

Register

A joint project of the Sylvester Comprehensive Cancer Ctr
and the Florida Department of Health

Division of Cancer Prevention and Control

Volume 46 – January, 2010

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. Unless otherwise specified, all application forms and documents can be found in the “Data Requests” section of <http://fcds.med.miami.edu>.

For a list of the variables available for data requests, please review the “Variables available for data requests” list. This list also contains the list of variables contained on the Public Use CD, Limited CD, and the Full CD.

Most data requests involve a data request fee. However, the public use CD is available free of charge (for more information see the Data CDs section), and each reporting facility has an annual \$300 credit, which can only be applied to data requests with regard to data submitted from their institution (for more information refer to the *Confidential Data* section under *DATA REQUESTS*). For all other fees, please review the *FEES AND BILLING* section of this document.

DATA REQUESTS

(1) Data CDs

Currently, FCDS provides three raw data CDs: a Public Use CD; a Limited CD and a Full CD. The data on the CDs are updated when necessary, with the most recent year being added as it becomes available. 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, SOL). All data CDs lack any personal identifiers (name, address, date of birth and social security number). All data CD application forms are available on the FCDS website in the “Data Requests”

section at <http://fcds.med.miami.edu/>, with the exception of the DOH IRB form which is available at <http://www.doh.state.fl.us/execstaff/irb/index.html>.

The *Public Use CD* is available to anyone free of charge. 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 for the Public Use CD is available under the “Data Requests” link on the FCDS web site. To obtain, please download the application and follow the submission instructions.

The *Limited CD* contains case level cancer data but no personal identifiers or geocoded data. DOH approval is required for release of the *Limited CD*. The *Limited CD* is available only to recognized academic, research, and governmental institutions. The DOH application form for the Limited CD is available under the “Data Request” link on the FCDS web site. To obtain, please download the application and follow

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the submission instructions. Payment is required along with the application.

The *Full CD* contains case level cancer data with geocoded address of diagnosis but no personal identifiers. DOH approval and DOH IRB approval is required prior to data release. The *Full CD* is available only to recognized academic, research, and governmental institutions. The DOH application form for the Full CD is available under the "Data Request" link on the FCDS web site. To obtain, please download the application and follow the submission instructions. Payment is required along with the application. Further information on the DOH IRB application process, the IRB application form and timeline can be found at <http://www.doh.state.fl.us/execstaff/irb/index.html>

For questions concerning the variables on the different Data CDs, contact FCDS. For questions involving the forms or the approval process please contact:

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

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

FCDS will fill data requests for data CDs within 20 business days once the application has been approved by DOH and DOH IRB (if applicable).

(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>. Generally, 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.

After the form has been received, FCDS will provide a cost estimate. 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 by the applicant.

(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 under the "Data Requests" link on the FCDS web site <http://fcds.med.miami.edu>. 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:

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Bureau of Epidemiology, Cancer Registry
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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 requestor's 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.

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(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 available under the "Data Requests" link on the FCDS web site <http://fcds.med.miami.edu>). 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).

The time and complexity of data linkage projects varies a great deal; therefore, the time needed for completion can vary as well. FCDS will discuss the time needed for completion with the investigator. Time for completion can vary from a few weeks to a few months for the larger projects. Most projects will be filled within 6 weeks but if the number of records to be matched exceeds 250,000 then the time needed for completion can be a few months.

(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

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
- Limited Confidential CD without geocodes - \$500.00
- Full Confidential CD with geocodes - \$1,000
- Statistical/Tabular or Confidential Data:

Minimum charge - \$150.00

Statistical analysis/programming/data coordination - \$150.00 per hour

- Overnight mailing - actual cost
- 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

Special Studies datasets containing geocodes or patient address information to be used for patient contact

	<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

Subsequent listings for special studies data sets (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 $\$2500 \times .50 = \$1,250$.

Please Note:

The billing procedure for the Confidential CDs is as follows: once payment and supporting documentation are received and approved, 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.

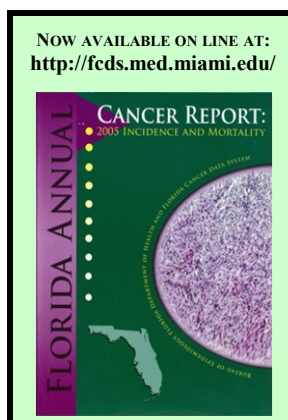
Other Information:

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. As a condition of the request, please notify FCDS of any subsequent publication using FCDS data. ☞



POLICY CHANGES IN THE CANCER REPORTING PROCEDURES

December 4, 2009

TO: Facility Administrator, Hospitals, Physician Offices, Ambulatory Surgical and Radiation Therapy Facility

FROM: Jill A. MacKinnon, PhD, CTR, Florida Cancer Data System

RE: Cancer Reporting Policy Change

As you know the Florida Cancer Data System (FCDS) is Florida's statewide, population-based, cancer surveillance system. Reporting cancer cases seen at your facility or office is legislatively mandated under Section 385.202 *Florida Statutes* and Rule 64D-3.034 *Florida Administrative Code*. Since inception, the FCDS data collection procedures have evolved in order to address the changing demands of the cancer control community, health care providers and facilities.

Effective January 1, 2010, the FCDS will no longer accept copies of medical records and will no longer perform the casefinding or abstracting for any facility or office. Protection of patient confidentiality has driven this policy change. Sending patient identifiers through the mail or via courier exposes the patient information to unnecessary risks.

The reporting deadline for submission of your 2009 cases is June 30, 2010. Therefore, in order to assist you with your abstracting, the FCDS has compiled a list of abstractors you may wish to contact. The list is available on the FCDS web site (address and instructions below). The FCDS does not endorse or vouch for any of the abstractors on the list. The list was compiled simply to help facilities such as yours identify a pool of potential contractors.

Should you have any questions please call Meg Herna, the FCDS Manager for Data Acquisition at (305) 243-4600.

Thank you.

FCDS Web Site: <http://fcds.med.miami.edu>

Click "Downloads" → "Data Files and Programs" → "Independent Contractor List".

FCDS POLICY UPDATE- EFFECTIVE JANUARY 7, 2010

CASES REQUIRING AN EDIT OVER-RIDE (FORCE)

FCDS is currently evaluating all processes and are finding ways to streamline some of our operations. In keeping up with our efforts to protect patient confidential information, FCDS is revising the overall process of how abstracts that require an edit over-ride or 'force' are handled.

Effective January 7, 2010, reporting facilities will not have to submit to FCDS hard copy supporting documentation for cases that require an edit over-ride or 'force.' An in-depth visual review will be performed on all cases that require a force, and if there is supporting documentation in the required text fields to justify the codes, FCDS will set the appropriate over-ride flag(s). In the event that the codes are not justified in the text fields, the reporting facilities will need to substantiate the codes by providing supplementary text. This process will be completed online via the FCDS web site. Go to this link <http://fcds.med.miami.edu/downloads/dam2009/FCDS%20edit%20that%20require%20an%20edit%20over.pdf> for a complete listing of FCDS edits that require an edit over-ride.

All reporting facility personnel and contractors with the appropriate data level access will be notified on Mondays via email when abstracts are ready for review. Following are the specific instructions on how to access abstracts to review and add supporting text:

1. Go to the FCDS web site <http://fcds.med.miami.edu> log on FCDS IDEA
2. Select the FORCES REVIEW (you will see this menu choice under 'Facility Abstractor' only if you have the proper data level access).
3. Select the facility.
4. Select the record to review.

FCDS hosted a webinar/teleconference on January 7, 2010 that give a demonstration of the new module. Please visit the FCDS website to download the slides, handout or recording of presentation.

If you have any questions, please contact your Field Coordinator at 305-243-4600.

New Abstractor Case Review FCDS Policy Update: December 1, 2009

All new abstractors in the State of Florida, regardless of their CTR credentials, are required to submit to FCDS twenty-five paper abstracts (or printed copies of the vendor abstracts) for review and approval to obtain a Florida Cancer Data System Cancer Abstractor Code.

In order to protect patient health information, all patient identifiers must be removed from the abstracts prior to submitting them to FCDS. The patient identifiers include the following data items: name, social security number, date of birth, current address and address at diagnosis, zip code, and telephone number. The abstracts may be faxed to 305-243-4871, attention Megsys Herna. FCDS recommends using UPS or Federal Express when mailing the abstracts to the FCDS office.

The twenty-five records must be from a variety of primary sites. The FCDS QC staff will perform visual review on the abstracts and will make suggestions offering information regarding educational resources available to assist the abstractors with developing their skills and enhancing their abilities. This cycle will be allowed to be repeated only twice in a row. If the FCDS QC staff deems that the abstractor is not competent to abstract in the State of Florida after the second attempt, the abstractor must wait three months before submitting another twenty-five paper abstracts for review. Approved abstractors will be eligible to obtain a Florida Cancer Data System Cancer Abstractor Code.

In the near future, FCDS will make the New Abstractor Case Review a web-based process. The 25 abstracts will be required to be submitted via the FCDS Web Site through upload or single entry.

If you have any questions, please contact Megsys Herna at 305-243-4600.

CALENDAR OF EVENTS

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NAACCR CANCER REGISTRY & SURVEILLANCE WEBINAR SERIES 2009-2010

- **Time:** 9:00 am—12:00 pm
- **Locations:** Baptist Regional Cancer Center (Jacksonville, FL) *New Site*
Boca Raton Community Hospital (Boca Raton, FL)
Gulf Coast Medical Center (Panama City, FL)
H. Lee Moffitt Cancer Center (Tampa, FL)
M.D. Anderson Cancer Center (Orlando, FL) *New Site*
Shands University of Florida (Gainesville, FL)
- **Contact:** Meg Herna at 305-243-2625 or mhera@med.miami.edu
- **To Register:** <http://fcfs.med.miami.edu>

Date	Topic
02/04/2010	Collecting Cancer Data: Soft Tissue Sarcoma and Gastrointestinal Stromal Sarcoma (GIST)
03/04/2010	Collecting Cancer Data: Kidney
04/01/2010	Collecting Cancer Data: Skin Malignancies
05/06/2010	Using Geographic Information Systems (GIS) for Mapping and Spatial Analysis
06/03/2010	Collecting Cancer Data: Esophagus and Stomach
07/01/2010	Using CINA Data in Cancer Surveillance Activities
08/05/2010	Collecting Cancer Data: Lip and Oral Cavity
09/02/2010	Coding Pitfalls

NAACCR CTR EXAM PREPARATION & REVIEW WEBINAR SERIES

- **Date:** January 12, 2010—March 2, 2010
- **Contact:** Shannon Vann at 217-698-0800 Ext 9 or svann@naaccr.org
Jim Hofferkamp at 217-698-0800 Ext 5 or jhofferkamp@naaccr.org
- **Website:** <http://www.naaccr.org>

NCRA CTR EXAM READNESS WEBINAR SERIES

- **Time:** 2:00 PM Eastern Standard Time
- **Website:** <http://www.ncra-usa.org>

Date	Topic
02/11/2010	Computers
02/25/2010	Statistics & Epidemiology
03/04/2010	CTR Exam Taking Tips

NCRA ANNUAL CONFERENCE





- **Date:** April 21-23, 2010
- **Location:** Palm Springs, CA
- **Website:** <http://www.ncra-usa.org>

COMPLETENESS REPORT—2009 CASE REPORTING

Month	Complete	Expected
July 2009	4%	8%
August 2009	9%	17%
September 2009	17%	25%
October 2009	24%	33%
November 2009	30%	41%
December 2009	40%	50%

State of Florida CTR Recipients



Register

*A joint project of the Sylvester Comprehensive Cancer Ctr
and the Florida Department of Health*

Miller School of Medicine ♦ University of Miami
PO Box 016960 (D4-11) ♦ Miami, FL 33101
305-243-4600 ♦ <http://fcds.med.miami.edu>

Principal Investigator/Project Director
Jill A. MacKinnon, PhD, CTR

Med Director
Lora Fleming, MD, PhD

Administrative Director
Gary M. Levin, BA, CTR

Editorial Staff
FCDS Staff

Contributors
Brad Wohler, MS
Betty Fernandez
Meg Herna, BA, CTR

Graphics Designer
Bleu Thompson



The FCRA/FCDS Task Force is actively working on many issues that all registrars are facing. If you have any questions, issues or suggestions that you would like the task force to review, please email them to taskforce@fcra.org.

The task force meets the first Thursday of every month. We will respond back to your inquiries as quickly as possible.



FLORIDA CANCER DATA SYSTEM
SYLVESTER COMPREHENSIVE CANCER CTR AT THE
UNIVERSITY OF MIAMI MILLER SCHOOL OF MEDICINE
PO Box 016960 (D4-11) ♦ MIAMI, FL 33101



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