

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 clinical 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, the Florida Department of Health (DOH), and the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) 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 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.

Please see supporting Federal and State Laws and Administrative Rules.

- Florida State Law: Title XXIX, Chapters - 381.0031, 385.202, 405.01, 405.02, 405.03, 408.07 – Establishment of and Governance of FCDS
- Florida Public Health Rule 64D-3.003, 64D-3.031, 64D-3.034, 64D-3.006 – Specifics and Clarifications of Cancer Reporting in Florida
- Federal Public Law 1070260 – Oct 29, 2002 116 Stat.1743 of the Public Health Service Act – Establishment of CDC NPCR
- HIPAA Privacy Rule 45 CFR 164.512(b) - FCDS is HIPAA-EXEMPT under the HIPAA Privacy Rule 45 CFR 164.512(b) as a Public Health Authority – FCDS under DOH conducts Public Health Activities.

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 additional select neoplasms that the Commission on Cancer/American College of Surgeons does not require such as benign and borderline brain and central nervous system tumors and certain reproductive site cancers.

The 2023 Updates to National Standards incorporate several new histologic types, subtypes, and changes to tumor behavior making some cancers new to our state reportable list due to reclassification by WHO as “malignancy” or other reportable cancer criteria.

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. Please review all standard cancer diagnosis codes and procedures codes.

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Patients whose “First Course of Therapy” is “Active Surveillance” or “Watchful Waiting” must be reported as their cancer has been diagnosed but will not be treated, until or unless the patient has clinical symptoms, imaging, or laboratory evidence of progression of disease. This treatment decision is usually for non-aggressive neoplasms and very early stage cancers that do not meet the standard threshold for active treatment.

“NO TREATMENT” is a different treatment decision than “Watchful Waiting” or “Active Surveillance” and should not be coded as ‘treatment given’ using Treatment Status = 2 (Active Surveillance/Watchful Wait).

Please be cautious when distinguishing the two very different types of cases – Active Surveillance/Watchful Waiting versus ‘No Treatment’. ‘No Treatment’ cases are usually patients with advanced or untreatable disease or when the patient has other comorbid factors that prohibit cancer treatment. Active Surveillance cases are often low grade, slow growing, early stage neoplasms that may not require intervention at this time.

“Consult-Only” and “Second Opinion” cases MAY be an exception to reporting depending upon what took place at the facility to confirm a diagnosis or establish or confirm the validity of a proposed treatment plan. Some second opinions/consultations include the ordering of new laboratory and/or imaging tests. Anytime a new test is ordered by your facility – the case is no longer a consult only...even if that is the only test done. Other second opinion/consults include only a review of tests already performed elsewhere.

A true “consult only” or “second opinion” case is any case where the facility provides a second opinion or expert panel review of earlier performed diagnostic or workup 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 perform any additional testing** for this or any other cancer and they have evidence of active disease or if they are undergoing treatment for cancer at any facility, **the case is reportable to FCDS**.

Exception 1: Patients undergoing planned first course or later course long-term hormonal treatment for breast or prostate cancer that continue to demonstrate no active neoplasm *should not be reported*. Any other type of cancer or 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 only where no chemotherapeutic or anti-neoplastic agent(s) is injected into the port *do not need to be reported*.

Many Florida healthcare facilities including Commission on Cancer/American College of Surgeons accredited cancer programs who wish to track ‘port-a-cath’ placement visits do continue to report these cases voluntarily as part of monitoring the full continuum of patient care available and monitored under the care of the facility.

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 only cases at their discretion. It is up to a formal decision by your Cancer Committee (if you have one) to include or not include these “port-a-cath” only cases. You must consult the Cancer Committee at your facility and document this decision in committee meeting minutes and in any facility procedures manuals. Please include the date that you stopped reporting.

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 below criteria must be reported to FCDS. Any patient with a coded diagnosis of cancer but not reported may be included in Casefinding Audits for review to ensure the case is truly not reportable. This may require a second complete review of the chart.

IMPORTANT NOTE: The start date for your registry for the state of Florida is 1/1/1981 or the day your facility opened. It is not the same start date that the Commission on Cancer assigns your facility. All reporting began in 1981. FCDS has cancer cases from your facility going back to 1981. If you submit a new cancer for a person already registered by your facility with FCDS, you must use the same Accession Number assigned to that person before your CoC Start Date. The older Accession Numbers can be found in the Alphabetical Listing Report of ALL Cases Every Reported to FCDS by your Facility. This ‘alpha list’ runs interactively and is the most up-to-date listing of all cases ever reported by your facility. It can be run in Accession Number Order or in Alphabetical Order in IDEA.

Reportable Patients

- a) all patients with an active, malignant neoplasm (in-situ or invasive), whether being treated or not (includes “active surveillance” cases) – with limited exceptions such as CIN III and PIN III (see Reportable Tumors)
- 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 and never treated)
- c) all patients undergoing prophylactic, neoadjuvant, or adjuvant therapy for malignancy,
- d) all patients undergoing ‘active surveillance’ or ‘watch and wait’ approach to therapy,
- e) patients seen as in-patient, out-patient, or in-clinic are reportable,
- f) all patients diagnosed at autopsy,
- g) all historical cases that meet FCDS reportable guidelines.

***Note: Patients with ‘chronic’ neoplastic conditions** such as chronic leukemia, myelodysplastic syndromes and myeloproliferative diseases, or other lymphoid/myeloid neoplasms designated as ‘chronic’ disease always have some level of active disease and must be reported. Treatment for these neoplasms may achieve a state of ‘clinical remission’. However, these conditions cannot be cured without aggressive therapy including high-dose chemotherapy plus bone marrow transplant or stem cell transplant. The chronic nature of their disease makes these cases always reportable, regardless of clinical status.*

2. Not Reportable Patients

- a) patients in complete remission with no evidence of cancer (NED) – **see Note regarding chronic neoplasms**
- b) patients with no evidence of cancer and not receiving prophylactic or adjuvant therapy,
- c) 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),
- d) 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 treatment of the same primary malignant neoplasm,
- e) patients who receive transient care to avoid interrupting a course of therapy started elsewhere.

***Note: Patients with ‘chronic’ neoplastic conditions** such as chronic leukemia, myelodysplastic syndromes and myeloproliferative diseases, or other lymphoid/myeloid neoplasms designated as ‘chronic’ disease always have some level of active disease and must be reported. Treatment for these neoplasms may achieve a state of ‘clinical remission’. However, these conditions cannot be cured without aggressive therapy including high-dose chemotherapy plus bone marrow transplant or stem cell transplant. The chronic nature of their disease makes these cases always reportable, regardless of clinical status.*

3. Reportable Neoplasms

Determination of whether or not a given primary neoplasm is reportable is made by reference to the histology and behavior codes of the International Classification of Diseases for Oncology, 3rd ed. including approved updates and errata published by WHO and approved by NAACCR for ICD-O-3.

FCDS Requires that all neoplasms with behavior of /2 (in-situ) or /3 (malignant) be reported to FCDS with minor exclusions including; CIN III and PIN III or carcinoma in-situ of the cervix or prostate.

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Additionally, FCDS requires reporting of all benign, borderline, and malignant tumors of the Brain, Central Nervous System, Cranial Nerves, Intracranial Glands, Meninges and Peripheral Nerve Tumors.

Please see [NAACCR Version 23: Table of Comparison of Reportable Cancers: CoC, SEER, and NPCR](#) found at the end of FCDS DAM Section I for clarification of cancers required to be reported to NPCR and FCDS. This table can also be found in [NAACCR Standards Volume III, Version 23 – Data Standards and Data Dictionary, Chapter 3 – Standards for Tumor Inclusion and Reportability](#) at <https://www.naacr.org/data-standards-data-dictionary/>. Additional resources for clarification of FCDS reportable neoplasms include the (current) Solid Tumor Manual and the (current) SEER Hematopoietic Database.

FCDS adopted ICD-O-3.2 in 2018. This includes all of the 4th edition ‘Blue Books’ published as a series entitled; IACR/WHO Classification of Neoplasms. **Currently, the WHO is publishing electronic 5th edition WHO Classification of Neoplasms** for all neoplasms described. Use the ICD-O-3.2 Tables from IACR/WHO in addition to the (current) Solid Tumor Manual and (current) SEER Hematopoietic Database to determine whether a neoplasm is reportable to FCDS and the current correct ICD-O-3.2 histology and behavior code.

IACR/WHO began publishing 5th edition Classification of Neoplasm volumes in 2020. The 5th edition WHO Classification Series incorporates new histology codes, new behavior codes, and other changes that may change the reportability of some neoplasms over time. **Appendix R of this Manual includes the 2023 Updates to the IARC/WHO Classification of Neoplasms.**

The 2023 ICD-O-3.2 Update Guidelines includes comprehensive tables listing all changes to ICD-O-3.2 including new ICD-O codes, terminology and reportability changes effective for cases diagnosed 1/1/2023 forward. The 2023 update represents changes identified in recently published 5th Ed WHO Classification of Tumors books. Included in these guidelines are instructions for using the tables together with ICD-O-3.2.

The update includes important information on reportable versus non-reportable high-grade dysplasia in specified gastrointestinal sites.

The following WHO Classification of Tumor, 5th editions were released after the 2022 ICD-O-3.2 update:

- WHO Classification of Tumors of the Breast (2019)
 - WHO Classification of Tumors of Digestive System (2019)
 - WHO Classification of Tumors of the Female Genital Tumors (2019)
 - WHO Classification of Tumors of Soft Tissue and Bone (2020)
 - WHO Classification of Thoracic Tumors (2020)
 - WHO Classification of Central Nervous System Tumors (2021)
 - WHO Classification of Urinary and Male Genital Tumors (2022) – pending review
- The IARC/WHO ICD-O Committee has published two versions of additions, changes and revisions to the ICD-O-3 since the original publication (ICD-O-3.1 and ICD-O-3.2)
 - The IARC/WHO Version of ICD-O-3.2 (Histology & Behavior Codes) is accessible from IARC/WHO @ http://www.iacr.com.fr/index.php?option=com_content&view=category&layout=blog&id=100&Itemid=577. This links to the January 25, 2021 edition of the ICD-O-3.2...but, it is not 100% current.
 - **The 2023-compliant NAACCR Annotated Histology List including Preferred Histology Terms, Synonyms, and Changes is available from the NAACCR Website at <https://www.naacr.org/icdo3>.**
 - The NAACCR Annotated Histology List does not include the Topography or Primary Site Codes.
 - The 2023-specific ICD-O-3.2 Coding Guidelines and Implementation Documents including changes to Histology & Behavior Codes are available in Appendix R of this manual.
 - Complete 2023 ICD-O-3.2 Coding Guidelines and Implementation Documents are also available from NAACCR at <https://www.naacr.org/icdo3/>.
 - **Registrars MUST use the current version of the Solid Tumors Rules to supplement the ICD-O-3.2 Tables for all solid tumors diagnosed 2018 and later.** <https://seer.cancer.gov/tools/solidtumor/>
 - **Registrars MUST use the current online version of the Rules for Hematopoietic and Lymphoid Neoplasms and the Hematopoietic Database to identify and code any myeloid or lymphoid neoplasm** <https://seer.cancer.gov/seertools/hemelymph/>. An instructional manual is located under ‘downloads’.

- a) **In Situ and Invasive Cancers** - FCDS includes all primary malignancies - 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. **Penile Intraepithelial Neoplasia Grade III (PeIN III)** is reportable to FCDS and should be included in casefinding activities.
 - iii. **Vulvar Intraepithelial Neoplasia Grade III (VIN III)** is reportable to FCDS and should be included in casefinding activities.
 - iv. **Vaginal Intraepithelial Neoplasia Grade III (VAIN III)** is reportable to FCDS and should be included in casefinding activities.
 - v. **Lobular Intraepithelial Neoplasia Grade III (LIN III)**
 - vi. The CoC does not require Lobular Carcinoma In-Situ (LCIS) be abstracted or reported to NCDB. **However, LCIS is reportable to FCDS and to all central cancer registries across the country.**
 - vii. **(Pancreatic Intraepithelial Neoplasia (PanIN III)** is reportable to FCDS (histology 8148/2) and should be included in casefinding activities.
 - viii. ***Glandular Intraepithelial Neoplasia, Grade III/High Grade Glandular Dysplasia** is reportable as adenocarcinoma in situ of the esophagus with histology code 8148/2.
 - ix. **Glandular Intraepithelial Neoplasia, Grade III/High Grade Glandular Dysplasia of other colorectal sites are not reportable unless the pathologist specifically states the tumor is ‘in-situ’ or ‘non-invasive’ or your Cancer Committee has agreed on this.**
 - x. **Specific Neoplasms with High Grade Dysplasia in Some Gastrointestinal Sites (C160-C166, C168-C169, C170-C173, C178-C179, C181)** are reportable as of 1/1/2022 (2022 List Below)
 - xi. **Non-invasive follicular thyroid neoplasm with papillary like nuclear features (NIFTP) is a low-grade tumor of the thyroid gland and is no longer reportable.**

2021/2022/2023 REPORTABLE NEOPLASMS OR RECLASSIFIED TUMORS
Please check individual year ICD-O-3 Update Guidelines for How to Use New Codes

2021 New Reportable Neoplasms/Reclassified Tumors

- a. Early or evolving melanoma, in situ and invasive – now reportable neoplasms
- b. ALL Gastro-Intestinal Stromal Tumors (GIST) – now classified ‘malignant’
- c. Thymoma Neoplasms – most now classified ‘malignant’ – see Histology/Behavior Codes
- d. **Pheochromocytoma and Medullary Paranglioma of Adrenal Gland**

2022 New Reportable Neoplasms/Reclassified Tumors

- a. LAMN – low grade appendiceal mucinous neoplasm (C18.1)
- b. HAMN – high grade appendiceal mucinous neoplasm (HAMN (C18.1)
- c. Serrated dysplasia, high grade (C160-C166, C168-C169, C170-C173, C178-C179)
- d. Adenomatous polyp, high grade dysplasia (C160-C166, C168-C169, C170-C173, C178-C179)
- e. Intestinal-type adenoma, high grade (C160-C166, C168-C169, C170-C173, C178-C179)
- f. Chondrosarcoma, grade 1
- g. 9 New Histology Codes with Associated New Histology Terms
 - o 8455/3 - Intraductal oncocytic papillary neoplasm with associated invasive carcinoma (C250-C254, C257-C259)
 - o 8483/3 - Adenocarcinoma, HPV-associated C530-C531, C538-C539)
 - o 8484/3 - Adenocarcinoma, HPV-independent, NOS C530-C531, C538-C539)
 - o 8859/3 - Myxoid pleomorphic liposarcoma
 - o 8976/3 - Gastroblastoma (C16.0 – C16.9)
 - o 9111/3 - Mesonephric-like adenocarcinoma
 - o 9366/3 - Round cell sarcoma with EWSR1-non-ETS fusions
 - o 9367/3 - CIC-rearranged sarcoma
 - o 9368/3 - Sarcoma with BCOR genetic alterations

2022 New Codes & New Terms – Do not Use for Cases Diagnosed Prior to 1/1/2022

ICD-O	Term
8033/3	Carcinoma with sarcomatoid component
8044/3	Small cell carcinoma, large cell variant (C56.9)
8085/3	Squamous cell carcinoma, HPV-associated
8086/3	Squamous cell carcinoma, HPV-independent
8086/3	Squamous cell carcinoma, HPV-independent
8144/2	Intestinal-type adenoma, high grade (C160 – C166, C168-C169, C170-C173, C178-C179)
8150/3	Oncocytic neuroendocrine tumor, non-functioning pancreatic
8150/3	Pleomorphic neuroendocrine tumor, non-functioning pancreatic
8150/3	Clear cell neuroendocrine tumor, non-functioning pancreatic
8163/2	Papillary neoplasm, pancreatobiliary type, with high grade intraepithelial neoplasia C241
8150/3	Cystic neuroendocrine tumor, non-functioning pancreatic
8174/3	Hepatocellular carcinoma, steatohepatic
8174/3	Hepatocellular carcinoma, macrotrabecular massive
8174/3	Hepatocellular carcinoma, chromophobe
8174/3	Hepatocellular carcinoma, neutrophil-rich
8174/3	Hepatocellular carcinoma, lymphocyte-rich

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8200/3	Solid-basaloid adenoid cystic carcinoma
8200/3	Adenoid cystic carcinoma with high-grade transformation
8210/2	Adenomatous polyp, high grade dysplasia (C160 – C166, C168-C169, C170-C173, C178-C179)
8211/2	Tubular adenoma, high grade
8213/2	Serrated dysplasia, high grade (C160 – C166, C168-C169, C170-C173, C178-C179)
8243/3	Goblet cell adenocarcinoma
8261/2	Villous adenoma, high grade
8262/3	Adenoma-like adenocarcinoma
8263/2	Tubulovillous adenoma, high grade
8310/3	Adenocarcinoma, HPV-independent, clear cell type
8455/2	Intraductal oncocytic papillary neoplasm, NOS (C250-C254, C257-C259)
8455/3	Intraductal oncocytic papillary neoplasm w/associated invasive carcinoma (C250-C259)
8480/2	Low grade appendiceal mucinous neoplasm (LAMN) (C181)
8480/2	High grade appendiceal mucinous neoplasm (HAMN) (C181)
8482/3	Adenocarcinoma, HPV-independent, gastric type (C530-C531, C538-C539)
8483/2	Adenocarcinoma in situ, HPV-associated (C530-C531, C538-C539)
8483/3	Adenocarcinoma, HPV-associated C530-C531, C538-C539)
8484/2	Adenocarcinoma in situ, HPV-independent, NOS C530-C531, C538-C539)
8484/3	Adenocarcinoma, HPV-independent, NOS C530-C531, C538-C539)
8500/2	DCIS of low nuclear grade
8500/2	DCIS of intermediate nuclear grade
8500/2	DCIS of high nuclear grade
8503/2	Ductal carcinoma in situ, papillary
8509/3	Tall cell carcinoma with reversed polarity
8520/2	Florid lobular carcinoma in situ
8576/3	Paneth cell carcinoma
8590/1	Uterine tumor resembling ovarian sex cord tumor
8804/3	Proximal or large cell epithelioid sarcoma
8804/3	Classic epithelioid sarcoma
8811/3	Epithelioid myxofibrosarcoma
8832/3	Myxoid dermatofibrosarcoma protuberans
8832/3	Dermatofibrosarcoma protuberans with myoid differentiation
8832/3	Plaque-like dermatofibrosarcoma protuberans
8859/3	Myxoid pleomorphic liposarcoma
8912/3	Congenital spindle cell rhabdomyosarcoma with VGLL2/NCOA2/CITED2 rearrangements
8912/3	MYOD1-mutant spindle cell/sclerosing rhabdomyosarcoma
8912/3	Intraosseous spindle cell rhabdomyosarcoma with TFCP2/NCOA2 rearrangements
8976/3	Gastroblastoma (C16.0 – C16.9)

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8990/3	NTRK-rearranged spindle cell neoplasm (emerging)
9110/3	Adenocarcinoma, HPV-independent, mesonephric type
9111/3	Mesonephric-like adenocarcinoma
9120/3	Post radiation angiosarcoma of the breast
9120/3	Epithelioid angiosarcoma
9133/3	Epithelioid hemangioendothelioma with WWTR1-CAMTA1 fusion
9133/3	Epithelioid hemangioendothelioma with YAP1-TFE3 fusion
9140/3	Classic indolent Kaposi sarcoma
9140/3	Endemic African Kaposi sarcoma
9140/3	AIDS-associated Kaposi sarcoma
9140/3	Iatrogenic Kaposi sarcoma
9200/1	Osteblastoma
9222/3	Chondrosarcoma, grade 1
9261/1	Osteofibrous dysplasia-like adamantinoma
9366/3	Round cell sarcoma with EWSR1-non-ETS fusions
9367/3	CIC-rearranged sarcoma
9368/3	Sarcoma with BCOR genetic alterations
9687/3	Endemic Burkitt lymphoma
9687/3	Sporadic Burkitt lymphoma
9687/3	Immunodeficiency-associated Burkitt lymphoma

2023 New Reportable Neoplasms/Reclassified Tumors

- **IMPORTANT FOR CASES Diagnosed 2023 FORWARD:** Beginning 1/1/2023, all cases diagnosed with pilocytic astrocytoma/juvenile pilocytic astrocytoma and related terminology are to be reported with behavior /1. They will no longer be collected with malignant behavior (/3).
- Code 9421/3 will be valid for diagnoses of high-grade astrocytoma with piloid features (HFAP).
- Coding instructions are in the remarks section for 9421/1 and 9421/3 in the 2023 ICD-O Update
- 2023 ICD-O Updates include:
 - **5 new ICD-O histology codes/terms**
 - 1 histology changed behavior and is reportable
 - 41 new preferred or related terms

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.

PLEASE REFERENCE APPENDIX R for the Complete Set of Changes for 2023 New Reportable Histology Codes, Retired Codes, New/Changes to Behavior and Reportability of Neoplasms.

ICD-O	New Codes and Terms
8272/3	Pituitary adenoma/pituitary neuroendocrine tumor (PitNET) (C75.1)
8693/3	Cauda equina neuroendocrine tumor (cranial and paraspinal nerves)
9385/3	Diffuse hemispheric glioma, H3 G34-mutant
9385/3	Diffuse midline glioma, H3 K27-altered

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ICD-O	New Codes and Terms
9385/3	Diffuse pediatric-type glioma, H3-wildtype and IDH-wildtype
9385/3	Infant-type hemispheric glioma
9391/3	Posterior fossa ependymoma, NOS
9391/3	Spinal ependymoma, NOS (C72.0)
9391/3	Supratentorial ependymoma, NOS
9396/3	Posterior fossa group A (PFA) ependymoma
9396/3	Posterior fossa group B (PFB) ependymoma
9396/3	Spinal ependymoma, MYCN-amplified (C72.0)
9396/3	Supratentorial ependymoma, YAP1 fusion-positive
9396/3	Supratentorial ependymoma, ZFTA fusion-positive
9400/3	Astrocytoma, IDH-mutant, grade 2
9401/3	Astrocytoma, IDH-mutant, grade 3
9413/0	Polymorphous low-grade neuroepithelial tumor of the young
9421/1	Diffuse astrocytoma, MYB- or MYBL1-altered
9421/1	Diffuse low-grade glioma, MAPK pathway-altered†
9421/3	High-grade astrocytoma with piloid features (HGAP)
9430/3	Astroblastoma, MN1-altered
9445/3	Astrocytoma, IDH-mutant, grade 4
9450/3	Oligodendroglioma, IDH-mutant and 1p/19q-codeleted, grade 2
9451/3	Oligodendroglioma, IDH-mutant and 1p/19q-codeleted, grade 3
9470/3	Medulloblastoma, histologically defined (C71.6)
9473/3	CNS embryonal tumor, NEC/NOS
9480/3	Primary intracranial sarcoma, DICER1-mutant
9500/3	CNS tumor with BCCR internal tandem duplication
9500/3	CNS neuroblastoma, FOXR2-activated
9509/0	Multinodular and vacuolating neuronal tumor
9509/1	Myxoid glioneuronal tumor
9509/3	Diffuse leptomeningeal glioneuronal tumor
9540/3	Malignant melanotic nerve sheath tumor
9699/3	MALT lymphoma of the dura
9749/1	Juvenile xanthogranuloma (C71.5)
9749/3	Rosai-Dorfman disease

***Note 1:** AJCC TNM Manual, 8th 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, 8th 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).

- a) **Specified malignant neoplasms of the skin are reportable conditions;** Kaposi sarcoma, malignant melanoma, in-situ melanoma, early melanoma, evolving melanoma, Merkel cell carcinoma, sebaceous adenocarcinoma, sweat gland adenocarcinoma, mycosis fungoides and T-cell or B-cell lymphoma of skin.
- b) **Dermatofibrosarcoma protuberans is no longer reportable to FCDS as of 1/1/2021.**
- c) **Patients with ‘chronic’ neoplastic conditions** such as chronic leukemia, myelodysplastic syndromes and myeloproliferative diseases, or other lymphoid/myeloid neoplasms designated as ‘chronic’ disease always have some level of active disease and must be reported. Treatment for these neoplasms may achieve a state of ‘clinical remission’. However, these conditions cannot be cured without aggressive therapy including high-dose chemotherapy plus bone marrow transplant or stem cell transplant. The chronic nature of their disease makes these cases always reportable, regardless of clinical status. See the SEER Hematopoietic and Lymphoid Neoplasm Manual for a complete listing of myeloproliferative diseases, myelodysplastic syndromes, chronic lymphoid leukemia, and chronic myeloid leukemia histology codes. **All of these are reportable neoplasms even when stated to be ‘in remission’.**
- d) **Carcinoid Tumor of Appendix Diagnosis Date 1/1/2015 forward is a Reportable Malignancy**
- e) **8323/3 – clear cell papillary renal cell carcinoma of kidney has been reclassified as a ISUP Grade 1 (low grade neoplasm) which is not malignant. However, this cancer is still reportable in the United States using the 8323/3 malignant clear cell papillary renal cell carcinoma of kidney code.**
- f) **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.**
- g) **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

- h) **Clarification for Reporting /2 and /3 Pancreatic Neoplasms** - The classification and reporting of tumors of the pancreas and of the pancreato-biliary system can be confusing in part due to the terminology associated with tumors arising within this body system, and complicated by the mixed nature of benign, borderline, in-situ and invasive neoplasms and various histologic subtypes associated with pancreato-biliary neoplasms. **ALL in-situ and invasive (malignant) neoplasms of the pancreas are reportable to FCDS.** However, some reportable neoplasms are associated with terminology registrars do not recognize as reportable malignancy. FCDS is making every effort to capture these pancreato-biliary primary tumors early in the disease process as endoscopic ultrasound (EUS) and new imaging is improving diagnosis.

Further Clarification has indicated any reportable tumor must include reference to one or more of the following terms; neoplasm with high grade dysplasia, noninvasive neoplasm, invasive neoplasm. Tumors, lesions, or abnormalities identified on endoscopic ultrasound associated only with adenoma, low grade dysplasia, moderate grade dysplasia, intermediate grade dysplasia or ‘not otherwise specified’ are classified by WHO as ‘benign’ and are not reportable. Pancreatic tumor

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(IPMN/IOPN/ITPN/CPEN) seen on endoscopic ultrasound without biopsy is not reportable unless clinically malignant due to metastasis. *Note: some of these patients still get a Whipple Procedure as if they had malignancy. So, treatment is not the defining characteristic of a malignancy in this case.* Please take care when reviewing these cases.

The IPMN Path Description must include at least one of the clarifying descriptive terms below;

- **IPMN, with high grade dysplasia**
- **IPMN, non-invasive**
- **IPMN, in-situ**
- **IPMN, associated with invasive carcinoma**
- **IPMN, invasive**

Reportable	ICD-O-3	Description
Yes	8150/3	Cystic Pancreatic Endocrine Neoplasm, invasive (CPEN)
Yes	8163/2	Papillary neoplasm, pancreatobiliary-type, with high grade intraepithelial neoplasia
Yes	8163/3	Pancreatobiliary-type carcinoma
Yes	8240/3	Neuroendocrine Tumor, Grade 1 (NET GR1) of the pancreas
Yes	8246/3	Neuroendocrine Carcinoma of the pancreas
Yes	8249/3	Neuroendocrine Tumor, Grade 2 (NET GR2) of the pancreas
Yes	8440/3	Cystadenocarcinoma of the pancreas
Yes	8452/3	Solid Pseudo-Papillary Neoplasm (SPN) of the pancreas
Yes	8453/2	Intraductal Papillary Mucinous Neoplasms (IPMN) of the pancreas with high grade dysplasia
Yes	8453/2	Intraductal Papillary Mucinous Neoplasm (IPMN) of the pancreas, non-invasive
Yes	8453/3	Intraductal Papillary Mucinous Neoplasm (IPMN) with an associated invasive carcinoma
Yes	8453/3	Intraductal Papillary Mucinous Carcinoma, invasive
Yes	8470/2	Mucinous Cystic Neoplasm (MCN) of the pancreas with high-grade dysplasia
Yes	8470/2	Non-invasive Mucinous Cystic Neoplasm (MCN) of the pancreas with high-grade dysplasia
Yes	8470/2	Mucinous Cystadenocarcinoma, non-invasive (MCN)
Yes	8470/3	Mucinous Cystadenocarcinoma of the pancreas
Yes	8470/3	Mucinous Cystic Neoplasm (MCN) of the pancreas with invasive carcinoma
Yes	8471/3	Papillary Mucinous Cystadenocarcinoma of the pancreas
Yes	8500/3	Infiltrating Duct Carcinoma of the pancreas
Yes	8503/2	Intraductal Oncocytic Papillary Neoplasm (IOPN) of the pancreas with high grade dysplasia
Yes	8503/2	Intraductal Oncocytic Papillary Neoplasm (IOPN) of the pancreas, noninvasive
Yes	8503/2	Intraductal Tubule-Papillary Neoplasm (ITPN) of the pancreas with high grade dysplasia
Yes	8503/2	Intraductal Tubule-Papillary Neoplasm (ITPN) of the pancreas, noninvasive
Yes	8503/3	Intraductal Tubule-Papillary Neoplasm (ITPN) with invasive carcinoma
Yes	8552/3	Mixed acinar-ductal carcinoma
No	n/a	Histologies with Behavior Code of /0 (benign)
No	n/a	Histologies with Behavior Code of /1 (borderline)
No	n/a	Serous cystadenomas, solid and cystic papillary (Hamoudi) tumors, lympho-epithelial cysts and simple cysts are all benign and not reportable

- i) **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.

Benign/Borderline Cancers diagnosed and/or treated before 1/1/2004 are not reportable to FCDS.

FCDS requires reporting of all benign, borderline, and malignant tumors of the Brain, Central Nervous System, Cranial Nerves, Intracranial Glands, Meninges and Peripheral Nerve Tumors.

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.

SEER has also published new 2021 requirements for abstracting benign/borderline brain and CNS tumors. Please be sure to reference the current **Solid Tumor Rules chapter for Non-Malignant CNS Tumors** for a complete listing of new required brain and central nervous system neoplasms required for 2018 and later.

- **Sphenoid Wing Meningioma is a Reportable Neoplasm beginning with 1/1/2004 diagnoses.**
- **Glomus Jugulare Tumors, Paraganglioma and Carotid Body Tumors are Reportable beginning with 1/1/2019 diagnoses for primary sites C75.4 and C75.5. Malignant Paraganglioma of Other Sites (C47.9) are reportable for pre-2019 diagnoses – see Solid Tumor Rules for clarifications.**
- **Pilocytic Astrocytoma/Juvenile Pilocytic Astrocytoma – CHANGES TO BEHAVIOR**

From 1976 to 2000, WHO assigned code 9421/3 to pilocytic astrocytoma of the brain. Beginning with the release of ICD-O-3 in 2001, WHO changed the behavior for this neoplasm from /3 to /1 making it non-reportable. 9421/3 was removed from ICD-O-3, however, the standard setting organizations in North America opted to continue collecting these tumors as 9421/3 in CNS sites. The practice did not change once benign/borderline CNS tumors became reportable in 2004. The exception being pilocytic astrocytoma/optic glioma of the optic nerve which are coded 9421/1 effective 2018 and forward.

The 5th Ed Central Nervous System Tumors reinstated code 9421/3 for a newly identified neoplasm: High-grade astrocytoma with piloid features (HGAP).

- **IMPORTANT FOR CASES Diagnosed 2023 FORWARD: Beginning 1/1/2023, all cases diagnosed with pilocytic astrocytoma/juvenile pilocytic astrocytoma and related terminology are to be reported with behavior /1. They will no longer be collected with malignant behavior (/3). ICD-O code 9421/3 will be valid for the diagnosis of high-grade astrocytoma with piloid features or HGAP only. Coding instructions are included in the remarks section for 9421/1 and 9421/3 in the 2023 ICD-O Update Tables 1 and 2.**
- **The 2023 Solid Tumor Rules Update for Malignant CNS and Non-malignant CNS provides coding instructions based on diagnosis date for pilocytic astrocytoma occurring in the CNS.**

Table of Anatomic (Primary) Sites for Reportable Benign and Borderline Tumors of Intra-cranial and other central nervous system tumors.

Anatomic Intracranial and CNS Sites for Reportable Benign / Borderline Tumors		
General Term	Anatomic Site	ICD-O-3 Code
Meninges	Cerebral meninges	C700
	Spinal meninges	C701
	Meninges, NOS	C709
Brain	Cerebrum	C710
	Frontal lobe	C711

Anatomic Intracranial and CNS Sites for Reportable Benign / Borderline Tumors		
General Term	Anatomic Site	ICD-O-3 Code
	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
Spinal cord, cranial nerves, and other parts of the central nervous system	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
Pituitary gland, craniopharyngeal duct and pineal gland	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.**

c) **AIN III of anus or anal canal (C21.0- C21.1) is reportable to FCDS.**

d) **BIRADS Category 4 and BIRADS Category 5 Diagnosis without biopsy is not reportable.**

e) **Using the Date of Mammography as Date of Initial Cancer Diagnosis for Imaging BIRADS Category 4 or 5 with positive biopsy:**

A positive/suspicious mammogram alone should never be used to code the date of diagnosis.

A positive/suspicious mammogram date should be used as the date of diagnosis ONLY when the patient goes on to subsequently have a positive biopsy and/or resection that confirms the suspicious abnormality is in fact a malignancy.

BI-RADS is not the only American College of Radiology and Data Systems Assessment (RADS)

classification system. You may see other RADS Diagnostic Imaging Standards referenced in the evaluation of diagnostic imaging findings and image results classification including but not limited to;

- C-RADS – CT Colonography
- LI-RADS – Liver Imaging
- Lung-RADS – lung imaging
- NI-Rads – Head and Neck Imaging
- O-Rads – Ovarian/Adnexal Imaging
- PI-RADS – prostate imaging
- TI-RADS – Thyroid Imaging

Do not use the newer RADS standards as a date of diagnosis until/unless SEER publishes this in manuals.

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.

2018 Solid Tumor Rules – current version – September 2023

The *2018 Solid Tumor Rules, September 2021 publication* 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 *2018 Solid Tumor Rules, September 2021 update* 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>

Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Rules and Heme DB – August 2021

The *Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual* and the accompanying Hematopoietic Database replaced the ICD-O-3 Book as the primary coding reference for Myeloid and Lymphoid Neoplasms. At the same time, the 2022 rules and DB have replaced earlier versions of the DB as well as the historical 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>.

IMPORTANT: DO NOT USE the ICD-O-3 Manual to code any histology 9590-9993. Use the most current Hematopoietic and Lymphoid Neoplasm MPH Rules Manual and Database as your primary reference.

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 cytological 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

Over the year’s registrars have grown more and more confused about the use of ‘ambiguous terminology’ on imaging and pathology reports. Training has focused more on clarifying when to use or not use ‘ambiguous terminology’ rather than reinforcing the use of ‘definitive terminology’ over ‘ambiguous terminology’ in diagnostic imaging reports. The result has been a grand misunderstanding of the preferred and priority use of ‘definitive terminology’ over ‘ambiguous terminology’ when determining when a case becomes reportable, the date of initial diagnosis, the primary site, histologic type, and the presence or absence of disease based on the terminology reflected in these reports.

Instruction and training have emphasized how to interpret ‘ambiguous’ terms to the detriment of how and when to apply ‘definitive’ terms as the preferred/priority terminology in decision-making. Unfortunately, many registrars look for the ‘ambiguous’ terms to confirm a diagnosis and often will ignore ‘definitive’ terms...or they expect the radiologist or pathologist who provides a ‘definitive’ statement to restate an abnormality as ‘suspicious for cancer’ when definitive terminology already says the abnormality is a cancer until or unless proven not to be a cancer – this is definitive terminology.

Registrars are looking for the terminology ‘suspicious for cancer’ particularly on imaging to confirm a cancer diagnosis when the ‘definitive terminology’ has already confirmed the presence or absence of cancer, date of initial diagnosis or histology type. The radiologist will not and does not need to restate that the tumor mass s/he has described is ‘suspicious for cancer’ because the definitive terminology that s/he has used already tells you it is a cancer or a specific type of cancer until/unless proven otherwise.

[The Following Guidelines should be used to differentiate between ‘Definitive Terminology’ and ‘Ambiguous Terminology’ and which terminology has priority over the other to establish the presence or absence of cancer or to delineate more clearly what a primary site, histology or other term should mean.](#)

- When ‘definitive terminology’ is used on a report, the radiologist/pathologist is already confident that a cancer is present – the diagnosis is not in question or ambiguous – it is cancer until or unless it is

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later proven not to be cancer. The physician has high confidence that a stated ‘definitive term’ is what they say it is – they do not have to repeat themselves and say that they are ‘suspicious’ about the presence or absence of disease – they are already confident it is what they say it is in the report.

- Registrars should always apply ‘definitive terminology’ over ‘ambiguous terminology.’ Reports do not have to restate ‘suspicious for cancer’ or ‘likely mucinous adenocarcinoma’ when a definitive assessment or terminology is used in the first confirmation of cancer or the to use the date of that report as the initial date of diagnosis or confirmed histology when a ‘definitive term’ is present.
- When a physician uses definitive terminology, they are stating that a mass, tumor, neoplasm or a specified histology is what they say it is unless or until it is otherwise proven not to be what they say it is based on some other test or if a subsequent test clarifies a more specific diagnosis.

For example; when an imaging report states, ‘mass in left lung,’ or they state measurements for a tumor or nodes or metastasis – the physician is telling you that they already think the abnormality is cancer until or unless it is later proven not to be a cancer or some other more definitive testing method rules out cancer. The use of a ‘definitive term’ is a statement made with confidence that it is what they say it is. Again, there is no need to restate ‘suspicious for cancer’ because the physician already thinks it is cancer – they are not even suspicious – it is cancer until/unless proven not to be.

- The report does not have to restate that the mass is ‘suspicious for cancer’...the definitive terminology has already made that statement and a cancer diagnosis is established at that time. Biopsy or resection may clarify the type of cancer – but the radiologist already believes with a high confidence that the mass is cancer. And, this report is used for the date of initial diagnosis of cancer – not the date of the biopsy or other test.
- Additionally, when ‘definitive terminology’ is used to describe a primary tumor, presence or absence of regional or distant lymph node(s) or the presence or absence of metastatic disease – the physician is stating with confidence that tumor, nodes or metastasis is present and is cancer unless otherwise proven not to be cancer by some other more definitive method or test.
- The ‘ambiguous terminology’ list of words and phrases for presence or absence of disease are applied only when ‘definitive terminology’ is NOT used to describe the presence or absence of tumor or a specific histologic type/subtype.
- There are some abnormalities that cannot be further described using a definitive term because they are too small or cannot be further characterized sufficient to state it is cancer such as ‘lung nodule’. Lung nodules are just too small to know if they are tumor nodules or nodules that are reactive such as reaction to an infectious process in the lungs. They cannot be characterized as tumor or mass.
- You use the ‘ambiguous terminology’ lists of words and phrases when only ‘ambiguous terminology’ is used and there is no ‘definitive terminology’ in the report. Not the other way around...

Another example would be a pathology report that states, ‘mucinous adenocarcinoma.’ This is a definitive diagnosis of ‘mucinous adenocarcinoma’ and you code the histology as ‘mucinous adenocarcinoma.’

- But, when a report states ‘suspicious for mucinous adenocarcinoma’ or ‘suggests mucinous adenocarcinoma,’ only then do you apply the ‘ambiguous terminology’ guidelines to determine whether or not you code the histology as ‘mucinous adenocarcinoma’ or ‘adenocarcinoma, NOS.’
- You only use the ‘ambiguous terminology’ guidelines when ‘definitive terminology’ is NOT present.
- ‘Ambiguous terminology’ does not have to be used on imaging to confirm the presence or absence of neoplasm, and, is never used instead of in place of ‘definitive terminology’.

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- Unfortunately, there is not and never has been a list of ‘definitive terminology’ – you must use your practical sense and the physician’s statement to decide if a term is ‘definitive’ not ‘ambiguous’.

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, genetic testing reports, immunophenotype reports, bone marrow biopsy reports, autopsy reports, diagnostic imaging reports, and results from medical testing.

Definitive Diagnostic Terminology ALWAYS supersedes use of Ambiguous Terminology in any report.

If the terminology describing the diagnostic assessment is ambiguous, use the following guidelines to determine whether a case should be abstracted and reported to FCDS. Words or phrases that are synonyms of these terms do not constitute a diagnosis. For example, “likely” alone does not constitute a diagnosis.

In the absence of definitive evidence, the following terms should be interpreted as diagnostic of cancer:

Apparent(ly)	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).

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.

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.

Ambiguous Terms - 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, 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 around the calcifications is negative for malignancy. Do not report the case.

Ambiguous Terms - 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. These are cases that were diagnosed months or years prior to the time they come to your facility with evidence of recurrent or progressive cancer. FCDS requires that these active cancers be reported even when your facility was not involved in the initial care of the patient's cancer. Many CoC Non-Analytic Cases are BOTH Reportable and Analytic to FCDS and NPCR. Please report as complete a case history as possible for these.

Non-Analytic Case Reporting - The Importance of These Case to Your Registry and to FCDS

- Analytic Cases (Class of Case 00-22) are the crux of the NCDB – a clinical research database with **voluntary** reporting that includes about 70-80% of hospitals in the United States – not 100% reporting.
- Analytic Cases are used in research and are important to understand how your facility performs on newly diagnosed cancers and adherence to new treatment regimens, 5-year survival, etc.
- State Cancer Reporting Laws in ALL States plus the CDC NPCR and NCI SEER require that ALL cases within a defined geographic region (state of Florida) be identified and reported for 100% of the United States.
- This is the definition of 'population-based reporting' and the crux of cancer incidence rates and cancer mortality rates...without all cases of cancer, the geographic area has 'holes' in it.
- While Hospital Analytic Cases are the crux of the NCDB and form a foundation for central registry data, they are not the only part of the central registry foundation. Non-analytic cases are equally important, particularly when the patient has evidence of cancer, recurrence of cancer, or progression of cancer.
- Furthermore, non-analytic cases of recurrent/progressive cancers bring in more revenue from workup/treatment than do your analytic cases. It is more expensive to treat metastatic cancers.
- These non-analytic reportable cancers have evidence of metastatic disease, recurrent disease, progressive disease, when they enter your facility. Their disease is active and needing treatment.
- Advanced, Recurrent and Progressive cancers require a greater level care, advanced diagnostic and treatment resources, clinical trials capabilities to offer multiple options for advanced disease, and repeat visits for continuity of care and eventually end of life care. These patients are more expensive to treat than patients with a new diagnosis, workup and initial course of therapy.

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" (Patient is without evidence of cancer).

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.

NOTE: DO NOT USE OBSOLETE HISTOLOGY CODES of any kind when reporting historical cases regardless of method for reporting these cases (Minimal Historical Grid or Full Abstract). The case will fail edits. 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 the most 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. When you send FCDS changes to one of the abstracts in your multi-facility shared cases, FCDS only changes the one abstract. It is up to the registry to identify every case effected by the change to a single case within a multi-facility reporting system.

FCDS does provide one option for multi-facility networked facilities. Some facilities may qualify to be classified as “**Umbrella Facilities**” using one umbrella facility number to report all cases within their network. There are pro’s and con’s to setting up (or taking apart) a set of umbrella facilities should any change of ownership occur within the network. It is fairly easy to set up an ‘umbrella’ group. However, it is much more difficult to take apart a set of ‘umbrella facilities’ and reassign each separate facility the cases seen only at that facility. Please contact the **Manager of Data Acquisition** with any inquiries regarding these options.

UPDATE/MODIFY Records: FCDS does not accept or receive Update or Modify Records from any Reporting Facility. FCDS only receives one initial report. FCDS makes any changes from that initial report if possible. There are times when FCDS cannot make all the necessary changes and must request that you resubmit the entire case for the case to be accepted into the FCDS Master File as a Completed Record. Please comply with these requests or the case will end up on your NOT REPORTED TO FCDS List and you will be asked to report a case that you think had already been reported...thank you.

h) Each Facility is Responsible for Reporting to FCDS/Use of Contract Abstracting Service Providers

It is the responsibility of the custodian of the medical record or the facility that is administering care to report the case to FCDS. If your facility employs a contracted abstracting service provider to meet Florida Cancer Reporting Requirements, the facility is still fully responsible for all cancer reporting activities, data quality activities, corrections, documentation, FCDS Audits, and special requests. FCDS does not contract directly with any individual, organization, company or service to perform abstracting services. These contracts are strictly between the reporting facility and the service provider. It is up to the facility to ensure that all data quality expectations are met, all deadlines are met, all requirements are met, and all activities are carried out to meet the facility responsibilities to the Florida Department of Health through the Florida Cancer Data System. FCDS is a state-mandated population-based statewide cancer surveillance system. Participation in FCDS is mandated under Florida Statute. FCDS is not a voluntary cancer reporting system like the CoC NCDB. Further, 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 30th

The June 30th Deadline is an annual milestone for cancer reporting in Florida. Florida law requires that all

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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 30th Deadline each year.

Reporting Compliance and Data Quality Reports are run following the annual June 30th 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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<p>Reportable Diagnoses</p>	<p>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)³⁹.</p> <p>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 Table 3.</p> <p>3. Carcinoid, NOS of the appendix C181 (as of 1/1/2015).</p>	<p>1. Behavior code of 2 or 3 in ICD-O-3.2 plus the ICD-O-3.2 updates posted on the NAACCR website or, for 2010 and later diagnoses, behavior code 3 according to the <i>WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues</i> (2008)³⁹.</p> <p>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 Table 3.</p> <p>3. As of 01/01/2021, early or evolving melanoma in situ, or any other early or evolving melanoma, is reportable.</p> <p>4. Carcinoid, NOS of the appendix C181 (as of 1/1/2015).</p> <p>5. All GIST are reportable as of 01/01/2021 except for those specifically stated to be benign. The behavior code for GIST is /3 in ICD-O-3.2.</p> <p>6. Nearly all thymomas are reportable as of 01/01/2021. The behavior code is /3 in ICD-O-3.2. The exceptions are microscopic thymoma or thymoma benign (8580/0), micronodular thymoma with lymphoid stroma (8580/1), and ectopic hamartomatous thymoma (8587/0).</p> <p>7. Lobular neoplasia grade III (LIN III)/lobular intraepithelial neoplasia grade III (LIN III) breast C500-C509 (as of 1/1/2016).</p> <p>8. Pancreatic intraepithelial neoplasia (PanIN III) (as of 1/1/2016).</p> <p>9. Penile intraepithelial neoplasia III (PeIN III) (as of 1/1/2016).</p> <p>10. Clear cell papillary renal cell carcinoma 8323/3 is reportable. The 2016 WHO Classification of Tumors of the Urinary System and Male Genital Organs, 4th Edition, has reclassified this histology as a /1 because it is low nuclear grade and is now thought to be a neoplasia. This change has not yet been implemented and</p>	<p>1. Behavior code 2 or 3 in ICD-O-3.2; behavior code 3 in <i>WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues</i> (2008)³⁹ (2010+); behavior code 2 or 3 in <i>WHO Classification of Tumours 5th Ed. (2022+)</i> (Refer to instructions provided by NPCR for detailed information.)</p> <p>2. Primary intracranial and central nervous system tumors behavior code 0 or 1, including juvenile astrocytoma (M9421/3)* for primary sites defined in Table 3 (2004+).</p> <p>3. Early or evolving melanoma in situ, or any other early or evolving melanoma (2021+).</p> <p>4. Carcinoid, NOS of the appendix C181, behavior changed to 3 effective 2015 (2015+).</p> <p>5. GIST tumors, all histologies changed to behavior 3 in ICD-O-3.2 (2021+).</p> <p>6. Thymomas, most behaviors changed to 3 in ICD-O-3.2. (2021+) See exceptions listed below.</p> <p>7. Lobular neoplasia grade III (LN III)/lobular intraepithelial neoplasia grade III (LIN III) breast C500-C509 (/2016+).</p> <p>8. Pancreatic intraepithelial neoplasia (PanIN III) (2016+).</p> <p>9. Penile intraepithelial neoplasia III (PeIN III) (2016+).</p> <p>10. Low-grade appendiceal mucinous neoplasm (LAMN) behavior changed to 2 effective 2022 (2022+).</p> <p>11. High-grade appendiceal mucinous neoplasm (HAMN) behavior changed to 3 effective 2022 (2022+).</p>
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		<p>it remains reportable. 11. Low-grade appendiceal mucinous neoplasm (LAMN) now has a behavior of /2 and /3 making it reportable. /2 = Tis(LAMN) confined by muscularis propria (T1-T2 are not used for LAMN), and such lesions are designated as Tis /3 = T3-T4 extending into subserosa or serosa. The ICD-O Committee and authors of the WHO Classification of Tumors of the Digestive System, 5th Edition agreed to issue corrigenda. Corrigenda – Appendiceal mucinous neoplasm 8480/2 Low-grade appendiceal mucinous neoplasm 8480/2 High-grade appendiceal mucinous neoplasm 8480/3 Appendiceal mucinous neoplasm with extra-appendiceal spread.</p>	
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<p>Exceptions (not reportable)</p>	<p>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 or SIN 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). 7. 8210/2 Adenomatous polyp, high grade dysplasia (C160 – C166, C168-C169, C170-C173, C178-C179) 8. 8211/2 Tubular adenoma, high grade 9. 8261/2 Villous adenoma, high grade 10. 8263/2 Tubulovillous adenoma, high grade 11. 8483/2 Adenocarcinoma in situ, HPV-associated (C530-C531, C538-C539) 12. 8484/2 Adenocarcinoma in situ, HPV-independent, NOS (C530-C531, C538-C539) 13. 8509/1 Uterine tumor resembling ovarian sex cord tumor 14. 9200/1 Osteoblastoma 15. 9261/1 Osteofibrous dysplasia-like adamantinoma.</p>	<p>1. Skin cancers (C44._) with histologies 8000-8005, 8010-8046, 8050-8084, 8090-8110. 2. CIS of the cervix and CIN III or SIN III of cervix (after 1/1/96). 3. PIN III (after 1/1/2001). 4. High grade dysplasia of the colon is not reportable even though it has been designated in situ (/2) in the latest WHO classification. 5. There are two new histology codes for HPV-related adenocarcinoma in situ of the cervix. These are not reportable. 8483/2 Adenocarcinoma in situ, HPV-associated (C530-C531, C538-C539) 8484/2 Adenocarcinoma in situ, HPV-independent, NOS (C530-C531, C538-C539)</p>	<p>1. Skin cancers (C44._) with histologies 8000-8005, 8010-8046, 8050-8084, 8090-8110. 2. CIS of the cervix and CIN III or SIN III. 3. PIN III (2001+). 4. Colorectal tumors with the following morphologic description: Serrated dysplasia, high grade; Adenomatous polyp, high grade dysplasia; Tubular adenoma, high grade; Villous adenoma, high grade; Tubulovillos adenoma, high grade. 5. Microscopic thymoma or thymoma benign (8580/0), micronodular thymoma with lymphoid stroma (8580/1), and ectopic hamartomatous thymoma (8587/0).</p>
<p>Multiple Primary Rules</p>	<p>2007 Multiple Primary and Histology Coding Rules (most recent version). 2018 Solid Tumor Coding Rules</p>	<p>2007 Multiple Primary and Histology Coding Rules (most recent version). 2018 Solid Tumor Coding Rules</p>	<p>2007 Multiple Primary and Histology Coding Rules (most recent version). 2018 Solid Tumor Coding Rules</p>

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<p>Ambiguous Terminology Diagnostic of Cancer**</p>	<p>apparent(ly) appears comparable with compatible with consistent with favors malignant appearing most likely presumed probable suspect(ed) suspicious (for) typical of</p> <p>Exception: if the cytology is reported using any of these ambiguous terms and neither a positive biopsy nor a physician's clinical impression supports the cytology findings, do not consider as diagnostic of cancer.</p>	<p>apparent(ly) appears comparable with compatible with consistent with favors malignant appearing most likely presumed probable suspect(ed) suspicious (for) typical of</p> <p>Exception: if the cytology diagnosis is reported using any of these ambiguous terms and neither a positive biopsy nor a physician's clinical impression supports the cytology findings, do not report.</p>	<p>apparent(ly) appears comparable with compatible with consistent with favors malignant appearing most likely presumed probable suspect(ed) suspicious (for) typical of</p> <p>Exception: if the cytology is reported using any of these ambiguous terms and neither a positive biopsy nor a physician's clinical impression supports the cytology findings, do not consider as diagnostic of cancer.</p>
<p>Ambiguous Terminology NOT Diagnostic of Cancer**</p>	<p>cannot be ruled out equivocal possible potentially malignant questionable rule out suggests worrisome</p>	<p>Any ambiguous terms not on the reportable list are not reportable.</p>	<p>cannot be ruled out equivocal possible potentially malignant questionable rule out suggests worrisome</p>

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).

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	BrainCerebrum 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. **Pathology Reports** (biopsy specimen, surgical specimen, bone marrow biopsy, FNA, core biopsy, molecular genetic testing, immunophenotyping, cytology, autopsy, addenda, consultation reports, etc.)
2. **HIM/Medical Record Disease Indices or Unified Billing System Report – All Services** (All Patient Services - Inpatient and Outpatient, Clinics, Inpatient Hospice, etc.)
3. **Radiation Therapy** Department (patient logs and/or billing reports)
4. **Infusion or Treatment 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, PET, x-ray, mammogram, etc.)

1) 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

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hematology, cytology, immune-histo-cytochemistry, immunophenotype, genetic studies, and autopsy reports and all addenda) for inpatients, outpatients and ambulatory care patients MUST be reviewed to determine whether or not a cancer is reportable.

Pathology reports must also be reviewed at least annually to insure that no cases have been missed.

Pathology may be included in Casefinding Audits in addition to the Annual ReCasefinding Audit.

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.

Electronic Copies of All Cancer-Related Pathology Reports MUST also be submitted electronically to FCDS under the FCDS E-Pathology Reporting Program. Please Contact Meg Herna at FCDS.


2) HIM/Medical Record Disease Index/Unified Billing System Report – All Services

Every patient record with a reportable 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 were adopted as the U.S. 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.

		AHCA Disposition Code List	4/4/2022 12:09:25 PM Page: 1 of 1
Code	Description	Match Status	
1	Reportable-Missed Case-Case to be Abstracted & Reported by Facility	M	
2	N/R - Tumor was Not Malignant - Behavior = 0 or 1	N	
3	N/R - NonReportable Skin Cancer - Site=C44.* and Morph = 8000 to 8110	N	
4	N/R - No Evidence of Cancer at This Time - NED	N	
5	N/R - Consultation Only	N	
6	N/R - Cancer Not Proven - Equivocal	N	
7	Case Previously Reported to FCDS by this Facility	M	
8	N/R - Outpatient Record with No Active Cancer Documented in Record	N	
9	N/R - Insitu Cancer of Cervix or CIN III	N	
10	N/R - Other	N	
11	Reportable-Case Abstracted BUT Not found in FCDS files - Abst Requested	R	
12	N/R - No Cancer Mentioned in Medical Record	N	
13	Skins we elected not to FB since most of them turn out N/R	N	
14	N/R - Hematopoietic Diseases Dx Prior to 2001	N	
15	N/R - Case DX Prior to FCDS Reference Date - Same Cancer/Same Facility	N	
16	N/R - Benign or Borderline Brain/CNS Tumor Dx Prior to 2004	N	
20	Unknown if Reportable - No Record of this Patient at this Facility	N	
21	Unknown if Reportable - Lost Medical Record	N	
30	Unknown if Reportable - No Follow-Back Ever Returned by this Facility	R	
40	N/R - Special Case - Other	N	
50	Hospice Case - Not A Hospital	U	
51	Transitional Care Center - Not A Hospital	U	
52	Not A Valid Facility Number	U	
60	This AHCA Record Matches a Vital Statistics Record (DCN-Identified)	U	
70	Closed Facility	U	
90	Not Cancer Related Cases	U	
998	Matching Algorithm Has Been Run	R	
999	Pending Match	R	

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.

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ICD-10-CM CASEFINDING LIST FOR REPORTABLE TUMORS – Oct 1, 2022 and later encounters

The following ICD-10-CM list is to be used to identify potentially reportable tumors. Some ICD-10-CM codes contain conditions that are not reportable. These records should be reviewed and assessed individually to verify whether or not they are reportable to FCDS. ICD-10-CM implementation is expected nationwide October 1, 2022 for all hospitals. A complete listing of ALL Required ICD-10-CM Code is in Appendix O of this manual.

ICD-10-CM Code	Description
C00.0 – C43.9	Malignant neoplasms
C44.13.1 – C44.13.92	Sebaceous Cell Carcinoma of Skin of Eyelid, Including Canthus
C45.0 – C96.9	Malignant neoplasms
C4A.0 – C4A.9	Merkel cell carcinoma
C49.A0 – C49.A9	GI stromal tumor
C7A.0 – C7A.8	Malignant carcinoid tumors
C84.A0 – C84.A9	Cutaneous T-cell lymphoma
C84.Z0 – C84.Z9	Other Mature T/NK-cell lymphoma
C91.A0 – C91.A2	Mature B-cell leukemia Burkitt-type
C91.Z0 – C91.Z2	Other lymphoid leukemia
C92.A0 – C92.A2	Acute myeloid leukemia with multi-lineage dysplasia
C92.Z0 – C92.Z2	Other myeloid leukemia
C93.Z0 – C93.Z2	Other monocytic leukemia
C96.A	Histiocytic sarcoma
C96.Z	Other specified malignant neoplasm of lymphoid, hematopoietic and related tissue
D00.0 – D09.9	Carcinoma in situ (exclude: skin, cervix, prostate– D04. _, D06. _ and D07.5)
D18.2	Hemangioma of intracranial structures
D32.0 – D32.9	Benign neoplasm of meninges (cerebral, spinal and unspecified)
D33.0 – D33.9	Benign neoplasm of brain and other parts of central nervous system
D35.00-D35.02	Benign neoplasm of adrenal gland - pheochromocytoma, medullary paraganglioma, chromaffin paraganglioma, chromaffin tumor, chromaffinoma
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)
D46.A – D46.Z	Other myelodysplastic syndromes
D47.02, D47.1-D47.9	Myeloproliferative diseases (9931, 9740, 9741, 9742, 9960, 9961, 9962, 9963, 9965, 9966, 9967, 9970, 9971, 9975, 9987)
D47.Z – D47.Z9	Post-transplant lymphoproliferative disorder (PTLD)
D49.6, D49.7	Neoplasm of unspecified behavior of brain, endocrine glands and other CNS
D72.110 – D72.1119	Hypereosinophilic Syndrome
R90.0	Intracranial space-occupying lesion found on diagnostic imaging of CNS

Note: Pilocytic astrocytoma are coded 9421/1 when diagnosed 1/1/2023 or later, Pilocytic astrocytoma are coded 9421/3 when diagnosed prior to 1/1/2023.

C. ABSTRACTING**1. Personnel Requirements – Abstractor Training and FCDS Abstractor Code**

Abstractor Training: Trained personnel must perform abstracting. FCDS provides references in Appendix P for numerous online training programs from basic programs to certificate and degree programs to obtain a CTR Certification. FCDS used to provide a basic abstracting course in our learning management system. However, due to the rapid nature of changes (annual changes) to manuals, instructions and references; FCDS can no longer maintain this basics course. Maintenance proved to be too intensive for the course to continue. An outline of the ABC Course Revision is still included in Appendix P for reference. The outline includes all the necessary components to complete a full basics course in cancer registration and abstracting. Professional registrars do not become professional abstractors or cancer registrars overnight. It takes 2 years or longer to become proficient in the profession. And, this is at the basics level. Simple abstracting to meet the minimum Florida Reporting Requirements does not require certification as a CTR. However, individuals must be attentive to details, task oriented, proficient in medical terminology related to cancer type/cancer treatment and must be willing to adhere to manuals that change instruction frequently – and stay current with all versions.

Further, 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 Test, 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 Test. Registration for testing and on-line testing can be found on the FCDS website in FLccSC Learning Management System.

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. Q&A will be updated to the 2022 Standards during Summer 2021.

While the FCDS Abstractor Code Requirement Policy remains unchanged, the FCDS Abstractor Code Exam is a tool introduced to help FCDS expedite FCDS Abstractor Code approvals, proficiency and data quality monitoring. Exams are short (20 multiple choice or T/F questions) with a variable mix of content questions.

Questions are updated annually to ensure the most current standards are familiar to the tester. Questions are selected at random from a pool of more than 350 questions covering 7 major topic areas. No two exams are alike. This is a skill set test, not a test of knowledge. Testers must know how to use all manuals to pass.

Appendix P: 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). Please see the annually updated document “2022 References and Resources for Cancer Registrars” published annually on our website and included as Appendix P in this manual.

FCDS Fundamental Learning Collaborative for the Cancer Surveillance Community (FLccSC)

The FCDS Fundamental Learning Collaborative for the Cancer Surveillance Community (FLccSC) learning management system (LMS) was developed to provide cancer surveillance professionals in Florida a web-based educational platform. Courses are designed for students of all experience/skill levels. There are courses and modules for those that are new to the cancer surveillance field and continuing education courses for the seasoned professional. The FCDS Abstractor Code Test is one of the modules in FLccSC.

FLccSC is a cancer surveillance community educational collaboration. FLccSC is a web-based portal, which allows Central Cancer Registries (CCR) to customize a fully functioning state-specific Learning Management System (LMS). The Florida Cancer Data System and the South Carolina Central Cancer Registry developed

FLccSC collaboratively. The initial development was funded by the respective State Departments of Health and the CDC/NPCR.

- Students access FLccSC from a link on each states CCR web-site. Once registered, the student will only see the LMS pages and content from their respective CCR. Once the student successfully completes an educational module, they will receive a Certificate of Completion including CEU where applicable.
- FLccSC is a web-based educational collaborative LMS that is available 24/7. It is cost efficient in that the students do not have to travel to a central training site or purchase training materials.
- FLccSC support includes access to a Help Desk for technical support and tutorials as a menu item on both the student site (frontend) and the Administration site (backend).
- Step by step tutorials detail how to develop and maintain the CCR FLccSC site and educational content.
- FLccSC allows educational material to be shared between CCRs at the e-Administrator's discretion.
- There are many e-administrator tutorials and tutorials for students available on the FLccSC Site.

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 Test, 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 Test. Annual re-testing is also required to ensure all abstractors retain current level understanding of cancer registry reporting requirements, abstracting and coding standards and procedures.

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, local or out-of-state contractor, interim service provider, or other registry staff - regardless of number of years' experience or certification).

FCDS will not accept any cases from individuals without an Active/Current FCDS Abstractor Code.

Exams are short (20 multiple choice or T/F questions) with a variable mix of content questions.

Questions are updated annually to ensure current standards are familiar to the tester. Questions are selected at random from a pool of more than 350 questions covering 7 major topic areas. No two exams will be alike.

The 7 topic areas include:

- Florida Reporting Requirements
- General Abstracting Knowledge
- Anatomy and Physiology
- Primary Site/Histology/Grade
- Stage at Diagnosis (SS2018, SSDI, Grade Coding Instructions)
- Latest Rule Changes
- Treatment and Survival

Standard References Used for Testing (2023 Updates):

- FCDS DAM (current version)
- 2023 Casefinding List
- ICD-O-3.2 and all Updates
- Solid Tumor Rules (current – September 2022)
- Hematopoietic/Lymphoid Neoplasms and Database Use (<https://seer.cancer.gov/seertools/hemelymph/>)
- SEER Summary Staging Manual 2018, September 2022 version
- Site-Specific Data Items, v3.0
- Grade Coding Manual, v3.0
- SEER*Rx (<https://seer.cancer.gov/seertools/seerrx/>)
- Self-Instruction <http://training.seer.cancer.gov/> and <https://seer.cancer.gov/archive/training/manuals/>
- Basic anatomy/physiology/medical terminology related to cancer – SEER Archived Instruction Manuals
 - Cancer Characteristics, Medical Terminology, 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 FCDS Abstractor Code Exam.
- ✓ Individuals with an ACTIVE (not yet expired) FCDS Abstractor Code can take the FCDS Abstractor Code Exam 30 days before expiration or once their code has expired.
- ✓ Individuals with an EXPIRED FCDS Abstractor Code will be required to take the FCDS Abstractor Code Exam each year in order to keep their FCDS Abstractor Code current and to renew their individual FCDS Abstractor Code, annually.
- ✓ If an individual's FCDS Abstractor Code has been expired for greater than 2 years, the individual must re-take and pass the FCDS Abstractor Code Exam.

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.

DO NOT SEND INCOMPLETE RCRS (Rapid Case Reporting System) CASES TO FCDS.

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.

Each Facility Must Sign Off Annually that they have completed the full year cycle of reporting each year. This Certification of Completeness is found in the FAA/HOSPADMIN Menu in FCDS IDEA Software.

FCDS monitors the number and percentage of total cases submitted after the FCDS Annual Reporting Deadline and the number and percentage of total cases submitted after the Facility has Certified Completeness in Reporting their annual cycle of cases. This is part of monitoring Timeliness at FCDS.

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 30th 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 partial abstracts for ACoS CoC Rapid Case Reporting System (RCRS).

Note: The CoC STORE 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.

Please do not submit incomplete Rapid Cancer Reporting System (RCRS) abstracts to FCDS. Please

wait until ALL first course therapy has been completed. FCDS continues to monitor patient/cancer to ensure first course therapy is consistent with stage of disease and specific biomolecular and genetic tumor markers for targeted therapies. Do not send cases too early. For cases not yet completed by the June 30th deadline, you may code the treatment as recommended, unknow if administered. All cases are required to be reported to FCDS by June 30th.

All abstracts are required to pass the FCDS EDITS metafile.

P. Maintain a ‘Medical Record Reviewed but Deemed Not Reportable to FCDS’ List of Cases

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 help annual AHCA Follow-Back activities.

The list should include the patient’s name, social security number, medical record number, date of birth, ICD-10-CM Cancer Diagnosis 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 annually at every reporting facility 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.

		AHCA Disposition Code List	4/4/2022 12:09:25 PM
Code	Description	Match Status	Page: 1 of 1
1	Reportable-Missed Case-Case to be Abstracted & Reported by Facility	M	
2	N/R - Tumor was Not Malignant - Behavior = 0 or 1	N	
3	N/R - NonReportable Skin Cancer - Site=C44.* and Morph = 8000 to 8110	N	
4	N/R - No Evidence of Cancer at This Time - NED	N	
5	N/R - Consultation Only	N	
6	N/R - Cancer Not Proven - Equivocal	N	
7	Case Previously Reported to FCDS by this Facility	M	
8	N/R - Outpatient Record with No Active Cancer Documented in Record	N	
9	N/R - Insitu Cancer of Cervix or CIN III	N	
10	N/R - Other	N	
11	Reportable-Case Abstracted BUT Not found in FCDS files - Abst Requested	R	
12	N/R - No Cancer Mentioned in Medical Record	N	
13	Skins we elected not to FB since most of them turn out N/R	N	
14	N/R - Hematopoietic Diseases Dx Prior to 2001	N	
15	N/R - Case DX Prior to FCDS Reference Date - Same Cancer/Same Facility	N	
16	N/R - Benign or Borderline Brain/CNS Tumor Dx Prior to 2004	N	
20	Unknown if Reportable - No Record of this Patient at this Facility	N	
21	Unknown if Reportable - Lost Medical Record	N	
30	Unknown if Reportable - No Follow-Back Ever Returned by this Facility	R	
40	N/R - Special Case - Other	N	
50	Hospice Case - Not A Hospital	U	
51	Transitional Care Center - Not A Hospital	U	
52	Not A Valid Facility Number	U	
60	This AHCA Record Matches a Vital Statistics Record (DCN-Identified)	U	
70	Closed Facility	U	
90	Not Cancer Related Cases	U	
998	Matching Algorithm Has Been Run	R	
999	Pending Match	R	

4. Abstracting Non-Analytic and Historical Cases

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. These cases require the same attention to detail and text as with any CoC “analytic” type case (abstracted and quality reviewed with the same rigorous data quality and documentation expectation). Include chronologic information about the cancer as available.

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. Historical Cancers that currently exhibit active disease (recurrence or progression of cancer) must be reported as a full and complete FCDS Abstract. Enter as much information as is available in your medical record.

Duplicate Case Submissions (cases previously reported to FCDS) can be problematic when they are resent to FCDS as a new submission after having already been reported. Always reference and use the Facility Alpha Listing found in the FCDS Reports Menu with your facility reference date of 1/1/1981, regardless of CoC Changes to Your State of Florida Reference Date. This report is updated every time you submit cases to FCDS. It is a complete reference of all cases ever reported to FCDS from your facility since 1981. New cancers for cases with old Accession Numbers must include the old Accession Number. FCDS recognizes many registrars do not utilize this listing properly to determine which cancers need which sequences reported and which cancers have been reported prior to your CoC Reference Date. Always remember your FCDS Reference Date is 1981 or the day your facility opened.

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: Do not report using obsolete histology codes.

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. Schema Discriminator 1
 10. Schema Discriminator 2
- 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: Schema Discriminator 1

Historical #1: Schema Discriminator 2

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 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 30th

The June 30th 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 30th Deadline each year.

Compliance and Data Quality Reports are run following the annual June 30th 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
Please refer to the document ‘[2022 References and Resources for Cancer Registrars](#)’ found in Appendix P of this manual.

9. MAKING CHANGES TO EXISTING ABSTRACTS from Field Coordinator Inquiry (corrections) or from QC Review (Visual Editing). You must comply with the messaging requirements for the FCDS Systems in order for FCDS to be able to view and process corrections, inquiries, deletions, or visual editing updates to abstracts.

Your Facility has 1 month to complete any Field Coordinator Correction/Inquiry or any QC Review Correction Inquiry. This FCDS Policy is loosely enforced but important to good quality abstracting and timeliness of operations and practices. Do not wait months to answer inquiries, make corrections, or update text and messaging in your facility queue.

FCDS does not accept or allow Update or Modify Records from any Reporting Facility. FCDS only receives one initial report. FCDS makes any changes from that initial report if possible. There are times when FCDS cannot make all the necessary changes and must request that you resubmit the entire case for the case to be accepted into the FCDS Master File as a Completed Record. Please comply with these requests or the case will end up on your NOT REPORTED TO FCDS AHCA/MORTALITY List and you will be asked to report a case that you think had already been reported.

SECTION I: GUIDELINES FOR CANCER DATA REPORTING

REQUIRED DESKTOP REFERENCES

REQUIRED REFERENCE	ORDERING INFORMATION
Current FCDS Data Acquisition Manual, 2022	FCDS, Florida Cancer Data System PO Box 016960 (D4-11) Miami, FL 33101 http://fcds.med.miami.edu/inc/downloads.shtml
FCDS IDEA – FCDS Secure Web-Based Software to abstract cases, upload batched cases, access FLccSC, QC Review, Audits	https://fcds.med.miami.edu/inc/welcome.shtml
FLccSC Learning Management System FCDS Abstractor Code Test, FCDS Continuing Education Webcast Series, NAACCR Webinar Recordings, FCDS Annual Conference, etc.	https://fcds.med.miami.edu/inc/flccsc.shtml
FCDSv23 EDITS Metafile	https://fcds.med.miami.edu/inc/downloads.shtml
2023 Instructional Manuals/Guidelines	https://www.naacr.org/v23referencepage/
Current Solid Tumor Manual, September 2022	http://seer.cancer.gov/registrars
Current Grade Coding Manual, v3.0	https://apps.naacr.org/ssdi/list/
Current Site-Specific Data Items Manual, v3.0	https://apps.naacr.org/ssdi/list/
Current SEER Site/Histology Validation List	https://seer.cancer.gov/icd-o-3/
Current SEER Summary Stage Manual, 2021	https://seer.cancer.gov/tools/ssm/
Current SEER RSA – Registrar Staging Assistant – online staging assistant	https://staging.seer.cancer.gov/
Current SEER*Rx – Interactive Drug Database	https://seer.cancer.gov/seertools/seerrx/
Current Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and Hematopoietic Database (desktop or web-based versions available), 2022	https://seer.cancer.gov/seertools/hemelymph/
Current NAACCR ICD-O-3 Coding Guidelines – Annotated Histology List	https://www.naacr.org/icdo3/
ICD-O-3.2 Excel Table downloaded from the IACR/WHO Website	Downloadable Excel File Version of ICD-O-3.2 http://www.iacr.com.fr/index.php?option=com_content&view=article&id=149:icd-o-3-2&catid=80&Itemid=545
International Classification of Diseases for Oncology, 3rd ed. Geneva, World Health Organization: 2000	The World Health Organization WHO Publications Center USA; 49 Sheridan Avenue; Albany, NY 12210 ISBN 9241545348 Order Number 11503350 http://www.who.int/classifications/icd/en/index.html

RECOMMENDED DESK REFERENCES

RECOMMENDED BOOK	ORDERING INFORMATION
<i>2023 CoC STORE Manual - CoC Standards for Oncology Registry Entry</i>	American College of Surgeons (ACS) 55 East Erie Street Chicago, IL 60611-2797 https://www.facs.org/quality-programs/cancer/ncdb/call-for-data/cocmanuals
<i>2023 SEER Program Code Manual</i>	National Cancer Institute Publications Ordering Service P.O. Box 24128, Baltimore, MD 21227, 301-330-7968 https://seer.cancer.gov/tools/codingmanuals/
<i>Cancer Registry Management Principles and Practice for Hospitals and Central Registries, 4th Edition, 2021</i>	National Cancer Registrars Association https://www.ncra-usa.org/About/Store/Store-Professional-Resources/BKct/ViewDetails/SKU/NCRCRMTXBK4ED ISBN 978-1-7329178-3-5
<i>NAACCR Standards for Cancer Registries Volume II: Data Standards and Data Dictionary, current edition (v23)</i>	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 http://www.naacr.org
EDITS Software – EditWriter 5 and GenEdits5 Install EditWRiter5 and the GenEdits5 Edit Engine to enable yourself and staff to read standard EDITS Logic used in your registry	https://www.cdc.gov/cancer/npcr/tools/edits/edits50.htm
NAACCR v23 EDITS Metafile	https://www.naacr.org/standard-data-edits/
FCDS v23 EDITS Metafile	https://fcds.med.miami.edu/inc/downloads.shtml
<i>Cancer Principles and Practice of Oncology, 10th edition</i>	Lippincott Williams & Wilkins Publishers 227 East Washington Square Philadelphia, PA 19106-3780 ISBN-10: 1451192940 ISBN-13: 9781451192940
<i>American Cancer Society Textbook of Clinical Oncology</i>	American Cancer Society Vermont Division, Inc. 13 Loomis Street Montpelier, VT 05602 http://www.cancer.org ISBN-13: 978-0944235072 ISBN-10: 0944235077
<i>CA: A Cancer Journal for Clinicians</i>	Lippincott Williams & Wilkins Publishers P.O. Box 1600 Hagerstown, MD 21741-9910 301-223-2300 (Voice) http://caonline.amcancersoc.org/
<i>CDC Data Collection of Primary Central Nervous System Tumors, National Program of Cancer Registries Training Materials, 2004</i>	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 http://www.cdc.gov/cancer/npcr/training/btr/

AJCC Cancer Staging System Products
 AJCC Cancer Staging Manual, 8th ed
 AJCC Cancer Staging, Version 9

<https://www.facs.org/quality-programs/cancer/ajcc/cancer-staging/manual>

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

ALL CASES MUST BE TRANSMITTED TO FCDS ELECTRONICALLY using the FCDS secure information and data sharing portal: the FCDS IDEA, and in accordance with all FCDS Data Submission Policies and Procedures and Transfer Protocols. Appendix Q for FAQs on 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

Quarterly Reporting

FCDS REQUIRES THAT FACILITIES TRANSMIT DATA AT LEAST QUARTERLY.

FCDS REQUIRES THAT QC REVIEW CASES, EDITS, CORRECTIONS, AND FIELD COORDINATOR INQUIRIES BE COMPLETED WITHIN 1 MONTH OF RECEIPT.

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

DO NOT SEND INCOMPLETE RCRS (Rapid Case Reporting System) CASES TO FCDS.

1. Electronic Submissions

Record Layout

All data must be submitted in the current NAACCR Version (currently v22).

ALL Cancer Registry Vendors and Cancer Registries transition to an XML Format for 2021 and later reporting.

This includes any electronic submission as well as utilization of the FCDS EDITS Metafile, v22.

The FCDS field positions and field lengths are standardized using the NAACCR transfer record layout, data definitions and data exchange guidelines. All fields identified in the FCDS Record Layout Appendix as Core ('C') must be completed. Historical cases may retain old standards.

2. Receipt on Upload

An Upload Receipt is generated after the upload is successfully transmitted. Please validate that the Upload Receipt and the expected upload are the same number of cases as a quick easy QC check.

3. Data Acceptance Policy – FCDS EDITS

Batch submissions will be edited immediately during the upload process 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.

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, unclear, equivocal, incomplete or incorrect, the reporting facility will have two weeks from the time of case transmission to send FCDS the

SECTION I: GUIDELINES FOR CANCER DATA REPORTING

appropriate information from the patient's medical records to support the code(s) assigned. FCDS QC Staff will use documentation provided to validate coding and set 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 - 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

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).

CAPIS: Electronic Reporting Options for Physicians delivering non-surgical treatment to cancer patients is an option that minimizes physician requirements to report cancers and streamlines the data submission process. This would include medical oncologists, hematologists, radiation therapy programs, and other non-surgical cancer treatment physician practices and centers. Electronic Reporting of Physician Claims is processed through the CAPIS System at FCDS. Please contact Meg Herna, FCDS Manager of Data Acquisition for more information on how to report claims from your physician office and help FCDS complete reporting of all therapies administered in physician offices.

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.

FCDS continues to bring on new labs every year. FCDS works with the larger labs on a consistent basis to improve reporting e-pathology reports to FCDS. Please contact Meg Herna, FCDS Manager for Data Acquisition, to learn about automated reporting of electronic pathology reports to FCDS.

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 Alternate Resources for Self-Instruction in Cancer Registration/Abstracting
- e. Provide Information to Candidate-CTRs regarding preparing for and writing the CTR Exam.
- f. 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:

- FCDS hosts a 2-day Annual Conference to Inform Registrars of New Initiatives and Standards
- FCDS hosts a 6-part educational web broadcast series each year focusing on special topics
- Appendix P provides multiple resources for beginner to advanced hospital and central cancer registry training: cancer surveillance, cancer registry, abstracting and coding cancers, etc.
- FCDS hosts 12 NAACCR Educational Webinars at 7 host sites around the state each year.
- ALL 12 NAACCR Educational Webinars are available in recorded session in FLccSC
- Additional free resources are 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.
- b. Completeness is also the extent to which each abstract includes all of the FCDS Required Data

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)
 - v. FCDS Audits and Visual Editing (QC Review)
 - vi. NPCR Audits and Visual Editing Evaluations (DQE)
- c. 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 25th Record – Visual Editing
 - v. On-Site Re-Abstracting Audits
 - vi. Remote Access Re-Abstracting Audits – Visual Editing
 - vii. Mail-In Re-Abstracting Audits
 - viii. FCDS Management Reports
- d. 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,

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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
- iii. Monitoring the number of cases reported to FCDS after each annual deadline
- iv. Monitoring the number of cases reported to FCDS after Certification of Completeness
- v. AHCA Audits – All In-Patient and Ambulatory Care Facilities in Florida
- vi. FAPTP Audits – Most Pediatric Facilities in Florida

FCDS Data Quality/Quality Control Program Components

1. 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 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

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2. 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”.

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 - In situ 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
55	DCO Replaced by Non-DCO- For FCDS Use Only
56	Report Source 7 or 8 is corrected and does not link back to proper Pt.
57	Demographic information changed. Death Certificate linkage was lost.

3. 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.

4. QC Visual Review Sampling of Every 25th Record – Visual Editing

FCDS Quality Control staff visually reviews at least one in every 25th 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 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.

New QC Review Report Available in IDEA

FCDS is happy to announce the addition of a new QC Report for hospitals. The report can be found under the QC Tab in IDEA. It is called the ‘QC Review Report’ or ‘QC Facility Analysis’ and is accessible to users with HOSPADMIN or FAA User Roles. We hope this new report will help to meet CoC Requirement 6.1.

The user can select the time period for the report. And, the report will display every single case that FCDS Visually Edited (QC Review – Every 25th Case) and the Result of that Review (See Below).

This report has been designed specifically to address CoC Cancer Program Requirement 6.1 by giving you a total of cases QC'd by FCDS in any given time period, the accession number and sequence of each case reviewed, and the outcome from each review including the Turnaround Time in Days with totals at the bottom of the report. The report is exportable to Excel or you can print it in PDF format.

If your program manages multiple facilities, you will need to run a separate report for each facility. The Report is not set up for a multi-facility network of facilities to be combined.

FCDS has no plans to add the FCDS Abstractor Code to this report - ever. We want to keep this information at the facility level, not the individual abstractor level. Why? The QC Sample is not a large enough sample of any single person's work to be used in a performance evaluation. FCDS highly recommends that nobody tries to incorporate this report into any annual performance reviews. It would not be a fair assessment.

Accession	Receipt	Completed	Turnaround	Corrected	Forced	Deleted	No Changes
	04/16/2020	08/10/2020	116	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	12/30/2020	01/17/2021	18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	05/04/2020	07/01/2020	58	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	01/20/2020	03/02/2020	42	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	12/22/2020	01/13/2021	22	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	12/14/2020	01/10/2021	27	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	07/30/2020	10/02/2020	64	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	08/27/2020	10/19/2020	53	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

5. FCDS Follow-Up Reports in IDEA

FCDS makes available updated/consolidated First Course of Treatment Data and Follow-Up Dates (including Dates of Death) via the FCDS Follow-Up Inquiry and Batch Reports Menu. This inquiry/report system has been available since 2014 in IDEA, but is often overlooked as a resource for patient follow-up for CoC Accredited Facilities; and, as a way to find and complete First Course of Therapy received in a physician office or other setting (not at your facility). This report is available to HOSPADMIN and FAA roles in FCDS IDEA.

All you need to do is provide the inquiry system with your 4-digit Facility Number, Accession Number and Sequence Number. The system will find your individual case to verify that you have reported the cancer to be matched. Then the system will pull down all of the First Course of Therapy Data (including start dates – but not the treatment text) from all facilities who have reported the cancer and have provided treatment data...this is via the ‘Consolidated Tumor Record’ a single-source FCDS Record that provides a summary of all of the data submitted to FCDS for this person for this cancer.

This report may provide you with more treatment data than you had access to while the patient was at your facility including; physician-office treatment, other facility treatment, radiation therapy, or other cancer-directed therapies. The system cannot provide you with any outpatient pharmacy data as these data are not part of the FCDS Cancer Reporting System at this time...but, it will give you a more complete course of Treatment Given for this cancer.

The report can be run one case at a time or in a batched mode. To batch cases you must create a file that includes the 4-digit facility number, 9-digit Accession Number and 2-digit Sequence Number. These data must be in a comma-delimited file with no spaces between items. You load the file and wait for the result. You will get individualized Treatment by Case for All Treatment that has been reported on this person/cancer to FCDS from any source. You will not know the source of the treatment, only that it was given and the date it started. And, you will also receive a date of last contact from AHCA and/or a State of Florida Death Certificate.

The report will also tell you which cases matched or did not match or if you have a problem with the format of the file...any of these inconsistencies will result in a ‘no-match’ for the case. And, you can either display the results on your screen, export them to a comma-delimited file, tab-delimited file, or export them to an Excel formatted file for review & entry.

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 Test, 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 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 Test is a tool introduced to help FCDS expedite FCDS Abstractor Code approvals, renewals, and monitoring. Tests are short (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 updated annually to ensure the most current standards are familiar to the tester. Questions are selected at random from a pool of more than 350 questions covering 7 major topic areas. No two exams will be alike.

Before taking the test, 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 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

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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

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 Test, 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 renew an Existing FCDS Abstractor Code must take and pass the FCDS Abstractor Code Test.

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, local or out-of-state contractor, interim service provider, or other registry staff - regardless of number of years' experience or certification).

FCDS will not accept any cases from individuals without an Active/Current FCDS Abstractor Code.

Tests are short (20 multiple choice or T/F questions) with a variable mix of content questions.

Questions are updated annually to ensure the most current standards are familiar to the tester.

Questions are selected at random from a pool of more than 350 questions covering 7 major topic areas. No two exams will be alike.

The 7 topic areas include:

- Florida Reporting Requirements
- General Abstracting Knowledge
- Anatomy and Physiology
- Primary Site/Histology/Grade
- Stage at Diagnosis (SS2018, SSDI, Grade Coding Instructions)
- Latest Rule Changes
- Treatment and Survival

Standard References Used for Testing (2022 Updates):

- **FCDS DAM (current version)**
- **2023 Casefinding List**

- ICD-O-3.2 and all Updates
- Solid Tumor Rules (current – September 2022)
- Hematopoietic/Lymphoid Neoplasms and Database Use (<https://seer.cancer.gov/seertools/hemelymph/>)
- SEER Summary Staging Manual 2018, September 2021 version
- Site-Specific Data Items, v3.0
- Grade Coding Manual, v3.0
- SEER*Rx (<https://seer.cancer.gov/seertools/seerrx/>)
- Self-Instruction <http://training.seer.cancer.gov/>
- Basic anatomy/physiology/medical terminology related to cancer – SEER Archived Instruction Manuals – 3 manuals - Cancer Characteristics, Medical Terminology, Anatomy as Related to Cancer <https://seer.cancer.gov/archive/training/manuals/>

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.

3. 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.

DO NOT SEND INCOMPLETE RCRS (Rapid Case Reporting System) CASES TO FCDS.

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 30th 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.

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.

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. Similar analyses may 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

Before submitting an application for data you are strongly advised to review the new Automated Data Request instructional videos on the FCDS Data Request Web page. The tutorials explain how to navigate the DREAMS system. FCDS will no longer accept paper applications.

Procedures for Data Release

All data requests, regardless of the nature of the request, must be submitted to FCDS via the FCDS Data Request Automated Management System (DREAMS) module on the FCDS Website. All requests require an FCDS IDEA account; if a researcher does not have an FCDS IDEA account, he or she must first establish one. Please refer to the video 'New IDEA User' instructions on the Data Requests page of the FCDS Website.

Requests for data fall into five broad categories: (1) stat data, (2) tabular, (3) ad hoc, (4) data linkage and (5) hospital specific requests. There are specific procedures and fees for each category. This document provides a description for each of the categories as well as the fee. It is recommended that you read this document prior to filling out a DREAMS application.

There are instructional videos for each category of request. Please refer to the respective video on the FCDS Data Request web page before you begin your automated data request.

There are four separate and distinct entities involved in the data release approval process.

The number of entities involved in processing your request depends on several factors. Please refer to the specific category to see which entities are involved.

- 1) **Florida Cancer Data System (FCDS)** maintains and collects the data. FCDS performs data extracts after approvals are obtained from Florida DOH Cancer Registry Program (CRP) and if required from Florida DOH IRB (IRB).
- 2) **Florida DOH Cancer Registry Program (CRP)** decides what variables will or will not be released based on scientific merit and if variables are available that will meet the research needs of proposed research. The CRP will also decide whether or not the application will require Florida DOH IRB approval. *It is essential that CRP approval is obtained prior to submitting for IRB approval.*
- 3) **Florida DOH IRB (IRB)** reviews data applications to ensure it is ethical, and that participants are protected. *The DOH IRB submission is outside of DREAMS.*
- 4) **Florida DOH Vital Statistics (VS)** requires requestor to submit an application for approval of data items derived from death certificates. This is also outside DREAMS.

Request Category	Approval Required by			
	FCDS	CRP	IRB	VS
Stat	X			
Tabular	X	X ¹		X ¹
Ad hoc	X ²	X	X ¹	X ¹
Linkage	X ²	X	X ¹	X ¹
Hospital Specific	X			

1 may or may not be required, dependent on cell size, geographic level, source, variable(s) requested, etc.

2 reviewed to make sure that application complete and all information has been submitted before forwarding to the CPR for approval; not reviewed for scientific merit.

DATA REQUEST CATEGORIES**(1) Stat Data Request**

Currently, FCDS provides one static dataset. ***This is a flat file. You will need some type of software to read in the data and analyze it (i.e. SAS, SPSS, SQL).*** For a complete list of variables contained in the dataset please refer to the “Variables available for request”. The list of variables in the Stat dataset file is fixed; it is strongly recommended that the requestor review the *STAT layout.pdf* prior to applying for a stat dataset.

The stat dataset is available free of charge; it 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. Refer to the Stat layout.pdf for the variables included in the dataset and to the aggregated demographic variables. Please log into DREAMS, select Stat Dataset and follow the submission instructions for this type of request.

Note: if your study requires record level data and the variables needed are not contained in the Stat dataset or the aggregated groups will not meet your research needs, you will need to apply for an Ad Hoc/ type request. Refer to the Ad hoc category for more information.

The Stat dataset is updated annually, with the most recent year being added as it becomes available.

FCDS will fill data requests for the Stat Dataset within 30 business days once the application is complete and approved.

Please view the Stat Data Request Video prior to filling out the DREAMS application for this type of request.

Entities involved in approving the Stat dataset: FCDS.

(2) Tabular Data

These types of requests concern requests that require output in the form of tables or some specific statistical output. An example of tabular data in a table could be a table such as

	Gender	
Cancer Site	Male	Female
Colon	A	B
Rectum	C	D

An example of tabular data could also be statistical output such as the mean age at diagnosis for brain cancer.

In an effort to protect the indirect identification of the patient, the "rule of ten" is applied; this rule suppresses any counts 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 CRP.

If data with counts fewer than 10 or below the county are needed, be sure to specify why it is needed in your

application; this information will be needed by the CRP.

In addition, if you are requesting output in the form of tables, it is highly recommended that the requestor submit templates of how the data is to be displayed.

FCDS will fill most tabular data requests within 30 business days once the application has been completed and cost has been approved; tabular requests are invoiced by the hour. Refer to fee and billing procedure section for additional information.

Please watch the Tabular Request Video prior to making this type of request.

Entities involved in approving tabular requests: FCDS and possibly CRP and VS. VS approval is only required for those studies wanting to obtain variables derived from death certificates

(3) Ad hoc

In DREAMS this category is also referenced as Ad hoc/patient.

Research which requires record level data for secondary analysis or for patient contact will need to make this type of request. Please review the variables available for release to make sure that FCDS has the variables that will meet your research needs. Note: date of birth month and day are NOT releasable.

Note: approval for ad hoc/patient requests by Florida Department of Health (CRP & IRB) can take anywhere from 8 weeks to 18 months, depending on complexity of the request and thoroughness of the application. Please plan accordingly.

FCDS will fill most ad hoc/patient requests within 30 business days once the application has been completed and cost has been approved; ad hoc requests are invoiced by the hour; patient contact studies are invoiced according to the number of records extracted. Refer to fee and billing procedure section for additional information.

Please watch the Ad Hoc Request Video prior to making this type of request.

Entities involved in approving ad hoc/patient requests: CRP and possibly VS and IRB. The CRP will determine whether or not IRB approval is required. VS approval is only required for those studies wanting to obtain variables derived from death certificates.

(4) Data Linkage

A data linkage project is a request that involves linking internal FCDS data to an external data set.

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 which require adjustment to the external data set will be charged to the requestor according to the fee schedule (Refer to Fees and Billing Procedure below).

At a minimum one of the following combinations are required to link records with FCDS:

- 1) First Name, Last Name, Sex, Date of Birth, Zip Code and Street Address*
- 2) First Name, Last Name, Sex, Date of Birth, and Social Security Number*

Additional information such as Middle Initial, Alias Name, Maiden Name, City, State, and Birthplace improve chances of successfully linking your records to FCDS and we strongly encourage you to submit these data items if available.

FCDS will fill data linkage requests within 8 weeks once the request and cost have been approved. Currently

FCDS uses a combination of R and Stata for data linkages. Requests using other software can be considered but likely will result in additional fees and time, in which case the 8 week time frame does not apply and the researcher may be charged additional fees. A copy of the required record layout “Data Linkage Record Layout” is available under the “Data Request” link on the FCDS web site <http://fcds.med.miami.edu> .

Please note that all linkages must occur at the office of the Florida Cancer Data System. No offsite linkages are permitted.

Please watch the Data Linkage Request Video prior to making this type of request.

Entities involved in approving linkage requests: CRP and possibly VS and IRB. The CRP will determine whether or not IRB approval is required. VS approval is only required for those studies wanting to obtain variables derived from death certificates

(5) Hospital Data Requests

Hospital data requests refer to requests for downloads for data which your facility has submitted.

You must be the Facility Access Administrator (FAA) in order to access this module.

You will be able to select the admission year(s) you would like to have extracted and the download will be available in the latest NAACCR version record layout.

Please watch the Hospital Specific Request Video prior to making this type of request.

Entities involved in approving hospital specific requests: FCDS

Fees and Billing Procedure

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 research applicant. The fees are as follows:

- STAT Dataset - No Charge
- Minimum charge - \$150.00
- Ad Hoc: Statistical analysis/programming/data coordination - \$150.00 per hour

- Data Linkage:

	<i>Number of Records</i>	<i>Cost</i>
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

	<i>Number of Records</i>	<i>Cost</i>
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

Please note:

The billing procedure is as follows: once approval is granted and the data request is processed, the researcher will be notified in DREAMS when the dataset is available for download. An invoice will be downloaded along with the results of the data request or linkage from DREAMS. Payment may be made by check, purchase order or credit card.

Data linkage fees are charged for those projects involving the matching of an outside data source to the Florida Cancer Data System database.

Other Information:

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

All media requests should be directed to The Director 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. Thank you

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.

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