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

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

Division of Cancer Prevention and Control **Volume 53 – October 2011**

Florida's Participation in "Enhancing Cancer Registry Data for Comparative Effectiveness Research"

By Monique Hernandez, PhD

In December of 2010 Florida was selected to participate in a Centers for Disease Control-sponsored National Program of Cancer Registries (NPCR) project entitled; "Enhancing Cancer Registry Data for Comparative Effectiveness Research (CER)." As described by the Agency for Healthcare Research and Quality, "Comparative Effectiveness Research is designed to inform health-care decisions by providing evidence of effectiveness, benefits, and harms of different treatment options." The CER project gives the Florida Cancer Data System (FCDS) the opportunity to contribute to important cancer surveillance and disease monitoring enhancements along with nine other states. Funded by the American Recovery and Reinvestment Act, the project addresses specific CER questions targeting colon, rectum, breast and chronic myeloid leukemia cases diagnosed in 2011. In addition to routinely collected data, the FCDS will enhance existing first course treatment information with data on tumor marker, genetic, laboratory data and systemic treatment regimens. The FCDS has identified a five-county catchment area to be included in this project: Miami-Dade, Broward, Palm Beach, Orange, and Hillsborough Counties.

The impact of the CER enhancement project on FCDS has resulted in an expanded workforce for CER project management, development, and implementation. Together with core staff, the project objectives and responsibilities will be carried out almost entirely by the FCDS. Specifically, the FCDS has been fortunate to have hired three very experienced Florida hospital-based Certified Tumor Registrars that will act as our CER outreach and QC coordinators for the data gathering portion of the project. Little effort will actually be required of hospital and physician staff in the five CER counties, apart from navigational support and access to select facility patient records. Registrars and abstractors can provide additional support by prioritizing the reporting of the four CER cancer sites.

(Continued on page 2)

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In addition to the collection of enhanced treatment information, the CER dataset will be linked to vital statistics records, area-based socioeconomic indicators, and area-based health indicators. Linked data sources include the National Death Index, 2010 U.S. Census, and Medicare and Medicaid databases. The project timeline extends to September 2013, at which time all relevant data will be submitted by FCDS, as well as the other nine states, to the CDC. The final dataset will reside at the Research Data Center of the National Center for Health Statistics, where access to data for research will be reviewed via a strict proposal process.

It is important to note that all CER project activities fall under the existing Florida Department of Health authority to capture and report cancer data. Current Florida statutes exempt DOH and FCDS from HIPPA restrictions as registry activities are in direct line with the legislatively mandated surveillance of cancer. As such, participation from healthcare facilities in the five CER counties is not voluntary. However, as previously mentioned, FCDS will assume almost all of the data collection responsibilities for the project.

More information on the Florida CER project, participating NPCR registries, and CER targeted questions can be found on our website: http://fcds.med.miami.edu/welcome.html . For specific questions and additional information please contact the FCDS CER Project Manager, Monique Hernandez, at mhernandez5@med.miami.edu.

References:
1. "What is Comparative Effectiveness Research." AHRQ Effective Health Care Program. Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. Accessed on 10/10/2011. www.effectivehealthcare.ahrq.gov/index.cfm/what-is-comparative-effectiveness-research1/

FLORIDA - GOLD CERTIFIED 2008 DATA

This year is the 14th anniversary of the NAACCR certification process. This award recognizes the population-based cancer registries that have achieved excellence in the areas of completeness of case ascertainment, quality of the data and timeliness.

THANKS TO ALL WHO HAVE CONTRIBUTED IN HELPING US ACHIEVE THIS EXCELLENCE AWARD!

FCDS Annual Meeting Renaissance Tampa International Plaza

July 28-29, 2011

By: Gema Midence, CTR, MBA

FCDS held its 2011 Annual Meeting on July 28-29th at the Renaissance Tampa International Plaza Hotel in Tampa, Florida. We were joined by over a hundred registry professionals from throughout the state for two days of informative sessions with topics ranging from the introduction of new projects underway to changes to the data collection standards for the upcoming year. Following the FCRA Annual Conference, the FCDS Annual meeting aimed to continue educating and training our corp. of registry professionals as the industry continues to see changes and face challenges. This year's conference topics included: The National Program for Cancer Registries (NPCR) CER and AHRQ Projects and Data Requirements, the 2011 Changes to FCDS Data Collection, Introduction to the Collaborative Stage Data Collection System Version 02.03.02, FCDS' Quality Control Feedback on Data Quality and a CSv2 Education Workshop. NCRA approved the program for 9.25 CE hours. The NCRA Program Recognition number is 2011-143.

For your convenience and reference, the agenda and all annual conference program materials are available on our website. With the understanding that two days cannot fully encompass the depth of the new material for 2011, we have rolled out our Fall 2011 Educational Webcast Series which will build upon information presented at the Annual Meeting.

The webcasts will provide a foundation and updated required training for Florida registrars and cancer case abstractors on 2011 data collection requirements for FCDS with specific coding instruction in the use of the newest release of the Collaborative Stage Data Collection System (CSv02.03.02) for Colon, Rectum, Breast, Myeloid Neoplasms, Lung, Genitourinary Cancers (Kidney, Bladder, Prostate), Brain and CNS Tumors (Benign, Borderline, Malignant), and Head and Neck Cancers. Additional new references and instruction will be provided describing the current standards of care for these neoplasms based on ASCO/NCCN or other published treatment guidelines. For an updated list of webcast schedule and reference material, please visit: http://fcds.med.miami.edu/inc/teleconferences.shtml. Our November Webcast is November 2, 2011. We will cover Myeloid Neoplasms (CML/AML/MDS) - MPH Rules/CSv02.03/Site Specific Factors and Treatment.

Judy Bonner, RN, MS, CTR – Judy comes to FCDS with an extensive background as a Certified Tumor Registrar and Cancer Registry Manager. Judy will be serving as an Outreach/Quality Control Coordinator for the CDC funded CER project.

Lynne Pearson, BHS, CTR, LHRM – Lynne comes to FCDS as a seasoned Certified Tumor Registrar with extensive experience working at Florida-based medical facilities. Lynne will be serving as an Outreach/Quality Control Coordinator for the CDC funded CER project.

Patricia Anderson, MS – Patricia Anderson comes to FCDS with a background in computer programming and computer applications development. Patricia will be serving as a Senior Research Analyst for the CDC funded CER project.

Loretta Young – Loretta comes to FCDS with a background in customer communications and customer service. Loretta will be serving as Administrative Assistant on the Agency for Healthcare and Research Quality project at FCDS.

Aja Scott – Aja comes to FCDS with experience in customer services and office management. Aja will be serving as the Head Receptionist at FCDS.

Susan K. Smith-Pierce, CTR – Susan comes to FCDS with an extensive background as a Certified Tumor Registrar and Cancer Registry Manager. Susan will be serving as an Outreach/Quality Control Coordinator for the CDC funded CER project.

SEER Incidence Site Recode

The values of SEER site recode variables are based on the primary site and histology data fields submitted to SEER by the registries. The site recode variables define the major cancer site/histology groups that are commonly used in the reporting of cancer incidence data. For example, there is a section of the SEER Cancer Statistics Review for each major site corresponding to groupings in a site recode variable. The site recode variables are added to the SEER databases as a convenience for researchers.

The table below contains definitions for the available site recode variables. Follow the links to view the values of primary site and histology for each grouping. Each definition shows the coding for an additional Site Recode in which mesothelioma and Kaposi sarcoma are separate categories.

SEER converts data originally coded in versions prior to ICD-O-3 to ICD-O-3, and uses the ICD-O-3 site recodes based on these converted data and cases originally coded in ICD-O-3. If all histologies for all years have been converted to ICD-O-3, use the ICD-O-3 (1/27/2003) recode. If the analyses includes any cases diagnosed 2010+, the ICD-O-3 recode with adjustment for WHO 2008 hematopoietic histologies should be used.

For cases originally coded and not converted, the ICD-O-2 (1/27/2003) and ICD-O-3 (1/27/2003) definitions can be used for cases coded in ICD-O-2 and ICD-O-3, respectively, and include the same set of site groups to ensure comparability to one another. Do **not** continue to use the ICD-O-2 (4/15/2002) recode except for historic analysis of ICD-O-2 cases only. Any comparisons between recodes dated 1/27/2003 and 4/15/2002 are invalid.

Version	Details
Current Definitions Supported by SEER*Prep 2.0 and later	
Site Recode ICD-O-3 2010+ cases WHO heme	• Based on ICD-O-3, updated for Hematopoietic codes based on *WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues (2008)*. • Recommended variable for analyses with any cases diagnosed in 2010 and later. SEER will use this recode for analyses that includes any cases diagnosed 2010+. • Can be used with Site Recode ICD-O-2 (1/27/2003) for consistent site/type definitions over time when data includes ICD-O-2 cases not converted to ICD-O-3. • Not available in SEER*Prep 1.9
Site Recode ICD-O-3 (1/27/2003)	• Used with Mesothelioma and Kaposi Sarcoma as separate groupings to produce the SEER Cancer Statistics Review, 1975-2001 and later versions which do not include any 2010+ cases. • Recommended variable for reporting based on the SEER Program Research Data 1973-2001, and later releases up to 1973-2009. • Can be used with Site Recode ICD-O-2 (1/27/2003) for consistent site/type definitions over time when data includes ICD-O-2 cases not converted to ICD-O-3. • Not available in SEER*Prep 1.9
Current Definitions Not Supported by SEER*Prep	
Site Recode B ICD-O-3 (12/19/2003)	• Based on ICD-O-3 • Developed for use in SEER*Stat within the MP-SIR session in collaboration with the Division of Cancer Epidemiology and Genetics • Differs from the original site recode variables in that it includes additional site subtotals, and in some cases, more detailed breakdown of sites • Not typically used by SEER to report incidence cancer statistics

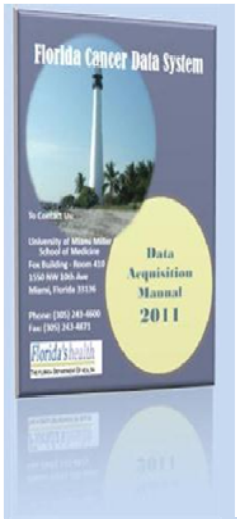
(Continued on page 5)

Source: http://seer.cancer.gov/siterecode/

(Continued from page 4: SEER Incidence Site Recode)

Version	Details
Historic Definitions	
Site Recode ICD-O-2 (1/27/2003)	• Based on ICD-O-2 • Used in tandem with Site Recode ICD-O-3 (1/27/2003) for consistent site/type definitions over time • Used to produce the SEER Cancer Statistics Review, **1975-2000** • Recommended variable for reporting based on the SEER Program Research Data (1973-2000), Nov 2002 submission
Site Recode ICD-O-2 (4/15/2002)	• **Use only to duplicate prior analysis of cases diagnosed prior to 2001** • Based on ICD-O-2 • Used to produce the SEER Cancer Statistics Review, **1973-1999** • Recommended variable for reporting based on the SEER Program Research Data (1973-1999), Nov 2001 submission • Not available in SEER*Prep 2.2 and later. Listed as "Site Recode (old-4/2002)" in SEER*Prep 2.0 and 2.1. Listed as "Site Recode" in SEER*Prep 1.9.

Other News/Update:



Florida Cancer Data System
Revisions as of October 2011

Data
Acquisition
Manual

Website:
http://fcds.med.miami.edu

Cancer Awareness

OCTOBER 2011
BREAST CANCER AWARENESS

NOVEMBER 2011
LUNG CANCER AWARENESS
PANCREATIC CANCER AWARENESS
STROMACH CANCER AWARENESS

"Source: 2011 National Health Observances, National Health Information Center, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, Washington, DC."

COMPLETENESS REPORT—2011 CASES

Month	Complete	Expected
Jul 2011	1%	8%
Aug 2011	2%	17%
Sep 2011	7%	25%
Oct 2011	14%	33%

CS MANUAL ON-LINE HELP FORMAT

The *Collaborative Stage Data Collection System User Documentation and Coding Instructions*, also known as the CS Manual, (version 0203) has been released in an online help format, available as a free download from the CS website, http://cancerstaging.org/cstage/manuals/coding0203.html. This release combines Part I of the manual, both sections 1 and 2, with Part II, the schemas, into a single online help system with combined index and robust navigation. The content of Part I is identical to the content of the PDF version. The content of Part II (the schemas) is expanded to include additional extra tables not included in the PDF format, especially useful for those who do CS training or perform quality control of CS data. The HTML online help system combines an index for Parts I and II, includes full text searching capability, and has multiple navigation methods. HTML online help systems are familiar to most users. Online help appears in a browser window using the standard Microsoft® HTML Help interface, with selected features enabled by third-party tools.

CDC NPCR Data Quality Audit Florida Cancer Data System (Diagnosis Year: 2008)

Excerpts from NPCR DQA Final Report: *CDC CONTRACT NUMBER: 200-2006-19096*

Since the beginning of the National Program of Cancer Registries (NPCR), the Division of Cancer Prevention and Control within the Centers for Disease Control and Prevention (CDC) has provided assistance to States funded under NPCR. This assistance includes support in developing and enhancing State cancer registries; continuing with effective registry operations; and monitoring the completeness, timeliness, and quality of data under the auspices of Public Law 102-515 (the National Cancer Registries Amendment Act). States are responsible for ensuring compliance with NPCR program standards for completeness, timeliness, and the quality of data reported to the central cancer registry.

Macro (now ICF Macro, an ICF International Company) was awarded a 5-year contract to assess the completeness and accuracy of data of State central cancer registries under the auspices of NPCR. The Data Completeness and Quality Audits (DCQA) Program follows the guidelines set by CDC and NPCR in assessing the completeness and quality of data collected by State cancer registries, providing a comparison of the State's performance with NPCR States' average in a post-audit presentation that recommends approaches to result in improvement of the State cancer registry's data completeness and accuracy. During this 5-year contract, audits are being conducted in a total of 45 States, the District of Columbia, and Puerto Rico.

The primary purpose of the NPCR-DCQA is to assess the level of quality of the data collected by NPCR-funded, statewide, population-based cancer registries. These data are a crucial part of cancer surveillance systems because they are used for planning, operating, funding, and evaluating cancer control programs. Complete and accurate data are essential for estimating variations in and changes among population subgroups

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Table 1

Caseload	# Hospitals Selected	No. of Records Reabstracted
High	5	165
Medium	4	132
Low	3	99
Total	12	396

Table 2

Data Accuracy for Data Elements, by Hospital Caseload Category

Caseload	No. of Data Elements Reviewed	No. of Data Elements With Discrepancy	No. of Data Elements Without Discrepancy	Percentage of Data Elements Error Free
High	4,140	217	3,923	94.76
Medium	3,316	257	3,059	92.25
Low	2,484	111	2,373	95.53
Total	9,940	585	9,355	94.11

(Continued from page 6: CDC NPCR Data Quality Audit Florida Cancer Data System Diagnosis Year: 2008)

over time. The audit assessment is based on the existence of the following:

1) Appropriate policies and procedures for data collection
2) Appropriate policies and procedures for assessment of data quality
3) Completeness and quality of data for all reportable cases within the central cancer registry, including hematopoietic and non-malignant central nervous system cases.

Table 1 shows a total of 396 cases (12 facilities * 33 records) were reviewed to assess the data quality in sample facilities. Sample size was determined to achieve sufficient precision for an expected case completeness rate of 95 %.

Table 2 describes data elements with and without discrepancies. **Of a total of 9,940 possible data elements that could have errors, 585 data elements (5.9 percent) were found to have discrepancies.** The resultant aggregate data accuracy rate was 94.11 percent. The low-caseload facilities had the highest data accuracy rate with 95.53 percent, followed by the high-caseload facilities with a data accuracy rate of 94.76 percent and the medium-caseload facilities with a data accuracy rate of 92.25 percent.

The overall data accuracy rate for FCDS was estimated at 94.11 percent.. The data accuracy rate for the high-caseload facilities was 94.76 percent. The medium-caseload facilities had a data accuracy rate of 92.25 percent, and the data accuracy rate for the low-caseload facilities was 95.53 percent.

FCDS Comments: Florida's 'accuracy rate' mirrors the national average. The 'accuracy rate' is crude rate, taking into account any discrepancy in coding. When viewed as major versus minor errors (errors that would incorrectly depict Florida's cancer incidence, the 'accuracy rate' can be adjusted to 95.5 %.

FCDS would like to thank the staff from ICF Macro, the CDC and the Florida hospital's that participated in the audit for their time and effort. Completeness, accuracy and timeliness is the cornerstone of the FCDS quality control endeavors. This is evident by our editing (both automated and visual review) our own internal on-site audits and the ongoing quality control checks which take place daily on the database. FCDS is very happy to have external validation of their efforts through additional audits.

Implementation of recommended procedures in this report will help FCDS improve this result. FCDS is strongly encouraged to continue conducting visual editing to improve data quality in the State, in addition to reviewing basic abstracting principles.

NPCR Summary of Recommendations:

1) A large number of treatment data items were recoded to 99 (unknown) due to a lack of medical record or central registry documentation. Education efforts should be directed toward text documentation training to support codes, especially in cases where information from outside/external sources is used to determine the coded value.

2) Provide a review of abstracting practices with a focus on:

   a. Reviewing FORDS Manual rules and conversion charts in coding the correct *Grade*
   b. Carefully reviewing all pathology report documentation and the FORDS Manual to accurately code *RX Summary Scope Regional Lymph Node Surgery*, particularly in breast cases, with a focus on coding sentinel lymph nodes
   c. Reviewing Collaborative Staging rules with an emphasis on *CS Extension*, especially for male genital system and respiratory system cases
   d. Coding *Histology* with a careful review of the MP/H Manual, especially as it applies to breast cases
   e. Reviewing all medical record documentation to assign *Subsite*, with an emphasis on utilization of the breast clock diagram for breast cases
   f. Reviewing all dictated reports, particularly operative/procedure reports, as well as radiographic imaging reports, with careful attention to dates and diagnostic language, including ambiguous terminology.

Acknowledgements: The staff of the Data Quality Audits Program would like to thank the staff at the Florida Department of Health, Youjie Huang, M.D., Dr.PH, M.P.H., and Tara Hylton, M.P.H., as well as the Florida Cancer Data System Project Director, Jill MacKinnon, Ph.D., CTR, her staff, and the staff of the participating hospitals for their assistance with this audit. Its success was made possible by their generous and diligent efforts. We gratefully acknowledge their invaluable contribution to achieving standards of data quality and completeness in the collection of data on cancer.

CALENDAR OF EVENTS

CALENDAR OF EVENTS

NAACCR CANCER REGISTRY & SURVEILLANCE WEBINAR SERIES 2011-2012

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)
Florida Cancer Data System (Miami, FL) *New
Contact: Steve Peace at 305-243-4600 or speace@med.miami.edu
To Register: http://fcds.med.miami.edu

Date	Topic
12/01/11	Collecting Cancer Data: Thyroid and Adrenal Gland
01/05/12	Collecting Cancer Data: Pancreas
2/02/12	Collecting Cancer Data: Lung

FCDS 2011 EDUCATIONAL WEBCAST SERIES

Time: 9:00 am—11:00 am
Dial-in Number: 888-296-1938
Participant Code: 619968
To Register: http://fcds.med.miami.edu/inc/whatsnew.shtml

Date	Topic
11/17/11	Lung Cancer - 2011 MPH Rules/CSv02.03/Site Specific Factors and Treatment
12/15/11	Genitourinary (Kidney, Bladder, Prostate) - MPH Rules/CSv02.03/SSFs and Treatment
1/19/12	Brain and CNS Tumors - MPH Rules/CSv02.03/Site Specific Factors and Treatment
2/16/12	Head and Neck Cancers - MPH Rules/CSv02.03/Site Specific Factors and Treatment

Calling All Florida CTRs Interested in Collaborative Stage Data Collection and Quality Control Activities at FCDS:

FCDS recognizes the added value when using Florida peer-to-peer CTRs to conduct re-abstracting field audits and other FCDS QC activities. CTRs who abstract on a daily basis are our best resource for providing peer-to-peer feedback on data quality and recommendations to improve our data, statewide. At this time FCDS is in need of several highly skilled abstractors willing to participate in the next FCDS Re-Abstracting Field Audit. This audit will take place in mid-winter (December-February), will include 80 or more facilities, and will focus on Collaborative Stage Core Data Elements and Site Specific Factor Coding for Cases Diagnosed in 2010. The actual data collection will take place during a 6-week window as yet defined but at some time during the in-the-field study window of December-February. FCDS needs registrars from across the state to visit hospitals either in person or via remote access to "re-abstract" key data elements; patient demographics, primary site, histology and collaborative stage data items. No treatment data will be collected. Thank you for your support and interest. Please contact Steven Peace, CTR directly at speace@med.miami.edu with your resume and letter of interest.

CE hours approved for the FCDS 2011 Annual Meeting and FCDS 2011 Educational Webcast Series

"Florida Cancer Data System Annual Meeting" program supports **9.25 CE hours**. This program has been assigned the following event number: **2011-143**.

"FCDS 2011: Text Documentation/Visual Editing and Introduction to CSv02.03.02" program supports **2 CE hours**. This program has been assigned the following event number***: 2011-162.***

"FCDS: Colon/Rectum Cancer - MPH Rules/CSv02.03/Site Specific Factors and Treatment" program supports **2 CE hours**. This program has been assigned the following event number***: 2011-167.***

"FCDS: Breast Cancer - MPH Rules/CSv02.03/Site Specific Factors and Treatment" program supports **2 CE hours**. This program has been assigned the following event number***: 2011-168.***

"FCDS: Myeloid Neoplasms (CML/AML/MDS) - MPH Rules/CSv02.03/Site Specific Factors and Treatment" program supports **2 CE hours**. This program has been assigned the following event number***: 2011-169.***

"FCDS: Lung Cancer - 2011 MPH Rules/CSv02.03/Site Specific Factors and Treatment" program supports **2 CE hours**. This program has been assigned the following event number***: 2011-170.***

"FCDS: Genitourinary (Kidney, Bladder, Prostate) - MPH Rules/CSv02.03/SSFs and Treatment" program supports **2 CE hours**. This program has been assigned the following event number***: 2011-171.***

"FCDS: Brain and CNS Tumors - MPH Rules/CSv02.03/Site Specific Factors and Treatment" program supports **2 CE hours**. This program has been assigned the following event number***: 2011-172.***

"FCDS: Head and Neck Cancers - MPH Rules/CSv02.03/Site Specific Factors and Treatment" program supports **2 CE hours**. This program has been assigned the following event number***: 2011-173.***

Register

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

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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.