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 new system. FCDS will no longer accept paper applications.

<div align="center">**Procedures for Data Release**</div>

All data requests, regardless of the nature of the request, must be submitted to FCDS via the FCDS Automated Data Request module on the FCDS Website. If the researcher does not have an FCDS IDEA account, they must first establish one. Please refer to the video *'New IDEA User'* instructions on the Data Request page of the FCDS Website.

Most requests for data fall into five broad categories: (1) static datasets (three different types), (2) statistical/tabular data, (3) ad hoc datasets (any dataset containing patient identifiable data and/or data requiring approval from DOH and/or DOH IRB approval), (4) linkage studies (data requiring approval from DOH and DOH IRB approval), and (5) hospital data requests. There are specific procedures and fees for data release based on the category of request.

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

(1) Static Datasets

Currently, FCDS provides one static dataset. ***Please note 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 Static file is fixed.*

A) The <u>STAT Dataset</u> is available without charge to anyone requesting FCDS data. The <u>STAT Dataset</u> contains county level case data for all sites, with many of the demographic variables collapsed into aggregate groups, i.e. age, race, marital status, etc. The automated application form along with the variable list for the <u>STAT Dataset</u> is available under the "Data Request" link on the FCDS web site http://fcds.med.miami.edu. Please log into the FCDS Automated Data Request module and follow the submission instructions.

If your study requires record level data and the variables are not contained on the Static datasets, you will need to request Ad Hoc data. Please review the *Procedure Guide for Studies that Utilize the Florida Cancer Data System Data for Patient Identification and Contact*. Refer to the confidential data section for more information.

For questions, please contact:

> Florida Department of Health
> Cancer Registry Program
> Cancer Registry
> Re: Confidential Data Request
> 4052 Bald Cypress Way, Bin A-12
> Tallahassee, FL 32399-1720
>
> Telephone: (850) 245-4444 ext 2441
> Fax: (850) 922-9299

The data on the Static datasets are updated when necessary, with the most recent year being added as it becomes available.

FCDS will fill data requests for the Static Dataset within 30 business days once the application have been received by FCDS.

(2) Statistical Analysis/Tabular Data (statistical output no raw data)

All requests for non-confidential statistical/tabular data must be received through the Automated Data Request module. Please click the button titled "Tabular Data" found on the "New Data Request' tab under the Automated Data Request module (link on the FCDS web site http://fcds.med.miami.edu). This type of data request can be approved directly by FCDS. The basic rule of thumb is that as long as the tabulation cannot either directly or indirectly identify any patient, the data may be released. In an effort to protect the indirect identification of the patient, the "rule of ten" is applied; this rule suppresses any cell containing fewer than 10 cases. Tabulated data may be released at or above the county code level with a count of 10 or greater; for counts less than 10 or data below the county level; approval will be required from the Department of Health.

Because each request is unique, FCDS staff will discuss the project with the requestor to verify the type of data required and determine if the system is capable of producing the required data and to determine approximately how long it will take to fill the request. Based on this information, an estimate of the cost is provided. The applicant will submit the request through the Automated Data Request module. FCDS staff may send a message the requestor through the Automated Data Request module as needed to discuss and clarify additional details of the request.

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

FCDS will fill most data requests for statistical/tabular data within 30 business days once the request has been finalized and the cost has been approved.

(3) Confidential Data

There are two types of confidential data; data that can directly identify a patient, and reporting facility data.

A) All requests for *data that can directly identify a patient* must be sent to the Florida Department of Health (DOH) for approval by both the DOH Cancer Registry Program and the DOH Institutional Review Board (IRB). If you are requesting facility identifiers for data other than that submitted by your facility) you will also need DOH Cancer Registry Program approval and possibly DOH IRB approval and or the Florida Bureau of Vital Statistics approval. Please refer to the *Procedure Guide for Studies that Utilize the Florida Cancer Data System Data for Patient Identification and Contact* for application materials and submission requirements. The Procedure Guide can be found at
http://www.fcds.med.miami.edu/inc/datarequest.shtml

Further information on the DOH IRB application process and timeline can be found at
http://www.doh.state.fl.us/execstaff/irb/index.html

Further information
For questions, please contact:

>   Florida Department of Health
>   Cancer Registry Program
>   Cancer Registry
>   Re: Confidential Data Request
>   4052 Bald Cypress Way, Bin A-12
>   Tallahassee, FL 32399-1720
>
>   Telephone: (850) 245-4444 ext 2441
>   Fax: (850) 922-9299

Approval is required from **both** the DOH Cancer Registry Program and DOH IRB for these types of data requests. The DOH IRB submission is **outside** the Automated Data Request module. You must get DOH Cancer Registry Program approval before getting DOH IRB approval. FCDS staff will begin to work directly with the researcher after approval has been obtained from both agencies. FCDS will not begin work on the project until we have received all of the necessary paperwork directly from the DOH Cancer Registry Program. Only those data items (variables) specified in the *Application for Research Use of the Florida Cancer Data System* will be extracted. FCDS will fill confidential data requests within 6 weeks time once the request and cost have been approved.

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

B) *Reporting facility data* is also considered confidential data. When requesting facility specific data (data other than that submitted from your facility), please mail the data request form along with original cover letters from all concerned facilities on their facility letterhead to FCDS. It is the requestors responsibility to obtain permission for data release from each of the medical facilities of interest prior to making the data request.   Requests should be submitted in writing on facility letterhead. If the data is to be sent to a third party, this request should be specified in the letter.

(4) Data Linkage

A data linkage project is a request that involves linking internal FCDS data to an external data set. The application process for data linkages is identical to that of confidential data requests. (Please refer to the confidential data requests section above).

Fields used in the linkage must be consistent in both data sets. The researcher should send FCDS the data in a fixed length ASCII file with the proper record layout and format. (Refer to Data Linkage Record Layout document). Any deviations from the record layout or format 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 the following information is required to link records with FCDS:
First Name, Last Name, Sex and Date of Birth and/or Social Security Number.

Additional information such as Middle Initial, Alias Name, Maiden Name, Race, Street Address, City, State, Zip Code 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. If the linkage will be done using matching software other than Automatch or LinkPlus, then additional samples of matched records and proofing the matching software or matching algorithm will be required, in which case the 8 week time frame does not apply and the researcher may be charged additional fees.

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

(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 in order to access this module. You will be able to select the admission year(s) you would like to have downloaded. The download file will be in the current NAACCR record layout.

Cancer Cluster Data

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

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

Subsequent patient lists (without changes to format, layout, or variables) will be charged 50 percent of the sliding scale fee for the number of records extracted. For example, subsequent request for another 30,000 patient listing would be $2,500 x .50=$1,250.

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 the dataset is available for download. An invoice will be downloaded along with the results of the data request or linkage from the Automated Data Request System. 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. Please contact FCDS directly to discuss fields and the associated record layout. A copy of the required record layout is available under the "DataRequest" link on the FCDS web site http://fcds.med.miami.edu .

Other Information:

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

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

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