SYLVESTER COMPREHENSIVE CANCER CENTER
UNIVERSITY OF MIAMI HEALTH SYSTEM
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FCDS Florida Cancer Data System
A Joint Project of the Sylvester Comprehensive Cancer Center and the Florida Department of Health

FLORIDA DEPARTMENT OF HEALTH

Register

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Notes from the Statistical Unit
Data in Action

The Issue of Late Reporting

By Jackie Button & Dr. Jill MacKinnon

The Florida Cancer Data System (FCDS) is a population-based registry established to collect accurate cancer information in a timely manner. Hospitals have reported cancer incidence cases since January 1, 1981; ambulatory diagnostic and treatment centers and pathology laboratories began reporting on July 1, 1997.

Florida Statute 385.202(2) states that "... cancer reports ... shall be maintained and available for use in the course of any study for the purpose of reducing morbidity or mortality," so the FCDS provides data to researchers for studies of risk factors, cancer clusters, survival, and efficacy of treatment; publishes the FCDS Annual Cancer Report (AR); and provides cancer statistics on the FCDS website (fcds.med.miami.edu/statistics). FCDS data is also used by cancer control and prevention programs charged with reducing the burden of cancer in Florida, determining optimal allocation of scarce public resources, and evaluating the effectiveness of specific interventions.

As Recinda Sherman explained in her article in the previous edition of the Register [(1)], research studies based on cases with missing variables can produce research errors. When whole cases are missing, the effect on research errors is magnified. Changes of interest in cancer rates for certain geographic areas, cancer sites, or populations could be obscured by missing cases, confounding studies with incomplete or skewed data.

The FCDS abstract reporting deadline is six months after the date of diagnosis for analytic cases, or after the date of first contact for non-analytic cases.[(2)] Every facility that diagnoses or treats a cancer patient is required to submit an abstract for each reportable tumor. One patient may have multiple abstracts, either because of multiple tumors, or through contact with more than one diagnosing and treating facility.

To avoid inflated case counts and rates, FCDS unduplicates cases. This means matching abstracts for the same patient and tumor from different facilities and setting a flag to NO (N)

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for the first or only abstract for a tumor, or to YES (Y) for the second and all other abstracts for the same patient and tumor. Only the "duplicated NO" or "N" cases received before final closing are included in published counts and rates. Matching duplicates depends on accurate reporting of each patient's name, sex, race, date of birth, and social security number, as well as the primary site code, morphology, and laterality. Without identical information in these fields, a single tumor may appear to be a different tumor, and will be left unmatched as another cancer.

Once a year, after AHCA and mortality follow-back are complete, a "snapshot" of the active cancer abstract file is created to provide stable rates for the year. The snapshot process is called "final closing."

Cancer incidence rates are calculated from unduplicated (N) Florida resident records, so that each tumor is counted only once. Final closing occurs about 23 months after the end of a diagnosis year and 17 months after the abstract reporting deadline.

When abstracts are received really late (RL), after final closing, any unduplicated RL cases are not included in the snapshot. They are not available to calculate the incidence rates published in the AR or on the FCDS statistics web page. This could make those rates inaccurate, introduce error into any research using the FCDS data, and compromise conclusions based on those counts and rates.

For the purposes of this report, cases designated "really late" (RL) are those received after the final file closing date, about 17 months (nearly 1.5 years) after the reporting deadline. Incidence rates are calculated by diagnosis year, so this report calculates "lateness" from the diagnosis date, regardless of class of case. This methodology simplifies the calculation of RL, but does not take into account that historical cases can only be reported after the date of first contact, so by default, historical cases are classified as RL.

Table 1 shows unduplicated (rate) cases by diagnosis year and by the number of years after the year of diagnosis that cases were received. The average percentage of unduplicated cases received for each year after final closing is shown in the last column. RL cases are received after final closing in Diagnosis Year+2, and in all subsequent years.

Table 1. Percentage of Cases Received before and after Final Closing

Incidence rate cases: FCDS site 1-80, Floida residents, stage>0 or bladder , duplicated=N

Cases Received	Diagnosis Year 1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	Average Percent Added
before Closing	72,660	75,972	74,887	85,439	89,499	91,362	94,705	96,058	94,910	95,931	99,745	100,303	103,075	100.00
DxYr+2	2653	132	999	1061	2627	2392	2613	1091	1082	1251	262	766	443	1.48
DxYr+3	2701	3075	3369	2470	3151	3638	3023	3249	4098	2991	3298	3519	2800	3.52
DxYr+4	1891	1256	1183	1450	1630	1785	1917	2046	1406	1479	1619	1162	x	1.60
DxYr+5	1170	873	1018	1224	934	1658	1475	1015	1051	939	902	x	x	1.04
DxYr+6	1234	829	896	862	781	1199	1072	783	826	541	x	x	x	0.77
DxYr+7	978	573	582	617	630	950	873	612	389	x	x	x	x	0.53
DxYr+8	665	471	491	514	484	718	702	378	x	x	x	x	x	0.38
DxYr+9	624	441	417	393	435	603	367	x	x	x	x	x	x	0.28
DxYr+10	635	405	380	419	397	343	x	x	x	x	x	x	x	0.22
DxYr+11	565	361	393	403	317	x	x	x	x	x	x	x	x	0.17
DxYr+12	373	294	295	214	x	x	x	x	x	x	x	x	x	0.10
DxYr+13	351	287	175	x	x	x	x	x	x	x	x	x	x	0.07
DxYr+14	355	160	x	x	x	x	x	x	x	x	x	x	x	0.04
DxYr+15	215	x	x	x	x	x	x	x	x	x	x	x	x	0.02

Why are so many cancer abstracts submitted Really Late? FCDS requires historical cases to be reported. Class of case for historical cases should be coded non-analytic, so they can be easily segregated. But some non-analytic cases are reported as Florida residents diagnosed only two or three years before a current (active) cancer, bringing the validity of their Florida residency into question. If they were Florida residents at the time of diagnosis, why wasn't the "historical" tumor reported at the time it was diagnosed? It is important that FCDS, as a population registry, include historical cases in the rates if, and only if, the cancer was diagnosed when the patient was a Florida resident at the time of diagnosis. Address-at-diagnosis fields (street address, city, state and zip code) should be carefully evaluated for historical cases. The cases of "snowbirds" and retirees recently moved to Florida are instances in which the address-at-diagnosis fields may have to be coded "unknown" if the place of residence at diagnosis is not known. Entering a Florida address for these cases may cause inflated Florida cancer counts and rates. A note in the DX_PLACE text field of the abstract can document unknown residence at diagnosis, or cases known to have been diagnosed out-of-state.

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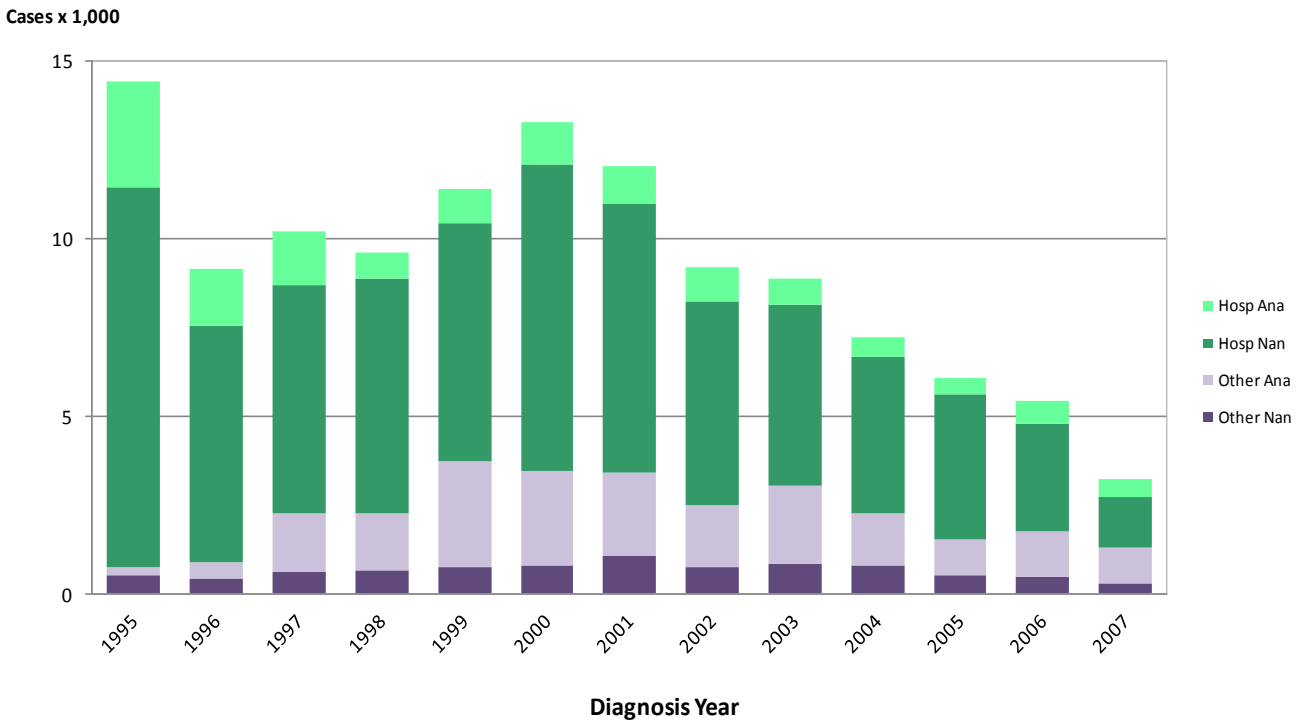
"Late" analytic ("Ana") cases are defined in the FCDS-Data Acquisition Manual (DAM) as cases received after June of the year following diagnosis; for free-standing ambulatory surgical centers, the DAM sets no deadline. Abstracts of non-analytic cases can be completed only after the date of first contact, and may be "late" or RL. Figure 1 shows the distribution of unduplicated RL cases stratified by four categories: hospital analytic; hospital non-analytic; other facility types analytic; and other non-analytic.

Figure 1. Really Late Incidence Rate Cases, Duplicated = N, by Diagnosis Year, Facility Type, and Class of Case, 1995 - 2007



Between 1995 and 2007, 1.736 million abstracts were submitted; 279,317 of those (16%) were RL. Ninety-five percent of all abstracts received during that period were from hospitals. The distribution of the RL abstracts by facility type is interesting. Thirty-eight percent of all RL abstracts were from hospitals. Radiation treatment facilities contributed 29% of all RL abstracts. During that time, 38% of all abstracts received from out-of-state were RL, 10% from physician offices, 21% from ambulatory surgical centers, and 23% from radiation treatment centers.

Unraveling the issue of late reporting requires action on several fronts: examination of abstracts, facility comparisons, and possibly follow-back to facilities with large proportions of RL abstracts, especially unduplicated and analytic abstracts. This is a very important issue because we must answer these questions: 1) Is the number of Florida cancer cases being over-counted by the use of incorrect Florida residency codes for historical cases? 2) Are Florida cases not counted in the appropriate incident year when cases are not reported in a timely manner? 3) Are cancer patients being managed in a physician office and not entering the hospital until years after the initial diagnosis? Any of these scenarios has the potential to cause inaccurate reporting of cancer among Floridians, and must be addressed.

FCDS is analyzing a subset of RL submissions to ascertain any patterns that may exist. There may be evidence in the abstracts of the three possibilities above: the residence at diagnosis field consistently coded to the current residence, valid RL cases for Florida residents, and class-of-case coding errors. Other patterns may emerge. After this analysis, edits may be devised to flag for verification any patterns common in RL cases.

If there are issues with the coding of the address-at-diagnosis fields that turn 'snowbirds' into Florida residents and therefore Florida cases, or transform the historical cases of new retirees into RL cases of Florida residents, the inclusion of these cases will over-estimate the burden of cancer among Floridians, resulting in incorrect rates. The FCDS depends on Florida's cancer registrars to accomplish its goal of providing accurate cancer counts and rates.

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Registrars can address the issue of RL cases by verifying address at diagnosis for historical cases, coding historical cases as non-analytic, and by aggressive case-finding within their own facilities. More vigilant case finding may obviate some of the late reporting.

If the RL cases are not Florida residents, they must be coded as out-of-state residents so that they will not be counted. However, if the cancer cases of Florida residents are not being counted, these cases must be added to the statewide incidence data. Better RL than never.

(1) Sherman, R. FCDS Register Vol. 49, October, 2010.
(2) 2010 Data Acquisition Manual, C.2 Abstracting, p.10.

Congratulations!

Florida CTR Recipients - Fall 2010

Abelardo De La Rua

Martha Duran

Angela Simmons

Save the Date!

FCDS Annual Meeting

July 28—29, 2011

Renaissance Tampa International Plaza Hotel

NPCR Data Quality Audit January 5th—20th, 2011

All NPCR-funded States including Florida are required to participate in an audit of compliance with NPCR standards on cancer registry data quality every 5 years. This is an audit of the state central registry (FCDS) and not the individual reporting facility. The audit involves re-abstracting primary source medical records at selected reporting facilities (hospitals) and comparing the re-abstracted field audit data to the FCDS Master File data. Inconsistent data are "reconciled" back to the facility through FCDS to ensure the most correct data are provided to the audit team. The last time Florida was audited by NPCR was during the 2004-2005 audit year.

NPCR Data Quality Audits are designed to evaluate the quality of the data, including correctness and completeness of coding for all types of reportable neoplasms, including hematopoietic neoplasms and benign or borderline brain tumor cases. Data abstracted include primary site, histology, CS, etc. This is an audit of 2008 cases, only. The intent of these audits is to assess the quality of the data within the central cancer Registry (FCDS) with an emphasis on the existence of appropriate policies and procedures for data quality assessment, statewide, and also in aggregate for comparison of Florida's data quality to the data quality findings in other states.

NPCR will conduct this audit in 12 Florida Hospitals between January 5 and January 20, 2011. Each facility has been asked to provide access to 33 medical records (electronic and/or paper) corresponding to 33 analytic cases randomly pre-selected by NPCR. Selected facilities have already been contacted regarding their participation. Your NPCR Auditor is Janice Gregoire, MSHS, CTR. She works for ICF Macro under contract with CDC NPCR conducting audits across the U.S.

Facilities selected for the NPCR Audit are excluded from the FCDS audit cycle for this year. FCDS would like to thank the 12 Florida Hospitals participating in the NPCR Data Quality Audit. We appreciate the time and attention required to accommodate the audit team before, during and after the audit, including reconciliation.

Selected Facilities Include:

- St Luke's Hospital – Jacksonville
- Bert Fish Medical Center – New Smyrna Beach
- Florida Hospital Cancer Institute South – Orlando
- Orlando Regional Lucerne Hospital – Orlando
- Westside Regional medical Center – Plantation
- Kendall Medical Center – Miami
- Peace River Regional Medical Center – Port Charlotte
- Northside Hospital heart Institute – St Petersburg
- Tampa General Hospital – Tampa
- Mease Countryside Hospital – Safety Harbor
- Memorial Hospital of Tampa – Tampa
- Lakeland Regional Medical Center – Lakeland

Welcome Gema!

Gema Midence has joined the Quality Control and Education/Training Team as a Quality Control Field Coordinator.

Farewell Betty!

Beatriz Hallo has left the FCDS family. She was a valued member of FCDS for the past 10 years.

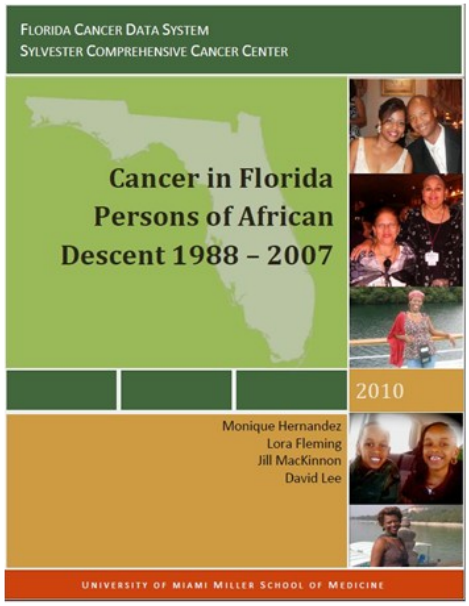
We wish her the very best in her new position with Jackson Memorial Hospital.

Cancer Awareness

JANUARY 2011
CERVICAL HEALTH AWARENESS MONTH

MARCH 2011
NATIONAL COLORECTAL CANCER AWARENESS MONTH

"Source: 2010 National Health Observances, National Health Information Center,
Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, Washington, DC."



Cancer in Florida: Persons of African Descent 1988-2007

Monique Hernandez, Ph.D.

This November FCDS published a monograph on cancer trends among Florida Persons of African Descent that span the years 1988 to 2007. The publication provides an overview of the cancer experience of Florida Persons of African Descent by gender, cancer site, and cancer stage to provide a more complete review of differences compared to the White population in Florida. Cancer incidence and staging trend data depict the changes in rates, both increasing and decreasing, over a 20 year period in these two populations for the purpose of understanding past, current, and potential future disparities in cancer outcomes. In addition to trends in cancer incidence, the monograph also includes the percentage of new cancer cases by race, site, and gender in 2007. The complete monograph and detailed tables are provided as electronic PDF files and can be located on the FCDS website under Statistics. (www.fcds.med.miami.edu).

THE LATEST RELEASE OF THE FCDS EDITS METAFILE IS DATED 12/3/2010

IF YOU OR YOUR VENDOR HAVE NOT UPDATED YOUR FCDS METAFILE, PLEASE VISIT THE FCDS WEBSITE AND DOWNLOAD THE CURRENT VERSION.
http://fcds.med.miami.edu/
and look under "What's New".

CALENDAR OF EVENTS

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NAACCR Cancer Registry & Surveillance Webinar Series 2010-2011

Time: 9:00 am—12:00 pm
Locations: Baptist Regional Cancer Center (Jacksonville, FL)
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)
Shands University of Florida (Gainesville, FL)
Contact: Steve Peace at 305-243-4600 or speace@med.miami.edu
To Register: http://fcds.med.miami.edu

Date	Topic
02/03/11	Collecting Cancer Data: Testis
03/03/11	Collecting Cancer Data: Bladder
4/07/11	Collecting Cancer Data: Breast

NCRA Advance Quality Abstracting Webinar Series Registration Open

Contact: www.ncra-usa.org

Date	Topic
2/17/11	Advance Quality Abstracting of Melanoma
3/31/10	Advance Quality Abstracting of Thyroid
4/14/11	Advance Quality Abstracting of Hematopoietics
5/26/11	Advance Quality Abstracting of Pancreas

NAACCR CTR Exam Preparation & Review Webinar Series

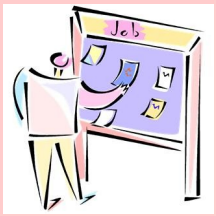
Date: March 2011
Contact: Jim Hofferkamp jhofferkamp@naaccr.org or Shannon Vann svann@naaccr.org
Content: Eight 2-hour Session, Live Lectures, Q&A Sessions, Study Materials.
Website: http://www.naaccr.org

NCRA Annual Meeting

Date: May 15—18, 2011
Location: Orlando, FL at Disney's Coronado Springs Resort
Website: http://www.ncra-usa.org

NAACCR Annual Meeting

Date: June 18—24, 2011
Location: Louisville, KY at the Kentucky International Convention Center
Website: http://www.naaccr.org



JOB OPENINGS AT FCDS (UNIVERSITY OF MIAMI)

FCDS has employment opportunities for 10 positions that have been established to provide technical support for the CDC/NPCR Comparative Effectiveness Research Project (CER) with 3-year funding provided by CDC and AHRQ under the American Recovery and Reinvestment Act of 2009 (ARRA).

Below is the information on the positions:

2 - Project Manager positions (CER and AHRQ)
3 - CER Field Coordinator positions (Sr. Compliance Representative)
3 - CER QC Coordinator positions (Senior Regulatory Analyst)
2 - Statistical Analysts (CER and AHRQ)

UM position numbers for Field Coordinator and QC Coordinator openings are noted below:

- CER Position Number(s) – Sr. Compliance Representative (Field Coordinator): 041840, 041841, 041842.
- CER Position Number(s) - Senior Regulatory Analyst (QC Coordinator): 041790, 041789, 041788.

Position Postings and How to Apply:

In order to apply for these positions, please go to the Official job postings located at: http://careers.med.miami.edu. Using the "Department/Hospital" pull down menu, scroll to Sylvester Comprehensive Cancer Center and click "Begin Search". Click on the position title "Sr. Compliance Representative" or "Senior Regulatory Analyst". Click "Apply Online".

Once you have applied, please e-mail your resume to Jill MacKinnon at jill_mackinnon@miami.edu

Register

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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.