

FCDS

Florida Cancer Data System

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

Procedures for Data Release

Most requests for data fall into five categories: (1) data CDs, (2) statistical/tabular data, (3) confidential data, (4) data linkage, and (5) data supporting potential cancer clusters. There are specific procedures and fees for data release based on the category of request. All data requests, regardless of the nature of the request, must be submitted to FCDS in writing using the appropriate form.

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

(1) Data CDs

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

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

B) The two versions of the *Confidential CD* are: 1) The Limited Confidential CD which contains no geocoded data, and 2) the Full Confidential CD containing geocoded data. Both Confidential CDs are void of any personal identifiers (name, address, date of birth, and social security number). The only difference between the CDs is that one contains geocodes, and the other does not. FCDS approval is required for release of the Limited Confidential CD. The application process for the Full Confidential CD requires DOH IRB approval prior to release. Both Confidential CDs are available only to recognized academic, research, and governmental institutions. There is a charge for both versions of the Confidential CD. Please see the Fees and Billing Procedure section of this document for information on these charges. The application forms for the Confidential CDs are available online under the "Data Request" link on the FCDS web site <http://fcds.med.miami.edu>. If you would like to request one of the CDs please download this document and follow the submission instructions. In addition, if applying for the Full Confidential CD, please note as stated above you will need to fill out the DOH IRB form as well. This form is available within the "Procedure Guide for studies that utilize FCDS for patient identification and contact" document under the "Data Request" link of our website. Further information on the DOH IRB application process and timeline can be found at <http://www.doh.state.fl.us/execstaff/irb/index.html>

For questions, please contact:

Florida Department of Health
Bureau of Epidemiology
Cancer Registry
Re: Confidential Data Request
4052 Bald Cypress Way, Bin A-12
Tallahassee, FL 32399-1720

Telephone: (850) 245-4444
Fax: (850) 922-9299

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

FCDS will fill data requests for data CDs within 20 business days once the application and any payment have been received by FCDS.

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

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

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

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

(3) Confidential Data

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 Bureau of Epidemiology and the DOH Institutional Review Board (IRB). Please refer to the *Procedure Guide for Studies that Utilize the Florida Cancer Data System Data for Patient Identification and Contact* for application materials and submission requirements. The Procedure Guide can be found at <http://fcds.med.miami.edu/inc/datarequest.shtml>. Further information on the DOH IRB application process and timeline can be found at <http://www.doh.state.fl.us/execstaff/irb/index.html>
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Once approval has been received from **both** the DOH Bureau of Epidemiology and DOH IRB, FCDS staff will then begin to work directly with the researcher. FCDS will not begin work on the project until we have received all of the necessary paperwork directly from the DOH Bureau of Epidemiology. Only those data items (variables) specified in the *Application for Research Use of the Florida Cancer Data System* will be extracted. FCDS will fill confidential data requests within 6 weeks time once the request and cost have been approved.

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

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. Keep in mind that all applicable fees apply. The exception to the above rule is when requesting data submitted from the originating institution; in which case each reporting facility has an annual \$300 credit, which can be applied to data requests only with regard to data submitted from their institution. Requests should be submitted in writing on facility letterhead. 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).

FCDS will fill data linkage requests within 6 weeks time once the request and cost have been approved.

(5) Cancer Cluster Data

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

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:

- Public use CD - No Charge
- Minimum charge - \$150.00
- Statistical analysis/programming/data coordination - \$150.00 per hour
- Limited Confidential CD without geocodes - \$500.00
- Full Confidential CD with geocodes - \$1,000
- Data Linkage:

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

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

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

- Overnight mailing - actual cost

Please Note:

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

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 1-800-906-3034 or 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