List." The list may be substituted with the facility "suspense" file based on available vendor tools.

The "Not Reportable List" is useful when FCDS is conducts casefinding audits based on AHCA data. Some facilities will save a "Not Reportable List" as an electronic file embedded within their software such as a "suspense" case and should include comments that the registrar reviewed the medical record and determined that the case does not meet reportable criteria. The "suspense" case should include documentation as to why the facility will not report the case either in text and/or using the FCDS AHCA Disposition Codes below.

Code	Description
1	Reportable-Missed Case-Case to be Abstracted & Reported by Facility
2	N/R - Tumor was Not Malignant - Behavior = 0 or 1
3	N/R - NonReportable Skin Cancer - Site=C44.* and Morph = 8000 to 8110
4	N/R - No Evidence of Cancer at This Time - NED
5	N/R - Consultation Only
6	N/R - Cancer Not Proven - Equivocal
7	Case Previously Reported to FCDS by this Facility
8	N/R - Outpatient Record with No Active Cancer Documented in Record
9	N/R - In-situ Cancer of Cervix or CIN III
10	N/R - Other
11	Reportable-Case Abstracted BUT Not found in FCDS files - Abst Requested
12	N/R - No Cancer Mentioned in Medical Record
13	Skins we elected not to FB since most of them turn out N/R
14	N/R - Hematopoietic Diseases Dx Prior to 2001
15	N/R - Case DX Prior to FCDS Reference Date - Same Cancer/Same Facility
16	N/R - Benign or Borderline Brain/CNS Tumor Dx Prior to 2004
20	Unknown if Reportable - No Record of this Patient at this Facility
21	Unknown if Reportable - Lost Medical Record
30	Unknown if Reportable - No Follow-Back Ever Returned by this Facility
40	N/R - Special Case - Other
50	Hospice Case - Not A Hospital
51	Transitional Care Center - Not A Hospital

## 2. Pathology Reports

**ALL ANATOMIC (SURGICAL) PATHOLOGY REPORTS (including reports from biopsy specimen, surgical resection specimen, bone marrow biopsy, needle biopsy and fine needle aspiration biopsy, diagnostic hematology, cytology and autopsy reports and all addenda) for inpatients, outpatients and ambulatory care patients MUST be reviewed to determine whether or not a case is reportable.**

**Pathology Reports MUST also be submitted electronically to FCDS under the FCDS E-Pathology Reporting Program.**

Since most cancer patients have a biopsy or operative resection performed, nearly all of the reportable cases can be identified by pathology reports alone. Check with your pathology department to see if the department information system can be used to facilitate the review of these reports.

Pathology reports must also be reviewed within each reporting facility at least annually to insure that no cases have been missed by the reporting facility.

## 3. Radiation Therapy Department

New patient registration rosters and radiation therapy summaries are excellent casefinding sources for patients treated with radiation. Unified Billing System Reports also can be used to identify these cases.

## 4. Outpatient Departments

New patient registration rosters for single-day surgery departments, oncology-related service areas (specialty clinics, chemotherapy clinics, infusion centers, day surgery, and other ambulatory care), outpatient departments (including outpatient diagnostic radiology and laboratory service areas) and emergency rooms are additional casefinding sources for patients seen only in an ambulatory care setting. Unified Billing System Reports also can be used to identify these cases.

## 5. Diagnostic Imaging (Radiology) Department

New patient registration rosters for patients receiving diagnostic imaging services (x-ray, CT scan, PET scan, MRI, or other imaging) are an excellent source for identifying new cancer cases.

**SECTION I: GUIDELINES FOR CANCER DATA REPORTING**

**ICD-9-CM CASEFINDING LIST FOR REPORTABLE TUMORS – Jan-Sept 2015**

The following ICD-9-CM list is to be used to identify all reportable tumors. Some ICD-9-CM codes may include conditions that are not malignant or otherwise not reportable. These records should be reviewed and assessed individually to verify whether or not they are reportable to FCDS. No Optional Codes are included.

<b>ICD-9-CM</b>	<b>Description</b>
140.00-209.36	Malignant neoplasms (excluding skin 173.0-173.9)
209.70-209.79	Secondary neuroendocrine tumors
225.0-225.9	Benign neoplasm of brain and spinal cord neoplasm
227.3-227.4	Benign neoplasm of pituitary gland, pineal body, and intracranial endocrine-related structures
228.02	Hemangioma; of intracranial structures
228.1	Lymphangioma, any site brain, other parts of CNS
230.0-234.9	Carcinoma in situ (exclude: skin, cervix and prostate– 232.0-232.9, 233.1, 233.4)
237.0-237.1, 237.5, 237.6, 237.9	Neoplasm of uncertain behavior (borderline) of intracranial endocrine glands, brain and CNS
238.4	Polycythemia vera (9950/3)
239.6-239.7	Neoplasms of unspecified nature Brain and CNS
273.3	Waldenstrom macroglobulinemia (9761/3)
511.81	Malignant pleural effusion (code first malignant neoplasm if known)
789.51	Malignant ascites (code the first malignant neoplasm if known)
V58.0	Encounter for radiotherapy
V58.1	Encounter for chemotherapy and immunotherapy
V58.11	Antineoplastic Chemotherapy
V58.12	Antineoplastic Immunotherapy

Note: Pilocytic/juvenile astrocytoma (M-9421) is reported with the behavior coded /3 (9421/3 not 9421/1).

**ICD-10-CM CASEFINDING LIST FOR REPORTABLE TUMORS – Oct-Dec 2015**

The following ICD-10-CM list is to be used to identify all reportable tumors. Some ICD-10-CM codes may contain conditions that are not malignant or otherwise not reportable. These records should be reviewed and assessed individually to verify whether or not they are reportable to FCDS. No Optional Codes are included.

<b>ICD-10-CM</b>	<b>Description</b>
C00._ - C43._	Malignant neoplasms
C45._ - C96._	Malignant neoplasms
D00._ - D09._	Carcinoma in situ (exclude: skin, cervix and prostate– D04._, D06._ and D07.5)
D18.02	Hemangioma; of intracranial structures
D18.1	Lymphangioma, any site brain, other parts of CNS
D32._	Benign neoplasm of meninges (cerebral, spinal and unspecified)
D33._	Benign neoplasm of brain and other parts of central nervous system
D35.2, D35.4	Benign neoplasm of pituitary gland, craniopharyngeal duct and pineal gland
D42._, D43._	Neoplasm of uncertain or unknown behavior of meninges, brain, CNS
D44.3-D44.5	Neoplasm of uncertain behavior of pituitary gland, craniopharyngeal duct and pineal gland
D45	Polycythemia vera (9950/3)
D46._	Myelodysplastic syndromes (9980, 9982, 9983, 9985, 9986, 9989, 9991, 9992)
D47.1	Chronic myeloproliferative disease (9960, 9963)
D47.3	Essential (hemorrhagic) thrombocytopenia (9962)
D47.4	Osteomyelofibrosis (9961)
D47.7	Other specified neoplasm of uncertain/unknown behavior of lymphoid, hematopoietic (9965, 9966, 9967, 9971, 9975, 9987)
D47.9	Neoplasm of uncertain behavior of lymphoid, hematopoietic and related tissue, unspecified (9960, 9970, 9931)
D49.6, D49.7	Neoplasm of unspecified behavior of brain, endocrine glands and other CNS
J91.0	Malignant Pleural Effusion
R18.0	Malignant ascites

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Z51.0	Encounter for antineoplastic radiation therapy
Z51.1	Encounter for antineoplastic chemotherapy and immunotherapy
Z51.11	Encounter for antineoplastic chemotherapy
Z51.12	Encounter for antineoplastic immunotherapy

Note: Pilocytic/juvenile astrocytoma (M-9421) is reported with the behavior coded /3 (9421/3 not 9421/1).

### C. ABSTRACTING

#### 1. Personnel Requirements – Abstractor Training and FCDS Abstractor Code

**Abstractor Training:** Trained personnel must perform abstracting. FCDS provides basic incidence abstracting training via web-based modules free of charge and available 24 hours a day, 7 days a week. The 20 modules constitute one “course” in the FCDS Learning Management System. The 20 modules include over 1000 slides with sound overlay, practice exercises, and quizzes to monitor progress. The entire course takes from 40-80 hours to complete, depending on individual knowledge level at the start of the course. It is highly recommended that each student enter the course with a strong understanding of human anatomy and medical terminology. Modules are available at <http://fcdsmoodle.med.miami.edu/>.

Other training is available through SEER\*Training, SEER\*Educate, the Commission on Cancer, the American Joint Committee on Cancer, the National Cancer Registrars Association (NCRA), the Florida Cancer Registrars Association (FCRA), and the North American Association of Central Cancer Registries (NAACCR).

**FCDS Abstractor Code:** Every registrar/abstractor planning to work in the State of Florida is required to obtain an individual FCDS Abstractor Code. This code is assigned by FCDS to persons who successfully pass the FCDS Abstractor Code On-Line Examination, regardless of certification by NCRA as a CTR, experience in the registry industry, or other factors. As of January 1, 2013 any individual planning to acquire a New FCDS Abstractor Code or planning to renew an Existing FCDS Abstractor Code must take and pass the FCDS Abstractor Code Exam.

The FCDS Abstractor Code Requirement has been FCDS Policy for many years and applies to every cancer registrar working in the state of Florida (CTR or non-CTR, Florida resident or out-of-state contractor, regardless of number of years’ experience). FCDS will not accept cases from individuals without an Active/Current FCDS Abstractor Code.

While the FCDS Abstractor Code Requirement Policy remains unchanged, the FCDS Abstractor Code Exam is a new tool introduced to help FCDS expedite FCDS Abstractor Code approvals, renewals, and monitoring. Exams are short (15-20 multiple choice or T/F questions) with a variable mix of content questions weighted differently depending on whether this is an exam for a New FCDS Abstractor Code or Renewal of an existing FCDS Abstractor Code.

Questions are electronically selected at random from a pool of more than 350 questions covering 6 major topic areas. No two exams will be alike.

#### **The 6 topic areas include;**

- General Abstracting Knowledge
- General Abstracting Rules and Florida-Specific Rules
- Primary Site/Histology/Grade
- Stage at Diagnosis
- Latest Rule Changes
- Treatment and Survival

#### **Standard References Used for Testing**

- FCDS DAM (current version)
- ICD-O-3 (including errata and updates)

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- MPH Rules for Solid Tumors (current)
- MPH Rules/Database for Hematopoietic/Lymphoid Neoplasms (current)
- Collaborative Stage Data Collection System – changes to TNM and SS2016 in 2015-2016
  - ◊ Part I – Section 1 – General Instructions
  - ◊ Part I – Section 2 – Lab Tests, Tumor Markers, SSF Notes
  - ◊ Part II – Site-Specific Schema
- SEER\*Rx (current)
- SEER Self-Instruction Manuals (basics)
  - ◊ Book 2 – Cancer Characteristics
  - ◊ Book 3 – Tumor Registrar Vocabulary: Composition of Medical Terms
  - ◊ Book 4 – Human Anatomy as Related to Tumor Formation

### **WHO NEEDS TO TAKE THE FCDS ABTRACTOR CODE EXAM?**

- ✓ Individuals hoping to acquire a NEW FCDS Abstractor Code will need to take the New FCDS Abstractor Code Exam.
- ✓ If an individual's FCDS Abstractor Code has been expired for greater than 2 years, the individual must re-apply and take and pass the New FCDS Abstractor Code Exam.

### **WHO NEEDS TO TAKE THE FCDS ABSTRACTOR CODE RENEWAL EXAM?**

- ✓ Individuals with an ACTIVE (not yet expired) FCDS Abstractor Code will be required to take and pass the FCDS Abstractor Code Renewal Exam once their code has expired.
- ✓ Individuals with an EXPIRED FCDS Abstractor Code will be required to take the FCDS Abstractor Code Renewal Exam each year in order to keep their FCDS Abstractor Code current and to renew their individual FCDS Abstractor Code, annually.

### **2. Case Abstracting Requirements – Timeliness**

Individual cases **must be abstracted no later than six months** after the date of first contact with the reporting facility. The only exceptions to this reporting timeline are the free-standing ambulatory surgical centers who are reporting under the Ambulatory Centers Cancer Reporting Program.

Cases may be abstracted earlier than six months after the date of first contact, but only if the required information regarding first course of therapy is available and complete.

All cases meeting the reporting requirements outlined in Section I.A must be abstracted following the guidelines set forth in Section II of this document. Questions regarding the interpretation of individual data items should be referred to the FCDS office.

**Note: The ACoS CoC changed CoC Cancer Program Standard 5.2 (abstracting timeliness) on 1/1/2014. This is a change for CoC Cancer Program Accreditation (only) and does not change the Florida 6-month reporting requirement or the FCDS June 30<sup>th</sup> Deadline.**

**Why?** Florida Statute requires that cases be completely abstracted (all information must be included regarding the diagnosis, staging, first course of treatment, cancer progression or recurrence) within 6-months of first patient encounter for cancer at your facility.

**Do not send FCDS a partial abstract as part of ACoS CoC Rapid Quality Reporting System (RQRS).**

Note: The CoC FORDS Manual instructs registrars from CoC Programs that the data item "Date Case Completed" should not be filled in until the case has been completed and all data required

have been abstracted/coded.

The case is “pending completion” until all first course treatment has been investigated and documented in the original abstract sent to FCDS and the final abstract that is sent to the NCDB.

All abstracts are required to pass the FCDS EDITS metafile.

### 3. Not Reportable List

A list of cases reviewed but not reported to FCDS (not reportable list) should be maintained by each reporting facility either in electronic or other format. This can be as part of your abstracting software maintained in your “suspense” file or in a separate document with easy access. A sample form is included at the end of this Section. Any patient encounter that appears on a facility casefinding list that does not meet the reporting requirements outlined in Section I should be recorded on the “Not Reportable List” with an explanation as to why the case will not be reported. FCDS suggests you also include the FCDS Disposition Code associated with the reason not reported to facilitate your annual AHCA Follow-Back activities.

The list should include the patient’s name, social security number, medical record number, date of birth, ICD-9-CM or ICD-10-CM code, admission date, and disposition code or reason they were not reported. The list may be kept in a paper notebook, spreadsheet, vendor software suspense file, or in any other easily accessible format. You may use the FCDS form or you may create your own.

Casefinding audits are performed periodically at every reporting facility as well as through annual case matching with the Florida Agency for Health Care Administration (AHCA) data files to assure completeness of reporting. The not reportable list will expedite resolution of cases that show up as ‘missed cases’ during these casefinding audits. Missed Cases Are Late Reported Cases – always.

Failure to keep the list will result in FCDS requesting that the reporting facility pull each ‘missed case’ record again and review whether or not it should have been reported to FCDS. An explanation must then be submitted to FCDS detailing any reason any case will not be reported to FCDS or the case must be abstracted and reported to FCDS.

FCDS Disposition Codes may be included in the file as reference for reason the case is not reportable.

Code	Description
1	Reportable-Missed Case-Case to be Abstracted & Reported by Facility
2	N/R - Tumor was Not Malignant - Behavior = 0 or 1
3	N/R - NonReportable Skin Cancer - Site=C44.* and Morph = 8000 to 8110
4	N/R - No Evidence of Cancer at This Time - NED
5	N/R - Consultation Only
6	N/R - Cancer Not Proven - Equivocal
7	Case Previously Reported to FCDS by this Facility
8	N/R - Outpatient Record with No Active Cancer Documented in Record
9	N/R - Insitu Cancer of Cervix or CIN III
10	N/R - Other
11	Reportable-Case Abstracted BUT Not found in FCDS files - Abst Requested
12	N/R - No Cancer Mentioned in Medical Record
13	Skins we elected not to FB since most of them turn out N/R
14	N/R - Hematopoietic Diseases Dx Prior to 2001
15	N/R - Case DX Prior to FCDS Reference Date - Same Cancer/Same Facility
16	N/R - Benign or Borderline Brain/CNS Tumor Dx Prior to 2004
20	Unknown if Reportable - No Record of this Patient at this Facility
21	Unknown if Reportable - Lost Medical Record
30	Unknown if Reportable - No Follow-Back Ever Returned by this Facility
40	N/R - Special Case - Other
50	Hospice Case - Not A Hospital
51	Transitional Care Center - Not A Hospital

### 4. Abstracting Non-Analytic and Historical Cases

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Although the Commission on Cancer/American College of Surgeons (COC/ACoS) does not require accredited facilities to abstract non-analytic or historical cases, a population-based cancer registry such as FCDS must record ALL cancers meeting the FCDS reporting requirements, regardless of class of case, place of diagnosis or date of diagnosis.

FCDS realizes that much of the information about the original diagnosis, staging and treatment of non-analytic and historical cancers may be unavailable or incomplete. The abstractor should attempt to complete each abstract with as much information as is available in the medical record.

- a. The following morphology codes are reportable as historical cases if they were diagnosed prior to 1/1/01 and the patient has another active reportable neoplasm. These neoplasms were historically reported with behavior /1 (borderline malignancy). They were changed to behavior /3 (malignant) when ICD-O-3 was released in 2001. This change in reporting rules is consistent with ICD-O-3.

8931/3	9960/3	9981/3	9989/3
9393/3	9961/3	9982/3	
9538/3	9962/3	9983/3	
9950/3	9980/3	9984/3	

If a patient diagnosed with any of the above hematopoietic disease morphology codes prior to 01/01/2001 undergoes transformation to another hematopoietic disease before 01/01/2010, enter the case into the registry using the histology and behavior (malignant) diagnosed on or after 01/01/2001 with the 2001 or later diagnosis date.

If the diagnosis date of a hematopoietic disease is unknown and the admission date is 01/01/2001 or later, the case is reportable using ICD-O-3 reporting criteria. Please refer to the FCDS Rules for Reporting Hematopoietic Diseases in Section II for specific instructions on reporting hematopoietic diseases.

- b. Benign and borderline brain and central nervous system tumors are reportable even if they were diagnosed prior to 1/1/04 and the patient has another active reportable neoplasm.
- c. Squamous Intraepithelial Neoplasia Grade III of vulva, vagina, and anus are reportable as historical cases, even if they were diagnosed prior to 01/01/2001, and the patient has another active reportable neoplasm.
- d. Carcinoid Tumor of the Appendix will become a reportable condition for diagnoses 1/1/2015 and forward. If the patient has a diagnosis date prior to 1/1/2015, the carcinoid of the appendix should not be abstracted, reported, or even included in your accession listing or sequencing of cancers.

### 5. Abstracting Historical Cases Optional Minimal Dataset

Historical case refers to a primary reportable neoplasm (malignant or benign/borderline brain/CNS tumors) that it is not active (no evidence of disease) and currently not receiving any treatment AND the patient is seen at the reporting facility for another cancer/benign reportable neoplasm that is active and/or undergoing treatment.

There are two methods for reporting a Historical Case:

FCDS will accept historical cases reported as full abstracts or reported using the minimal dataset. **DO NOT INCLUDE OBSOLETE CODES of any kind when reporting historical cases** regardless of method for reporting these cases (Minimal Historical Grid or Full Abstract). This includes obsolete histology codes (do not include), obsolete treatment codes (do not include), obsolete staging system or stage code(s), etc. Abstract cases according to the current coding standard.

- a. For every abstract submitted, the record layout will allow for the entry of up to five (5) historical cases. The fields required for each of the five cases include:
    1. Sequence Number
    2. Diagnosis Date
    3. Primary Site (ICD-O-3)
    4. Histology (ICD-O-3)
    5. Behavior (ICD-O-3)
    6. Laterality
    7. State of Residence at Diagnosis (State Abbreviation)
    8. County of Residence at Diagnosis (FIPS County Code)
    9. CS SSF 25 - Discriminator
  - b. These fields will be edited at time of transmission and will include Sequence Number and Diagnosis Date edit checks as well as State and County edit checks.
  - c. **These fields should ONLY be used when abstracting a historical case with insufficient information.**
  - d. **A complete abstract MUST be reported to FCDS for cases with sufficient information in the patient's medical record or when the patient has evidence of the historical cancer at the time of patient encounter (persistent disease, progression of disease or disease recurrence – patient with evidence of this cancer at the time of patient encounter).**
  - e. REMEMBER, the minimal dataset only applies to Class of Case 33 Historical Cases with insufficient information. All other Non-Analytical cases, including Class of Case 33 historical cases with sufficient information REQUIRE a full abstract be reported to FCDS.
  - f. Historical Cases should not include Unknown Primary Cancers (C80.9 or C76.\*).
  - g. Quality Control for these cases will be increased and documentation supporting the minimal dataset may need to be provided.
6. Reporting Historical Cases in the State Specific fields

- a. Historical information must be completed starting with the eight fields in HISTORY1. Every additional historical case would use the next sequential group of eight fields (i.e. HISTORY2 through HISTORY5). No gaps in the groups can exist.

**Examples:**

**One Historical Case** – MUST use Historical #1 group of nine fields.

**Two Historical Cases** – MUST use Historical #1 and Historical #2 groups of nine fields.

In the example of Two Historical cases, if Historical #1 and Historical #3 groups of nine fields are populated, than abstract will not be accepted due to a gap in Historical #2 group.

- b. When a particular group is selected (Historical #1), all nine fields must be filled.

Historical date must be completed in accordance with the current standards. If any of these fields are left blank, then the abstract and possibly the entire batch will be rejected.

**Examples:**

**Historical #1: Sequence Number,**

**Historical #1: Dx Date,**

**Historical #1: Primary Site,**

**Historical #1: Histology,**

**Historical #1: Behavior,**

**Historical #1: Laterality,**  
**Historical #1: Dx State Abbreviation,**  
**Historical #1: Dx County FIPS**  
**Historical #1: CS SSF25 Discriminator**

Once these historical groupings pass structure check edits, a full abstract will be generated from the data provided. The derived Historical abstracts will be subject to our full set of edit checks. If any failures exist, the abstract and batch will be rejected.

**DO NOT INCLUDE OBSOLETE CODES of any kind when reporting historical cases** regardless of method for reporting these cases (Minimal Historical Grid or Full Abstract). This includes obsolete histology codes (do not include), obsolete treatment codes (do not include), obsolete staging system or stage code(s), etc. Abstract cases according to current coding standard.

7. Annual Reporting Deadline – June 30<sup>th</sup>

The June 30<sup>th</sup> Deadline is an annual milestone for cancer reporting in Florida. Florida law requires that all cancer cases diagnosed/treated for cancer, having a cancer-related health visit while undergoing cancer treatment, or having any evidence of disease at the time of encounter must be abstracted and transmitted to FCDS within 6 months of the date of first encounter for cancer. FCDS reinforces the 6-month reporting standard with a June 30<sup>th</sup> Deadline each year.

Compliance and Data Quality Reports are run following the annual June 30<sup>th</sup> Deadline.

Facilities not in compliance with the 6-month reporting rule will be notified by FCDS of the delinquency. Each facility will be asked to develop a remedial plan to bring the facility back into compliance with state statutes with a plan to remain in compliance. If no action is taken or delinquency continues, FCDS will notify the Florida Department of Health that the facility is non-compliant and further action will be taken. Any remediation or other action plan must be approved by the Florida Department of Health and FCDS. FCDS will monitor the plan.

8. Required/Recommended Desktop References – paper and/or electronic – current version

**REQUIRED DESKTOP REFERENCES**

<b>REQUIRED REFERENCE</b>	<b>ORDERING INFORMATION</b>
<b>Current FCDS Data Acquisition Manual</b>	FCDS, Florida Cancer Data System PO Box 016960 (D4-11) Miami, FL 33101 <a href="http://fcds.med.miami.edu/inc/downloads.shtml">http://fcds.med.miami.edu/inc/downloads.shtml</a>
<i>International Classification of Diseases for Oncology, 3<sup>rd</sup> ed. Geneva, World Health Organization: 2000, including three published errata and the 2011 ICD-O-3 Update</i>	The World Health Organization WHO Publications Center USA; 49 Sheridan Avenue; Albany, NY 12210  ISBN 9241545348 Order Number 11503350 <a href="http://www.who.int/classifications/icd/en/index.html">http://www.who.int/classifications/icd/en/index.html</a>
<b>Current Multiple Primary and Histology Coding Rules for Solid Tumors</b>	National Cancer Institute, SEER Program, Bethesda, MD Johnson CH, Peace S, Adamo P, et al. National Cancer Institute, Surveillance, Epidemiology and End Results Program. Bethesda, MD: 2007 <a href="http://seer.cancer.gov/registrars">http://seer.cancer.gov/registrars</a>

**SECTION I: GUIDELINES FOR CANCER DATA REPORTING**

<b>Current</b> <i>Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual</i> and Hematopoietic Database (desktop or web-based versions available)	Download latest version from the National Cancer Institute, SEER Program, Bethesda, MD <a href="http://seer.cancer.gov/registrars">http://seer.cancer.gov/registrars</a>
<i>SEER Summary Staging Manual 2000</i> , including 3 published Errata (2001, 2002, 2012)	Download e-version (no printed versions available) National Cancer Institute, SEER Program, Bethesda, MD <a href="http://seer.cancer.gov/registrars">http://seer.cancer.gov/registrars</a>
<b>Current</b> <i>Collaborative Staging Data Collection System Coding Instructions</i> <i>Part I – Section 1 – General Instructions</i> <i>Part I – Section 2 – Tumor Markers and SSFs</i> <i>Part II – Site Specific Schema</i> , current edition	American Joint Committee on Cancer (AJCC) <a href="http://cancerstaging.org/">http://cancerstaging.org/</a>
<b>Current</b> <i>SEER*Rx – Interactive Drug Database</i>	National Cancer Institute, Surveillance, Epidemiology and End Results Program, Bethesda MD. Available for download at <a href="http://seer.cancer.gov/registrars/">http://seer.cancer.gov/registrars/</a>

**RECOMMENDED DESK REFERENCES**

<b>RECOMMENDED BOOK</b>	<b>ORDERING INFORMATION</b>
<i>Facility Oncology Registry Data Standards (FORDS)</i> , current edition	American College of Surgeons (ACS) 55 East Erie Street Chicago, IL 60611-2797 <a href="http://www.facs.org/cancer/coc/">http://www.facs.org/cancer/coc/</a>
<i>CA: A Cancer Journal for Clinicians</i>	Lippincott Williams & Wilkins Publishers P.O. Box 1600 Hagerstown, MD 21741-9910 301-223-2300 (Voice) <a href="http://caonline.amcancersoc.org/">http://caonline.amcancersoc.org/</a>
<i>Cancer Principles and Practice of Oncology</i> , 9 <sup>th</sup> edition	Lippincott Williams & Wilkins Publishers 227 East Washington Square Philadelphia, PA 19106-3780 ISBN-10: 1451105452
<i>Cancer Registry Management Principles &amp; Practice for Hospitals and Central Registries</i> , 3rd Edition, 2011	Kendall/Hunt Publishing Company 4050 Westmark Drive, PO Box 1840 Dubuque, IA 52004-1840 1-(800) 228-0810 <a href="http://www.kendallhunt.com/ncra">www.kendallhunt.com/ncra</a> ISBN 978-0-7575-6900-5
<i>AJCC Cancer Staging Manual</i> , 7th ed. American Joint Committee on Cancer, Chicago IL. Springer: 2009	Edge, S.B.; Byrd, D.R.; Compton, C.C.; Fritz, A.G.; Greene, F.L.; Trotti, A. (Eds.) 7th ed. 2010, 2010, X, 646 p. 130 illus. With CD-ROM. Softcover, ISBN 978-0-387-88440-0  <a href="http://www.springer.com/">http://www.springer.com/</a>
<i>American Cancer Society Textbook of Clinical Oncology</i>	American Cancer Society Vermont Division, Inc. 13 Loomis Street Montpelier, VT 05602 1-800-227-2345; 1-800-ACS-2345 <a href="http://www.cancer.org">http://www.cancer.org</a>

**SECTION I: GUIDELINES FOR CANCER DATA REPORTING**

<p><i>Registry Plus Online Help</i></p>	<p>Download the free desktop reference, <i>Registry Plus Online Help</i> at <a href="http://www.cdc.gov/cancer/npcr">http://www.cdc.gov/cancer/npcr</a>  <i>Online Help</i> is an interactive tool that incorporates many of the references above and is maintained by the CDC. The <i>Registry Plus Online Help</i> application includes fully indexed versions of the FORDS Manual, Collaborative Stage, and Multiple Primary and Histology Coding manuals as well as the NAACCR Data Dictionary, the SEER Coding Manual and the ICD-O-3.</p>
<p><i>NAACCR Standards for Cancer Registries Volume II: Data Standards and Data Dictionary, current edition</i></p>	<p>North American Association of Central Cancer Registries, Inc. (NAACCR)                  2121 West White Oaks Drive, Suite B                  Springfield, Illinois 62704-7412                  Phone: (217) 698-0800 Fax: (217) 698-0188  <a href="http://www.naacr.org">http://www.naacr.org</a></p>
<p><i>SEER Self Instructional Manuals 1-4, 7; Book 1 – Objectives and Functions of a Tumor Registry (1999)</i>  <i>Book 2 – Cancer Characteristics and Selection of Cases(1991)</i>  <i>Book 3 – Tumor Registrar Vocabulary: The Composition of Medical Terms (1992)</i>  <i>Book 4 – Human Anatomy as Related to Tumor Formation (1995)</i>  <i>Book 7 - Statistics/Epidemiology for Cancer Registries(1994)</i></p>	<p>National Cancer Institute                  Publications Ordering Service                  P.O. Box 24128, Baltimore, MD 21227, 301-330-7968                  To order by phone, contact 1-800-4-CANCER and select the option to order publications. You may use our online Publications Locator at  <a href="http://www.cancer.gov/publications">http://www.cancer.gov/publications</a></p> <p>The <i>SEER Program Coding and Staging Manual</i> can be downloaded and they are available in both PDF and ZIP formats. <a href="http://seer.cancer.gov/registrars">http://seer.cancer.gov/registrars</a></p> <p><a href="http://www.seer.cancer.gov/registrars">http://www.seer.cancer.gov/registrars</a> / See order for SEER publications <a href="http://seer.cancer.gov/publications/">http://seer.cancer.gov/publications/</a></p> <p><i>SEER Program: Instructional Manuals on CD-ROM</i></p> <p>Historical Staging and Coding Manuals on CD-ROM</p>
<p><i>SEER Program Code Manual, current edition</i>                  Order SEER Publications <a href="#">Online-order form</a>                  SEER publications available in hardcopy include reports and monographs, coding manuals, self-instructional manuals for tumor registrars, and ICD conversion materials</p>	<p>National Cancer Institute                  Publications Ordering Service                  P.O. Box 24128, Baltimore, MD 21227, 301-330-7968  <a href="http://www.cancer.gov/publications">http://www.cancer.gov/publications</a></p> <p><a href="http://seer.cancer.gov/tools/codingmanuals/index.html">http://seer.cancer.gov/tools/codingmanuals/index.html</a></p>
<p><i>CDC Data Collection of Primary Central Nervous System Tumors, National Program of Cancer Registries Training Materials , 2004</i></p>	<p>Cancer for Disease Control and Prevention (CDC)                  National Program of Cancer Registries                  4770 Buford Hwy, NE, Mail Stop K-53                  Atlanta, GA 30042 -3717                  Phone: 1(888) 842-6355 Fax: (770) 488-4760  <a href="http://www.cdc.gov/cancer/npcr/training/btr/">http://www.cdc.gov/cancer/npcr/training/btr/</a></p>

**D. DATA TRANSMISSION (Batched Records or Single Case Entry plus Edits/Corrections/QC)**

ALL CASES MUST BE TRANSMITTED TO FCDS ELECTRONICALLY using FCDS secure information and data sharing portal: the FCDS IDEA, and in accordance with all FCDS Data

Submission Policies and Procedures. See Appendix Q for FAQs on the FCDS IDEA.

**RELEASE OF INFORMATION** – FCDS will not release any patient information directly to any contractor due to liability and confidentiality issues regarding contractual agreements not involving FCDS. Furthermore, new guidelines set forth under HIPAA (Health Insurance Portability and Accountability Act) have introduced additional restrictions regarding releasing and re-releasing patient information under many circumstances. FCDS understands that this policy may present some challenges to some contractors. Any contract between a healthcare facility and a private contractor where FCDS is not a party to the contract cannot include allowances for FCDS to release patient information to anyone other than the reporting facility.

Contractors must make arrangements with their clients (facilities) to forward any FCDS correspondence that includes patient information to them (contractor). This includes, but is not limited to edit discrepancies, quality control inquiries, verification of patient information, death certificate notification, AHCA casefinding audits, etc. Any discrepancies or omissions that are discovered after an abstract has been transmitted and processed will be posted to FCDS IDEA for review and/or correction. A *SAMPLE* FCDS Discrepancy Journal is provided at the end of this Section.

As a courtesy, FCDS will make every attempt to inform contractors of outgoing edits, quality control inquiries, verification of patient information, death certificate notification, AHCA casefinding audits, etc. However, the contractor and the reporting facility are ultimately responsible for assuring these reports and inquiries reach the contractor through appropriate channels.

**CONFIDENTIALITY** - Patient information, personal health information, medical records and healthcare facility data are all confidential and continue to be a concern with regard to cancer and other disease reporting. Please do not fax or email patient information to FCDS. Also, please take care when discussing cases over the phone with FCDS staff.

**DO NOT E-MAIL, FAX OR MAIL PATIENT INFORMATION (PHI) TO FCDS UNDER ANY CIRCUMSTANCES** unless you are provided specific instructions for using our Secure Fax Service.

**CONFIDENTIAL INFORMATION** includes any HIPAA-defined Protected Health Information.

**PHI information in the healthcare includes:**

- Patient name, address including street, city, county, zip code and equivalent geo codes,
- Name of relatives,
- Name of employers,
- All elements of date pertaining to patient ( ex-admission, discharge and birthdate)
- Telephone numbers
- Fax numbers
- Electronic email addresses
- Social Security number, medical record number,
- Health plan beneficiary number,
- Account number
- Certificate and license number,
- Any vehicle or other device serial number
- Web Universal Resource Locator (URL)
- Internet Protocol (IP) address number
- Finger or voice prints
- Photographic images

**1. Quarterly Reporting**

**FCDS REQUIRES THAT FACILITIES TRANSMIT DATA AT LEAST QUARTERLY.**

MONTHLY DATA SUBMISSION IS RECOMMENDED FOR LARGE FACILITIES (facilities reporting over 500 cases/year).

**2. Electronic Submissions**

Record Layout

All data must be submitted in the current NAACCR Version transfer record layout. The FCDS field positions and field lengths are standardized using the NAACCR transfer record layout, data definitions and data exchange guidelines. All fields identified as Core ('C') must be filled using valid codes. Any field identified as Optional ('O') may be submitted to FCDS as optional.

**3. Receipt on Upload**

An Upload Receipt is generated after the upload is successfully transmitted.

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**4. Data Acceptance Policy – FCDS EDITS**

Batch submissions will be edited immediately upon upload using the standard FCDS EDITS metafile. This metafile is published on the FCDS website and is available for use by software vendors and other interested parties who wish to run edits prior to data submission.

Each record must pass all inter and intra-item edits before acceptance by FCDS.

Records that require a NAACCR edit override (FORCE) will pass the edit check process and will be accepted. However, upon review at FCDS it may be determined the case does not meet the criteria for edit override (FORCE) and a Correction may be made to the case. Information about corrections to cases will be returned to the facility so you can correct your database as well.

For the cases requiring an edit override or Force, FCDS staff will review submitted text to determine if sufficient information has been provided to override the edit in question. If the information provided in text is insufficient, the reporting facility will have two weeks from the time of case transmission to send FCDS the appropriate information from the path report, discharge summary, or other source to support the code(s) assigned. The FCDS Quality Control Staff will use the documentation provided to validate the coding and set the relevant override flag(s).

**E. PSYCHIATRIC, MILITARY AND VETERANS ADMINISTRATION FACILITIES**

United States military and Veterans Administration healthcare facilities are requested to report cancer under Rule 64D-3.006 of the Florida Administrative Code. While these institutions are not mandated to report, FCDS encourages them to voluntarily report their cancer cases in order to provide complete cancer incidence in Florida.

**F. AMBULATORY SURGERY CENTERS**

In July 1997, the Florida legislature amended state cancer reporting legislation to include cancer case reporting by ambulatory patient care facilities. The Florida Department of Health and FCDS agreed that in order to ease the burden of reporting by ambulatory centers FCDS would take on the responsibility of cancer case identification, the critical first step in the reporting of cancer cases.

Administrative Options for Reporting for Ambulatory Surgical Centers:

1. Facilities with a History of Reporting – Several ambulatory surgical centers already voluntarily report complete cancer cases to FCDS. Reporting by these facilities will continue as in the past. The FCDS notification of cases for cancer reporting for these facilities will actually be a quality control exercise. Cases identified through the notification process will be considered ‘Missed Cases’ and will need to be reported in a timely manner.
2. Annual reporting through the FCDS Notification of Cases (Annual AHCA Audit) - The AHCA discharge data from the surgical centers is matched with the complete FCDS Master-file database regardless of the type of cancer or the date of discharge. Records are matched on Social Security Number, Date of Birth, Sex, Race and County of Residence. Each AHCA record that does not match with a case in the FCDS Master-file is identified on the AHCA Unmatched Cancer Records Request listing for reporting.
3. Unmatched Ambulatory Surgery Center Cases are posted to the FCDS IDEA. Cases must be reviewed for reportability and abstracted using FCDS IDEA Single Entry. If the case is “not reportable” the appropriate AHCA Disposition Code must be entered in FCDS IDEA to explain why the facility will not report the case.

Code	Description
1	Reportable-Missed Case-Case to be Abstracted & Reported by Facility
2	N/R - Tumor was Not Malignant - Behavior = 0 or 1
3	N/R - NonReportable Skin Cancer - Site=C44.* and Morph = 8000 to 8110
4	N/R - No Evidence of Cancer at This Time - NED
5	N/R - Consultation Only
6	N/R - Cancer Not Proven - Equivocal
7	Case Previously Reported to FCDS by this Facility
8	N/R - Outpatient Record with No Active Cancer Documented in Record
9	N/R - Insitu Cancer of Cervix or CIN III
10	N/R - Other
11	Reportable-Case Abstracted BUT Not found in FCDS files - Abst Requested
12	N/R - No Cancer Mentioned in Medical Record
13	Skins we elected not to FB since most of them turn out N/R
14	N/R - Hematopoietic Diseases Dx Prior to 2001
15	N/R - Case DX Prior to FCDS Reference Date - Same Cancer/Same Facility
16	N/R - Benign or Borderline Brain/CNS Tumor Dx Prior to 2004
20	Unknown if Reportable - No Record of this Patient at this Facility
21	Unknown if Reportable - Lost Medical Record
30	Unknown if Reportable - No Follow-Back Ever Returned by this Facility
40	N/R - Special Case - Other
50	Hospice Case - Not A Hospital
51	Transitional Care Center - Not A Hospital

**G. FREE-STANDING RADIATION THERAPY CENTERS**

Those facilities that do not voluntarily report full cancer abstracts to FCDS will have to upload minimal data on all cancer patient encounters for casefinding using the FCDS IDEA. FCDS will match the cancer records identified by each facility against the FCDS Master file. Each record that does not match with a case in the FCDS Master file will be identified for reporting.

**H. PRIVATE PHYSICIAN OFFICES**

Practitioners licensed under Chapters 458, 459, 464, F.S., are required to report to the Florida Cancer Data System as required by Section 385.202, F.S., within six (6) months of each diagnosis and within six (6) months of the date of each treatment. Each physician office shall submit each cancer case report electronically. FCDS currently requires physician office (claims) reporting from medical oncology, hematology, urology, and other physician practices. Dermatology practices report under the Dermatology Reporting Module (abbreviated reporting mechanism designed to report skin cancers).

**I. CLINICAL LABORATORY CANCER IDENTIFICATION PROGRAM**

Every anatomic pathology laboratory that reads biopsy specimens and/or surgical resection specimens collected from patient encounters within the state of Florida MUST electronically submit the specified data for every malignant cancer case. This includes ALL hospital labs and ALL non-hospital labs.

Complete information, reporting specifications and pathology lab case report record layout can be found on the FCDS website at <http://fcds.med.miami.edu>. Each pathology laboratory has multiple submission choices; generating a tab delimited file from their existing database, using the web-based software provided by FCDS, generating an HL7 formatted file for download or generating an HL7 formatted file for transmission using PHINMS. Click on the PATH LAB icon then scroll down to the Path Labs File Layout. The document describes in detail the various formats that are acceptable to FCDS. The rest of the PATH LAB page includes important information for reference, including; the NAACCR/FCDS cancer terms, SNOMED codes and ICD-9 code files you should use to filter and select only the lab records that identify cancer as specified in these standard files.

**J. FCDS RESPONSIBILITIES****1. Data Acquisition**

In order to support the data acquisition aspect of the statewide registry, FCDS will:

- a. Provide manuals, which specifically define data collection and reporting requirements,
- b. Provide a data collection tool(s) and user manual(s) for electronic/web-based data submission,
- c. Train facility staff and interested parties in incidence data collection via FCDS sponsored training programs (NAACCR Webinars), FCDS web-based training modules, teleconferences, FCDS web broadcasts or recorded educational events and programs. All FCDS-originated training materials and web broadcasts are recorded and available free on the FCDS website.
- d. Provide specific routine reports to verify data submission and resolve data discrepancies.

**2. Training and Education**

FCDS develops, teaches, and supports a full range of Education and Training Options including:

- o FCDS educational web broadcasts are organized up to 6 times a year or as needed.
- o The FCDS On-Line web based Abstractor Training Course consisting of 20 modules and 1000 informational slides with voice-over recordings and testing is available on the FCDS website.
- o FCDS hosts 12 NAACCR Educational Webinars at 7 host sites around the state each year.
- o Additional resources are available and advertised through the FCDS Memo and via blast e-mail.

**3. Quality Control**

The primary objective of the Florida Cancer Data System (FCDS) is to maintain a high quality database of useable, timely, complete and accurate data for every case of cancer identified in the state of Florida.

- a. Completeness is the extent to which all required cases have been reported to FCDS.

Completeness is assessed using:

- i. Historical data from facilities
- ii. On-Site or Remote Access Casefinding Audits
- iii. Annual Linkage to Florida's Agency for Health Care Administration statewide patient encounter files – AHCA Casefinding Audits (AHCA Match)
- iv. Annual Linkage to Florida's Bureau of Vital Statistics statewide death files - Mortality Casefinding Audits (Death Certificate Notifications)

- b. Accuracy is the extent to which the data submitted have been correctly coded and match the information contained in the medical record. Accuracy encompasses correct interpretation and application of coding rules and guidelines, identifies data entry and data submission errors and evaluates case correctness.

Accuracy is assessed using:

- i. FCDS Abstractor Code Testing
  - ii. FCDS Abstractor Code Annual Renewal Testing
  - iii. Field-Item, Inter-Item and Intra-Item Data Edits
  - iv. QC Visual Review Sampling of Every 25<sup>th</sup> Record
  - v. On-Site Re-Abstracting Audits
  - vi. Remote Access Re-Abstracting Audits
  - vii. Mail-In Re-Abstracting Audits
  - viii. FCDS Management Reports
- c. Timeliness involves how quickly each reporting facility submits cases to FCDS once a patient enters the health care system. The standard set forth by NAACCR, CDC/NPCR, ACOS/COC and FCDS is 95% of all new reportable cancer cases seen at any facility must be abstracted, submitted and any corrections for edit failures be completed within 6 months from the date of service. 100% of cases must be submitted by June 30 of any given year.

Timeliness is assessed using:

- i. Admissions by Facility Report
- ii. Facility Timeliness Report

### **FCDS Data Quality/Quality Control Program Components**

#### **1. On-Site and/or Remote Access Casefinding Audits**

The FCDS Quality Control staff will periodically perform review of casefinding procedures by auditing the casefinding sources within each facility. This may be done in-person at the facility or may be completed remotely utilizing a variety of facility-generated data streams matched to the FCDS files. Names identified will be compared to the FCDS Master File by the auditor. The registrar at the facility will be asked to review their “Not Reportable List” and identify the reason for any case(s) found by the auditor that were not abstracted. Medical records for cases not found in the FCDS Master File or on the “Not Reportable List” will have to be reviewed by the facility abstractor.

If any case is found to meet the cancer reporting requirements outlined in Section I, the case must be abstracted and reported to FCDS. For any case found that does not meet the cancer reporting requirements outlined in Section I, an explanation must be submitted to FCDS detailing the reason it will not be reported.

#### **2. FCDS/Agency for Health Care Administration (AHCA) Casefinding Audits**

FCDS staff will perform annual matching of the FCDS Master File to the Florida Agency for Health Care Administration (AHCA) files for both inpatient and outpatient/ambulatory patient encounters. FCDS will provide the reporting facility with an electronic list of Unmatched AHCA Cases (cases that appear in the AHCA files but have no matching record in the FCDS Master File) available on the FCDS website.

#### **Consolidated AHCA and Vital Statistics Follow-Back (Casefinding Audits).**

The Consolidated AHCA and Vital Statistics Follow-Back will be available via FCDS IDEA

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following the June 30 Reporting Deadline.

The facility abstractor then must compare the list of Unmatched AHCA Cases to the facility “Not Reportable List”. Cases that appear on the Unmatched AHCA Cases listing but do not appear on the “Not Reportable List” will need to be reviewed by the facility abstractor. Upon review, if any case is found to meet the cancer reporting requirements outlined in Section I, the case must be abstracted and reported to FCDS. These cases are a priority reporting item and must be abstracted as soon as possible. Please reference the AHCA Disposition Codes List for “reason not reported to FCDS”.

Code	Description
1	Reportable-Missed Case-Case to be Abstracted & Reported by Facility
2	N/R - Tumor was Not Malignant - Behavior = 0 or 1
3	N/R - NonReportable Skin Cancer - Site=C44.* and Morph = 8000 to 8110
4	N/R - No Evidence of Cancer at This Time - NED
5	N/R - Consultation Only
6	N/R - Cancer Not Proven - Equivocal
7	Case Previously Reported to FCDS by this Facility
8	N/R - Outpatient Record with No Active Cancer Documented in Record
9	N/R - Insitu Cancer of Cervix or CIN III
10	N/R - Other
11	Reportable-Case Abstracted BUT Not found in FCDS files - Abst Requested
12	N/R - No Cancer Mentioned in Medical Record
13	Skins we elected not to FB since most of them turn out N/R
14	N/R - Hematopoietic Diseases Dx Prior to 2001
15	N/R - Case DX Prior to FCDS Reference Date - Same Cancer/Same Facility
16	N/R - Benign or Borderline Brain/CNS Tumor Dx Prior to 2004
20	Unknown if Reportable - No Record of this Patient at this Facility
21	Unknown if Reportable - Lost Medical Record
30	Unknown if Reportable - No Follow-Back Ever Returned by this Facility
40	N/R - Special Case - Other
50	Hospice Case - Not A Hospital
51	Transitional Care Center - Not A Hospital

### 3. FCDS/Bureau of Vital Statistics Casefinding Audits (Death Clearance Audit)

FCDS staff will perform annual matching of the FCDS Master File to the Florida Bureau of Vital Statistics death files. FCDS will provide the reporting facility with a list of unmatched Vital Statistics cases (deaths) that show the place of death as the reporting facility.

#### **Consolidated Vital Statistics and AHCA Follow-Back (Casefinding Audits).**

The Integrated Vital Statistics and AHCA Follow-Back will be available via FCDS IDEA following the June 30 Reporting Deadline.

The facility abstractor will need to research these cases to determine if the patient did expire at the facility and whether or not the case meets the cancer reporting requirements. If any case is found to meet the reporting requirements, the case must be abstracted and reported to FCDS. For each case that will not be reported to FCDS or did not expire at the reporting facility, FCDS requires a brief statement be submitted that sufficiently explains why the case will not be reported. Please reference the Death Clearance Disposition Codes Listing below for “reason not reported to FCDS”.

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Code	Description
0	Pending Follow Back
1	Missed Case - Case Abstracted & Reported by Facility
2	N/R - Tumor was Not Malignant - Behavior = 0 or 1
3	N/R - NonReportable Skin Cancer - Site=C44.* and Morph = 8000 to 8110
4	N/R - No Evidence of Cancer at This Time - NED
5	N/R - Consultation Only
6	N/R - Cancer Not Proven - Equivocal
7	Case Previously Reported to FCDS by this Facility
8	N/R - Outpatient Record with No Active Cancer Documented in Record
9	N/R - Insitu Cancer of Cervix or CIN III, VIN III, VAIN III, PIN III
10	N/R - Other
11	Case Abstracted by Facility but Not found in FCDS Masterfile
12	N/R - No Mention of Cancer in Medical Record
13	This follow-back code no longer valid
14	N/R - Non-Reportable Myeloproliferative Disease - Dx Prior to 2001
15	N/R - Case DX Prior to FCDS Reference Date - Same Cancer/Same Facility
16	N/R - Benign or Borderline Brain/CNS Tumor Dx Prior to 2004
20	Unknown if Reportable - No Record of this Patient at this Facility
21	Unknown if Reportable - Lost Medical Record
30	Unknown if Reportable - No Follow-Back Info ever Returned by Facility
40	N/R - Special Case - Other
41	This Vital Statistics Record Matches an AHCA Record- For FCDS Use Only
50	Hospice Case - Not A Hospital
51	Transitional Care Center - Not A Hospital
52	Not A Hospital, NOS
53	Closed Facility - No Records Available
54	Nursing Home Death or Residence Death, Not A Hospital Death

#### 4. FCDS EDITS Metafile includes Field-Item, Inter-Item and Intra-Item Data Edits

FCDS uses a standard EDITS Metafile that has been modified to meet Florida requirements. The FCDS EDITS Metafile can be found on the FCDS website as well as a master listing of changes by date. FCDS EDITS include data edits to validate codes, crosscheck related data items and records and check for blank fields. The Florida specific data edits were created for all Florida only fields as well as for common abstracting errors identified through re-abstracting audits. Edits are reviewed as needed (monthly). New edits are added as needed.

#### 5. QC Visual Review Sampling of Every 25<sup>th</sup> Record

FCDS Quality Control staff visually reviews every 25<sup>th</sup> record submitted by each reporting facility. The Quality Control Visual Review is designed to facilitate visual editing of abstracted data. It allows a trained eye to detect inconsistent coding that electronic edit checks cannot identify; it is a tool to identify deficiencies in abstractors' understanding of abstracting concepts, data definitions and coding selections that may require additional training. The QC Abstract Review Case Selection Process is fully automated and randomly selects one of every 25th record processed, which accounts for nearly 4% of cases being visually reviewed for accuracy. Each case selected is placed in a QC file ready for visual review by the FCDS QC staff. Records with discrepant data must be resolved by the reporting facilities through FCDS IDEA by making return comments on each case (agree/disagree/add documentation to support original coding/other rationale). The case is then reviewed again by FCDS QC staff (different staff than the original FCDS Reviewer) and a final decision is made based on all information available.

This three-step process provides the registry every opportunity to rebut identified “errors” or “deficiencies” in the abstract by having three CTR or CTR-eligible staff review each case and provide documented input to what they interpret from the documentation provided in the original abstract. This process also serves as an educational tool for new and experienced registrars regarding where they have deficiencies in their abstracting tool kit and what they should be doing when abstracting specific cases by providing comment on a case-by-case basis.

Registry Managers should always share results with staff member responsible for the original abstract. Otherwise, they will continue to make the same error without knowledge they are doing something incorrectly, inconsistently, or out of synch with national reporting standards and guidelines.

6. On-Site or Remote Access Re-Abstracting Audits

The FCDS Quality Control staff and/or outside contract agents working on behalf of FCDS will perform on-site or remote access review of abstracting procedures by auditing individual reports and/or entire medical records of cases previously submitted to FCDS. The data validation or re-abstracting audit serves to verify that coded data submitted to FCDS can be validated when compared to original source documents at the hospital or central registry level. Discrepant data are followed back to the originating institution for clarification.

Reconciliation of the Re-abstracting Audit: Key data items will be evaluated and any discrepancy noted between the auditor's findings and the original abstract findings will be returned to the facility for reconciliation. If the auditor's findings are disputed, documentation must be submitted to clarify the originally abstracted codes.

These audits allow assessment with regard to standardized interpretation of data definitions, coding rules and guidelines, policies and procedures and serve to identify areas that may require further education and training.

7. Remote Access Re-Abstracting Audits

FCDS may substitute On-Site Re-Abstracting Audits with Remote Access Re-Abstracting Audits. Should FCDS decide to perform Remote Online audits, facilities will be asked to make available pertinent reports from medical records and/or other data sources to FCDS for review or FCDS will utilize existing source documents used in routine reporting.

8. FCDS Abstractor Code Policy

Every registrar/abstractor planning to work in the State of Florida is required to obtain an individual FCDS Abstractor Code. This code is assigned by FCDS to persons who successfully pass the FCDS Abstractor Code On-Line Examination, regardless of certification by NCRA as a CTR, experience in the registry industry, or other factors. As of January 1, 2013, any individual planning to acquire a New FCDS Abstractor Code or planning to Renew an Existing FCDS Abstractor Code must take and pass the FCDS Abstractor Code Exam. Registration for testing and real-time on-line testing can be found on the FCDS website.

The FCDS Abstractor Code Requirement has been FCDS Policy for many years and applies to every cancer registrar working in the state of Florida (CTR or non-CTR, Florida resident or out-of-state contractor, regardless of number of years' experience). FCDS will not accept cases from individuals without an Active/Current FCDS Abstractor Code.

While the FCDS Abstractor Code Requirement Policy remains unchanged, the FCDS Abstractor Code Exam is a new tool introduced to help FCDS expedite FCDS Abstractor Code approvals, renewals, and monitoring. Exams are short (15-20 multiple choice or T/F questions) with a variable mix of content questions weighted differently depending on whether this is an exam for a New FCDS Abstractor Code or Renewal of an existing FCDS Abstractor Code.

Questions are electronically selected at random from a pool of nearly 300 questions covering 6 major topic areas. No two exams will be alike.

**The 6 topic areas include;**

- General Abstracting Knowledge
- General Abstracting Rules and Florida-Specific Rules

- Primary Site/Histology/Grade
- Stage at Diagnosis
- Latest Rule Changes
- Treatment and Survival

**Standard References Used for Testing**

- FCDS DAM (current version)
- ICD-O-3 (including errata and updates)
- MPH Rules for Solid Tumors (current)
- MPH Rules/Database for Hematopoietic/Lymphoid Neoplasms (current)
- Collaborative Stage Data Collection System – to be changed to TNM and SS2000
  - ◊ Part I – Section 1 – General Instructions
  - ◊ Part I – Section 2 – Lab Tests, Tumor Markers, SSF Notes
  - ◊ Part II – Site-Specific Schema
- SEER\*Rx (current)
- SEER Self-Instruction Manuals (basics)
  - ◊ Book 2 – Cancer Characteristics
  - ◊ Book 3 – Tumor Registrar Vocabulary: Composition of Medical Terms
  - ◊ Book 4 – Human Anatomy as Related to Tumor Formation

**WHO NEEDS TO TAKE THE FCDS ABTRACTOR CODE EXAM?**

- ✓ Individuals hoping to acquire a NEW FCDS Abtractor Code will need to take the New FCDS Abtractor Code Exam.
- ✓ If an individual's FCDS Abtractor Code has been expired for greater than 2 years, the individual must re-apply and take and pass the New FCDS Abtractor Code Exam.

**WHO NEEDS TO TAKE THE FCDS ABTRACTOR CODE RENEWAL EXAM?**

- ✓ Individuals with an ACTIVE (not yet expired) FCDS Abtractor Code will be required to take and pass the FCDS Abtractor Code Renewal Exam once their code has expired.
- ✓ Individuals with an EXPIRED FCDS Abtractor Code will be required to take the FCDS Abtractor Code Renewal Exam each year in order to keep their FCDS Abtractor Code current and to renew their individual FCDS Abtractor Code, annually.
- Registrars will be required to navigate, use and apply standard cancer registry desk and electronic desktop or web-based references and resources to pass the examination.
- References used include but are not limited to: Current FCDS DAM, Current MPH Rules for both Solid Tumors and Hematopoietic and Lymphoid Neoplasms, Collaborative Stage Data Collection Rules and Schema including Site Specific Factors, SEER\*Rx, the Hematopoietic Database and SEER Self Instructional Manuals including Books 2, 3, 4.
- Examinations are timed with a maximum of 1 hour allowed to take the annual renewal exam (15 Q&A) and 2 hours allowed for initial exam (20 Q&A).
- The registrar will be given two opportunities to successfully pass the examination with a score of 80% or greater.
- If the registrar fails twice, s/he must wait at least one week to take the examination again. Registrars should not abstract cancer cases between failed exams.
- Abstractors who successfully pass the examination will be assigned a Florida Cancer Data

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System Abstractor Code. Codes are renewed annually.

- NEVER share your abstractor code or your code may be suspended or revoked.

Before taking the exam, please read through and become familiar with the FCDS DAM to ensure you understand all of the Florida abstracting and data collection requirements. The current version FCDS DAM can be found on our website, <http://fcds.med.miami.edu>. There are a few Florida-specific requirements critical to complete reporting in Florida that many out-of-state registrars miss – reporting of non-analytic cases and all sequences for historical cancers.

FCDS monitors use of individual codes and is alert to the practice of sharing abstractor codes for new staff, temporary staff, and even permanent staff.

Please be secure with your abstractor code, abstracted data, personal information, and all confidential materials.

A breach of confidentiality and/or of protected personal health information or PHI, also known as a HIPAA Violation, may result in substantial civil monetary penalties (up to \$1.5 million in a single calendar year) and/or criminal penalties of up to 10 years in federal prison.

Personal Health Information (PHI) includes:

- Patient name, address including street, city, county, zip code and equivalent geo codes,
- Name of relatives,
- Name of employers,
- All elements of date pertaining to patient ( ex-admission, discharge and birthdate)
- Telephone numbers
- Fax numbers
- Electronic email addresses
- Social Security number, medical record number,
- Health plan beneficiary number,
- Account number
- Certificate and license number,
- Any vehicle or other device serial number
- Web Universal Resource Locator (URL)
- Internet Protocol (IP) address number
- Finger or voice prints
- Photographic images

### 9. Admissions by Facilities Report

FCDS Data Acquisition staff will review the Admissions by Facilities Report (an internal FCDS report) on a regular basis. This report makes a comparison of observed to expected numbers of cases reported by each facility for any time period requested. The report is based on a five-year historical summary of cases reported to FCDS by each facility. The ratio of observed to expected is reported as a percent of completeness. Either FCDS Staff or a representative of the Department of Health will notify facilities that have not reported the expected number of cases. These same data are included in the Quarterly Activity Report.

### 10. Facility Timeliness Report

FCDS Data Acquisition staff will review the Facility Timeliness Report on a regular basis. This report shows the average amount of time (in days) that it takes the reporting facility to

submit a case to FCDS. It specifically; 1) calculates the difference between the date the reporting facility had the first contact with the patient and the date the case was abstracted, 2) calculates the difference between the date the case was abstracted and the date the case entered the FCDS Master File, and 3) calculates the difference between the date the reporting facility first had contact with the patient and the date the case entered the FCDS Master File. The time between the date the reporting facility had contact with the patient and the date the case entered the FCDS Master File should be 180 days or less. These same data are included in the Quarterly Activity Report (see Section Forms).

#### 11. Other Quality Control Studies and Audits

FCDS Quality Control staff will run quarterly reports to help identify areas of concern regarding reporting by individual facilities. These quarterly reports will be used to identify trends in case reporting that may need to be addressed at a facility or at the state level. For example, if a facility reports that 95% of their prostate cases are "unstaged" at the time of first contact with their facility there may be a problem with the abstractor's understanding how to correctly interpret the field 'FCDS Stage at First Contact' and/or how to code it correctly. Similar analyses will be conducted for individual abstractors within the facility. The FCDS Quality Control staff will perform ad-hoc inquiries to the FCDS Master File when data requests are made. Any unusual data will be reviewed, and facility-abstracting staff may be requested to review individual cases to confirm the reporting of certain data items.

#### 12. Facility Evaluation Report

The report is a graphical and numerical representation of the performance of a reporting facility over a given time period, detailing the three principles of data appraisal: Timeliness, Completeness and Accuracy.

#### 13. FCDS Data Quality Indicator Report (DQIR)

The FCDS Data Quality Indicator Report is designed to provide feedback to registries on the completeness of case abstracts by examining the frequency of coding "unknown" or "ill-defined" values in key analytic data items. Data must meet rigorous national quality standards to be included in local, regional, state, and national cancer rates, reports to Congress, numerous surveillance-related publications and for registry certification.

The percent of "unknown" and "ill-defined" values is an indicator used in ranking Florida's overall data quality and completeness of case reporting and is used when comparing Florida data to other states for overall data validity and reliability. These data are also early indicators of problem areas and areas where FCDS and local registries can improve upon cancer reporting as data are available. The report includes the Florida state and National distribution of "unknown" value used for comparison. The report uses data from analytic cases only

*Note: This report is a scaled down model of a similar report the CDC National Program of Cancer Registries (NPCR) provides to Florida and each NPCR state as an assessment of our state-wide data.*

## **4. Data Requests**

Filing the appropriate FCDS and DOH forms is required for data requests. The forms are available on the FCDS website (<http://fcds.med.miami.edu/inc/datarequest.shtml>)

Requests for special reports involving release of personal identifiers will be reviewed by a data use committee of DOH for cost effectiveness, research worthiness, and to ensure patient confidentiality.

In general, most requests for data fall into five categories: CD's with raw non-confidential data, statistical/tabular data, confidential data, data linkages, and data for investigation of potential cancer clusters. There are specific procedures for data release based on the category of request and associated fees. All data requests, regardless of the nature of the request, must be submitted to FCDS in writing.

Reporting facility data is considered confidential data. When requesting facility specific data (data other than that submitted from your facility), please mail the data request form along with original cover letters from all concerned facilities on their facility letterhead to FCDS. It is the requestors responsibility to obtain permission for data release from each of the medical facilities of interest prior to making the data request. Keep in mind that all applicable fees apply. The exception to the above rule is when requesting data submitted from the originating institution. Each reporting facility has an annual \$300 credit, which can be applied to data requests only with regard to data submitted from their institution. Requests should be submitted in writing on facility letterhead and signed by the supervisor or the administrator listed in the FCDS database. If the data is to be sent to a third party, this request should be specified in the letter.

Data are extracted from two main files: the master file and the commercial file. The master file is a data file containing all cancer records that have successfully passed the SEER (Surveillance Epidemiology and End Results, National Cancer Institute program) and FCDS standard edit checks. This file is continually updated as new records are received. The commercial file is a 'snapshot' of the master- file at the exact moment it is created; therefore it remains static while the master-file is dynamic. Depending on the nature of the request, FCDS will determine from which file to extract the data. Generally, the commercial file is used to fill requests for incidence data because the data are relatively static and menu rates are calculated from this file. For a complete list of data items available, please refer to FCDS data items list document. Data on the website uses the commercial file.

### **Availability of Data by Type, Media, Format, and Data Request Fees and Billing Procedures**

#### 1) Data CD's

FCDS provides three raw data CD's: a Public Use CD and two versions of the Confidential CD. *Please note these are flat files in a fixed layout, (approximately 2 million records each year) therefore you will need some type of software to read in the data and analyze it (i.e. SAS, SPSS, SQL).*

FCDS will fill data requests for data CD's within 20 business days once the application has been approved and payment has been received by FCDS.

- a. The *Public Use CD* is available without charge to anyone requesting FCDS data. The Public Use CD contains county level case data for all sites, with many of the demographic variables collapsed into aggregate groups, i.e. age, race, marital status, etc. The application form along with the variable list for the Public Use CD are available under the "Data Request" link on the FCDS web site <http://fcds.med.miami.edu>. Please download the application and follow the submission instructions.
- b. The two versions of the *Confidential CD* are: 1) The Limited Confidential CD which contains no geocoded data, and 2) the Full Confidential CD containing geocoded data. Both Confidential CDs are void of any personal identifiers (name, address, date of birth, and social security number). The only difference between the CDs is that one contains geocodes, the other does not. FCDS approval is required for release of the Limited Confidential CD. The application process for the Full Confidential CD requires DOH IRB approval prior to release. Both Confidential CDs are available only to recognized academic, research, and governmental institutions. There is a charge for both versions of the Confidential CD. Please see the Fees and Billing Procedure section of this document for information on these charges. The application forms for the Confidential CDs are available online under the "Data Request" link on the FCDS web site <http://fcds.med.miami.edu> . If you would like to request one of the CDs please download this document and follow the

## **SECTION I: GUIDELINES FOR CANCER DATA REPORTING**

submission instructions. In addition, if applying for the Full Confidential CD, please note as stated above you will need to fill out the DOH IRB form as well. This form is available within the "Procedure Guide for studies that utilize FCDS for patient identification and contact" document under the "Data Request" link of our website. Further information on the DOH IRB application process and timeline can be found at <http://www.doh.state.fl.us/execstaff/irb/index.html>.

For questions, please contact:

Florida Department of Health  
Bureau of Epidemiology  
Cancer Registry  
Re: Confidential Data Request  
4052 Bald Cypress Way, Bin A-12  
Tallahassee, FL 32399-1720  
Telephone: (850) 245-4401  
Fax: (850) 922-9299

The data on the CDs are updated when necessary, with the most recent year being added as it becomes available. FCDS will **fill data requests** for data CDs **within 20 business days** once the application has been approved and payment has been received by FCDS.

### 2) Statistical/Tabular Data (All non-CD requests for Data)

All requests for non-confidential statistical/tabular data must be received in writing, please use the form titled "Data Request Form (for statistical and tabular data)" found under the Data Requests link on the FCDS web site <http://fcds.med.miami.edu>. This type of data request can be approved directly by FCDS.

The basic rule of thumb is that as long as the tabulation cannot either directly or indirectly identify any patient, the data may be released. In an effort to protect the indirect identification of the patient, the "rule of ten" is applied; this rule suppresses any cell containing fewer than 10 cases. Tabulated data may be released at or above the county code level with a count of 10 or greater; for counts less than 10 or data below the county level; approval will be required from the Department of Health.

Because each request is unique, FCDS staff will discuss the project with the requestor to verify the type of data required and determine if the system is capable of producing the required data and to determine approximately how long it will take to fill the request. Based on this information, an estimate of the cost is provided. Then the applicant will need to submit the request in writing. FCDS staff may contact the requestor as needed to discuss and clarify additional details of the request.

FCDS will fill data requests for statistical/tabular data within 20 business days once the request has been finalized and the cost has been approved.

### 3) Confidential Data

All requests for confidential data (any data that can directly identify a patient) must be sent to the Florida Department of Health (DOH) for approval using both the DOH Bureau of Epidemiology and the DOH Institutional Review Board (IRB). Please refer to the *Procedure Guide for Studies that Utilize the Florida Cancer Data System Data for Patient Identification and Contact* for application materials and submission requirements. The Procedure Guide can be found at <http://fcds.med.miami.edu/inc/datarequest.shtml>. Further information on the DOH IRB application process and timeline can be found at <http://www.doh.state.fl.us/execstaff/irb/index.html>

For questions, please contact:

Florida Department of Health  
Bureau of Epidemiology

Cancer Registry  
Re: Confidential Data Request  
4052 Bald Cypress Way, Bin A-12  
Tallahassee, FL 32399-1720  
Telephone: (850) 245-4401  
Fax: (850) 922-9299

Once approval has been received from **both** the DOH Bureau of Epidemiology and DOH IRB, FCDS staff will then begin to work directly with the researcher. FCDS will not begin work on the project until we have received all of the necessary approval and paperwork directly from the DOH Bureau of Epidemiology. Only those data items (variables) specified in the *Application for Research Use of the Florida Cancer Data System* will be extracted. FCDS will fill confidential data requests within 6 weeks time once the request and cost have been approved.

**Please note that approval for confidential data through Florida Department of Health can take anywhere from 8 weeks to 18 months, depending on complexity and thoroughness of the request of the application. Please plan accordingly.**

#### 4) Data Linkage

A data linkage project is a request that involves linking FCDS data to external or internal data sets. The preliminary steps involving linkages are identical to those of confidential data requests. (Please refer to the confidential data requests section above).

Fields used in the linkage must be consistent in both data sets. The researcher should send FCDS the data in a fixed length ASCII file with the proper record layout and format. (Refer to Data Linkage Record Layout document). Any deviations from the record layout or format will require extra work and will be charged to the requestor according to the fee schedule. (Refer to Fees and Billing Procedure below).

FCDS will fill data linkage requests within 6 weeks following approval of the request and fees.

#### 5) Cancer Cluster Data

Requests for information regarding potential cancer clusters should be directed to the County Health Department. If necessary, staff at the County Health Department will contact the appropriate division at the central office of the Florida Department of Health for assistance.

#### 6) Fees and Billing Procedure

Each reporting facility has an annual \$200 credit, which can be applied to data requests only with regard to data submitted from their institution. Requests should be submitted in writing on company letterhead. If the data is to be sent to a third party, this request should be specified in the letter.

The billing procedure for the Confidential CDs is as follow: once payment and supporting documentation are received, the CD is mailed out. For all other data requests, an invoice will be mailed (via email or postal service) along with the results of the data request or linkage.

Most requests generate a fee. The FCDS does not receive additional funding to perform special, ad-hoc data analysis; therefore actual costs are passed on to the applicant.

The fees are as follows:

- Public use CD - No Charge
- Minimum charge - \$150.00
- Statistical analysis/programming/data coordination - \$150.00 per hour
- Limited Confidential CD without geocodes - \$500.00

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- Full Confidential CD with geocodes - \$1,000
- Data Linkage:

Sliding scale: <10,000	\$3,000
10,000 – 24,999	\$2,500 fee plus .05 cents per record
25,000 – 49,999	\$3,000 fee plus .03 cents per record
50,000 – 99,999	\$3,500 fee plus .02 cents per record
100,000 – 249,999	\$4,000 fee plus .015 cents per record
250,000+	\$5,000 fee plus .011 cents per record
- Geocoded & Patient Contact lists

Sliding scale: <10,000	\$1,500
10,000 – 24,999	\$2,000
25,000 – 49,999	\$2,500
50,000 – 99,999	\$3,000
100,000 – 249,999	\$3,500
250,000+	\$4,000

Subsequent listing (without changes to format, layout, or variables) will be charged 50 percent of the sliding scale fee for the number of records extracted. For example, subsequent request for another 30,000 patient listing would be 2500\*.50=\$1,250.

- Overnight mailing - actual cost

Data linkage fees are charged for those projects involving the matching of an outside data source to the Florida Cancer Data System database. Please contact FCDS directly to discuss fields and the associated record layout. A copy of the required record layout is available under the “Data Request” link on the FCDS web site <http://fcds.med.miami.edu>.

Data coordination fees apply to all data linkage projects; they involve manually reviewing possible matches and correcting for any deviations in field length or variable formats.

Please contact FCDS prior to submitting a written request to discuss the analysis/data extraction and to obtain an estimate of any fees.

Additional information such as published resources and statistics are available on the FCDS website: <http://fcds.med.miami.edu/inc/statistics.shtml>

If a data request does not fall into any of the above categories please contact us at 1-800-906-3034 or 305-243-4600.

All media requests should be directed to Irv Kokol of the FL DOH Office of Communications at 850- 245-4111.

FCDS maintains a list of all published articles using FCDS Data. Please provide information on any scientific publications resulting from a data request.

### **K. FCDS MANAGEMENT REPORTS**

#### **FCDS Quarterly Activity Status Report**

This report summarizes the FCDS file activity for each facility on a quarterly basis. Every facility should have some file activity during every quarter of the year. The report documents information about the number and quality of cases submitted during the previous quarter, timeliness of reporting, and also provides an annual incidence and completeness summary, which compares observed-to-expected numbers of cases reported for the year. (See Forms Section)

**FCDS Data Quality Indicator Report**

This report is a scaled down model of a similar report the CDC National Program of Cancer Registries (NPCR) provides to Florida and each NPCR state as an assessment of state-wide data. The report reflects 5 years of data and examines the frequency of assignment of “unknown” or “ill-defined” values to key analysis variables over the course of the five-year period with comparison to national.

The percent of “unknown” and “ill-defined” values in certain variables is a data quality indicator used to rank Florida’s overall data quality and completeness of the data for each case reported and is used when comparing Florida data to other states for overall data reliability. These data are also indicators of problem areas where FCDS and local registries can improve upon cancer reporting as data are available.

**Annual AHCA Unmatched Report**

The AHCA Unmatched Report and subsequent follow-back procedures are used to assess casefinding completeness at the facility level.

**Consolidated AHCA and Vital Statistics Follow-Back Reports (Casefinding Audits).**

Consolidated AHCA and Vital Statistics Follow-Back Reports will be available via FCDS IDEA following the June 30 Reporting Deadline.

**Annual Bureau of Vital Statistics Unmatched Report**

FCDS staff will perform annual matching of the FCDS Master File to the Florida Bureau of Vital Statistics death files. FCDS will provide the reporting facility with a list of unmatched Vital Statistics cases (deaths) that show the place of death as the reporting facility.

**Consolidated Vital Statistics and AHCA Follow-Back Reports (Casefinding Audits).**

Consolidated Reports Vital Statistics and AHCA Follow-Back Reports will be available via FCDS IDEA following the June 30 Reporting Deadline.

**FCDS EDITS Master List**

This is a listing of all FCDS edits included in the latest FCDS EDITS Metafile and includes the edit number, edit category, and edit message. The current list can be found under Downloads on the FCDS website. This list is updated regularly and can be found on the FCDS Website under Downloads.

**L. AWARDS**

**Jean Byers Memorial Award for Excellence in Cancer Registration**

**Pat Strait Award for Excellence in Cancer Registry Abstracting** – The Pat Strait Award for Excellence in Cancer Registry Abstracting is awarded to individuals who contribute to a facility achieving the annual Jean Byers Memorial Award.

Criteria for receipt of the Jean Byers Award and the Pat Strait Award are based on a standard set of criteria that meet or exceed the completeness, timeliness and accuracy requirements determined by FCDS and CDC. The criteria may change between years, depending on annual reporting conditions but generally are a factor of a combination of successful data quality metrics including; Reporting Deadline, percent of missed cases as determined using AHCA and Vital Statistics Matching and Follow-Back Results (missed cases cannot exceed 10% of the facility’s annual caseload), and other established data quality indicator metrics.

M. FCDS GENERAL MAILING INSTRUCTIONS:

DO NOT MAIL ANY MATERIALS CONTAINING PERSONAL HEALTH INFORMATION

In order to protect and properly handle all packages FCDS is making the following recommendations:

1. We ask that if you are mailing a package to FCDS use Federal Express, UPS, Airborne Express or any other type of courier service.

- a. The FCDS street address below must be used for courier packages:

FCDS  
University of Miami School of Medicine  
1550 NW 10 AVE  
Room 410  
Miami, FL 33136

Include the following text on a separate header page in the package.

- b. Always request a signature upon delivery.
    - c. Make sure that the addressee at FCDS knows that she/he is to expect a package.
    - d. Track the package to ensure that it has reached its destination. You may want to explore the e-mail tracking and notification features that the courier of choice offers.
2. **For non-confidential information**, if using US Postal Service, which may include Express mail, Priority mail, and Certified mail, you must use the FCDS PO Box address below:

FCDS  
University of Miami School of Medicine  
PO BOX 016960 (D4-11)  
Miami, FL 33101

3. All shipments must adhere to the [FCDS Confidential Information Security Policy](#).

N. CALENDAR/FORMS/TEMPLATES/SAMPLE REPORTS

- FCDS Annual Reporting Calendar
- FCDS 2015 Abstract Form - Sample
- FCDS Discrepancy Journal - Sample
- Not Reportable List - Template
- FCDS Quarterly Activity Status Report – Sample
- FCDS Data Quality Indicator Report - Sample