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.

	Approval Required by			
Request Category	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 will 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:

	Number of Records	Cost
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

	Number of Records	Cost
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