

Register

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

Division of Cancer Prevention and Control

Volume 48 – July 2010

Who What Why 5 W's and 1 H Where How When

By Brad Wohler

The 5 W's and 1 H regarding cancer data requests from the Florida Cancer Data System. The basics of who, what, where, when, why and how people use data reported to the Florida Cancer Data System.

Who? Who is using FCDS data?

During the year 2009, there were 5,826 hits to the Statistics webpage from IP addresses outside of the University of Miami, with an additional 2,825 hits to the map/rates page from IP addresses outside of the University of Miami.

In addition, there were 61 formal data requests made directly to FCDS. Of the 61 formal data requests nearly one third came from Academic institutions, with another 25% coming from non-governmental institutions. Throughout the remainder of this article only the formal requests will be examined in more detail unless otherwise noted.

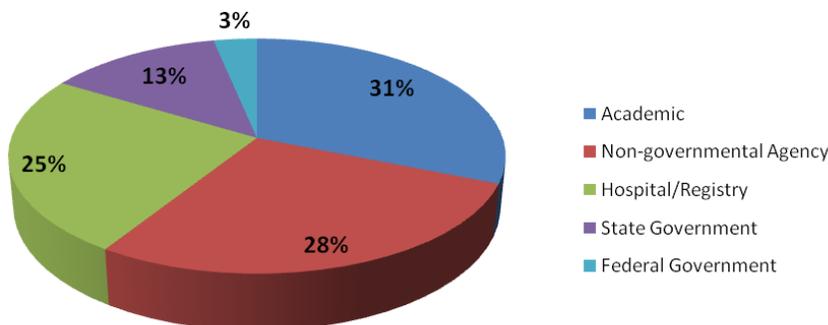
What? What's the story?

What data did the customers request? Data requests ranged from routine counts and rates to much more complicated data linkages. Requests for counts covered everything from counts by county to counts broken down by stage, sex, race, age and other demographic variables. There were also a couple of requests that included zip code level counts. (Note: all zip code level requests are approved by Florida Department of Health.) Of the 61 requests, 16 were for Data CDs – 2 Full CDs, 3 Limited CDs, 8 Stat CDs, 2 DOH CDs and 1 special studies CD.

The number of linkages continues to increase and this trend is expected to continue. There were 25 requests for counts and/or rates. In 2009, there were 9 linkages with external data sets submitted by outside researchers to be linked with the Florida Cancer Data System. The Projects submitted were:

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Who Requested FCDS Data



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Studies that Linked with FCDS		
Study Title	Principal Investigator	PI Institution
Black Women's Health Study	Lynn Rosenberg, ScD	Boston University
CPS-II Cancer Prevention Study Nutrition Survey	Susan Gapstur, PhD, MPH	American Cancer Society
Health Professionals Follow-up Study #1	Meir Stampfer, MD, DrPH	Brigham & Womens Hospital
Health Professionals Follow-up Study #2	Meir Stampfer, MD, DrPH	Brigham & Womens Hospital
National Institute for Occupational Safety and Health PanAM flight Attendants Study	Lynne Pinkerton, MD, MPH	Centers for Disease Control
National Institute of Health AARP Study	Arthur Schatzkin, MD	National Cancer Institute
Nurses Health Study	Meir Stampfer, MD, DrPH	Brigham & Womens Hospital
Southern Community Cohort Study data linkage	William Blot, PhD	Vanderbuild University Medical School
Measuring pregnancy outcomes of cancer survivors in Medicaid	Caprice Knapp, PhD	University of Florida

In addition there were 2 data sets extracted related to the Acreage Cancer Cluster investigation. These data sets were submitted to the Florida Department of Health.

Finally there were 9 data extracts for studies that are contacting cancer patients. Seven of the data extracts were for the same patient contact study – the Osteosarcoma Surveillance Study.

Patient Contact Studies		
Study Title	Principal Investigator	PI Institution
Osteosarcoma Surveillance Study	Alicia Gilsean, PhD, RPh	Research Triangle Institute
Rural and Underserved Breast Cancer Survivors Telephone Intervention	Karen Dow Meneses, PhD, RN	University of Alabama - Birmingham
Cognitive Behavioral Stress Management and Prostate Cancer	Michael Antoni, PhD	University of Miami

(Continued on page 3)

CONGRATULATIONS!
New CTRs from Florida
Stacey Applegate
Elizabeth Melendez
Joyce Newhouser
Kathleen Saslow

(Continued from page 2: 5 W's and 1 H)

Where? Where is the Requestor From?

The vast majority (70%) of the formal data requests were made from institutions in Florida.

State	Frequency (%)
Florida	43 (70)
North Carolina	7 (11)
Massachusetts	4 (7)
Georgia	2 (3)
Maryland	2 (3)
Ohio	2 (3)
Texas	1 (2)

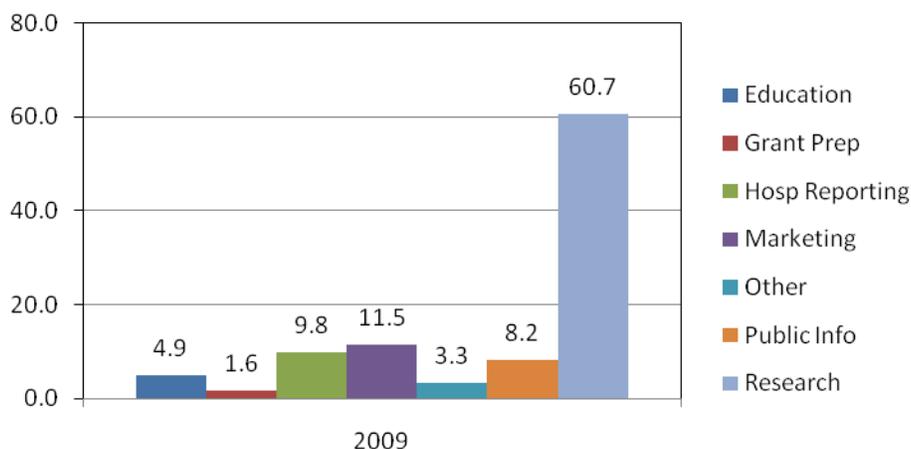
When? When did it take place?

All of the data requests examined in this article took place in 2009.

Why? Why did they request data?

The majority of the requestors used the data obtained from the Florida Cancer Data System for Research (60.7%). Marketing and Hospital Reporting (11.5% and 9.8% respectively) were the second and third most common use for Florida Cancer Data.

Purpose of Data Request

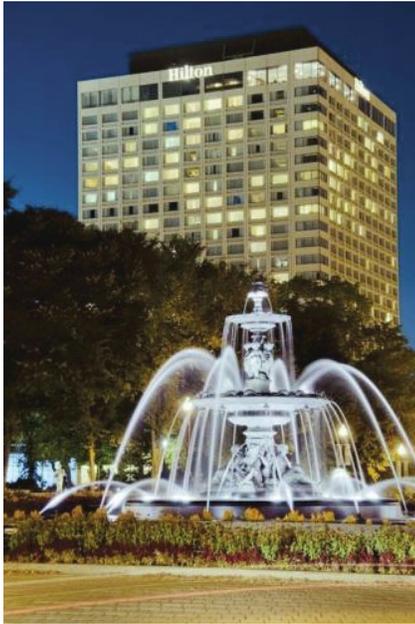


How? How did it happen?

Of course the how depends on what the customer requested. Any confidential data must first be approved by the Florida Department of Health. After request forms have been received and approved (if needed) FCDS tabulates or extracts the data. Sometimes the output is simple tabular data and other times complex tables; large data sets need to be extracted and assembled. Each data request and dataset is unique. Counts and rates can be run on the FCDS IDEA web statistics page or in SEER*Stat. Complex data sets are usually assembled using either SAS or SPSS and output to an ASCII file in the latest NAACCR version file layout. The linkages take place using the Automatch software and while it is NOT user friendly and is very difficult to use, it is a work horse.

Conclusion

There you have the 5 W's and 1 H regarding data requests from the Florida Cancer Data System for 2009. And while the number of formal data requests to FCDS have decreased over the last few years the complexity and level of difficulty has increased. ❖



NAACCR

2010 Annual Conference

"Renewed Collaboration: A Modern Paradigm for Cancer Surveillance"

June 19-25, 2010
Québec City, QC, Canada

By Dr. Jill A. MacKinnon, CTR

The 2010 NAACCR Annual Conference held in Quebec City was a wonderful meeting. Quebec City was breathtaking with the 'Old City' giving you the feel you were in the heart of Europe. The program was fantastic and underscored the value of the data we collect and generate, addressing just how essential sharing resources and knowledge is to successfully dealing with the challenges we are all faced with day after day but especially now in this time of change. The Program Committee did an excellent job in selecting the speakers and topics for the conference which really illustrated the shifting paradigm of cancer surveillance and the ever increasing need to address relevancy of the registry data to a broad range of shareholders.

I am happy to report that Florida was well represented and illustrated how our joint partnership is addressing cancer surveillance. Your data were used in four oral presentations from Dr. Monique Hernandez; Recinda Sherman; Brad Wohler and yours truly and in three poster presentations from Aruna Surendera Babu of the Florida DOH; Dr. David Lee and Dr. Monique Hernandez.

It is your continued dedication and professionalism which allows Florida to continue to be recognized in disease surveillance nationally and internationally. As always, I am very grateful for your efforts day in and day out.

Florida was well represented with four oral presentations and three posters as follows:

"Inter-Registry Records Linkage Without Releasing Patient Level Data: Examining the Feasibility of Establishing a National Clearinghouse Using One-Way Data Encryption" by Dr. Jill MacKinnon; **"The Gist on G.I.S.T"** by Mr. Brad Wohler; **"Colorectal Cancer Trends in Florida Hispanics: Data from the Hispanic Monograph -A Florida Cancer Data System (FCDS) Publication"** by Dr. Monique Hernandez; and **"Utility of Hospital Discharge Data for Registry Enhancement"** by Ms. Recinda Sherman. **"The Hispanic Monograph - A Florida Cancer Data System (FCDS) Publication of Hispanic Cancer Trends in Florida"** by Dr. Lora Fleming; **"National Health Interview Survey (NHIS)- Florida Cancer Data System (FCDS) Linkage Project"** by Dr. David Lee; **"Co-Morbidities Among Female Breast Cancer Patients In Florida, 2000-2008"** by Aruna Surendera Babu.

Below is a summary of each of the abstracts submitted for Oral Presentations:

INTER-REGISTRY RECORD LINKAGE WITHOUT RELEASING PATIENT LEVEL DATA: EXAMINING THE FEASIBILITY OF ESTABLISHING A NATIONAL CLEARINGHOUSE USING ONE-WAY DATA ENCRYPTION

Jill A. MacKinnon, Paul Sterns, Maria J. Schymura, Betsy Kohler

(Continued on page 5)

Background: Many cancer patients move from one registry jurisdiction to another. Often times, a different “permanent residence” at diagnosis is listed and therefore, the cancer can become an ‘incident’ case in multiple CCR’s resulting in overestimation of cancer in the respective states and at the national level.

Purpose: A central database could link and identify the potentially duplicate cancers. However due to patient confidentiality, the release of patient level identifiers is not feasible for many CCR’s. We have examined the use of one-way encryption of patient level identifiers to overcome this limitation. One-way encryption cannot be un-encrypted unlike two-way encryption.



Methods: One-way encryption converted the patient identifiers into a series of characters called hashes and then deterministically compared them using a series of 10 passes. This project linked Florida’s 160,000 mortality records against 1.2 million consolidated patient records.

Results: Approximately 99% of the records were linked deterministically using one-way encryption with fewer than 0.0002% false positives. The linkage took less than one minute per pass to run.

Implications: Using this innovative approach to de-duplicating cases between CCR’s may allow CCR’s to share their de-identified data with a central clearing database, resulting for more accurate data by eliminating non-incident cases from the respective CCR’s which in turn will provide more accurate national data.

THE GIST ON G.I.S.T.

B. Wohler, S. Manson; Florida Cancer Data System University of Miami Miller School of Medicine

Beginning in 2001, gastrointestinal stromal tumors (GIST) was given a proper ICD03 code. Since then, 1,203 have been reported in Florida. GIST are considered rare tumors that occur throughout the digestive tract, anywhere from the esophagus to the rectum or in the abdominal cavity. Originally GISTs were thought to be from muscle or nerve cells, but in the last 20 years it was discovered that they actually originate from the interstitial cells of Cajal (ICC) located in the walls of the GI tract. Currently there is some debate regarding whether or not all GISTs should be considered malignant. Some clinicians and pathologists have suggested that the term “benign GIST” be discarded as there is no such thing as a “benign” GIST. Currently reporting guidelines stated that only records stating malignancy somewhere in the record are reportable. Leading to the question, should we be collecting information on all GISTs whether or not it is stated to be malignant?

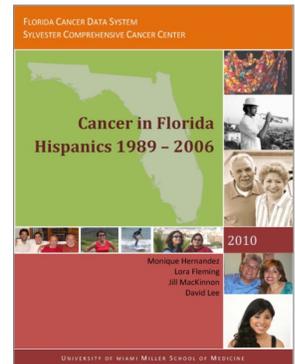
We will present descriptive epidemiology on GISTs in Florida and the U.S. with regard to site, age at dx, sex, race, ethnicity and stage. In light of the debate on “benign” GISTs we will also be discussing reportability problems, implications and possible solutions.

COLORECTAL CANCER TRENDS IN FLORIDA HISPANICS: DATA FROM THE HISPANIC MONOGRAPH – A FLORIDA CANCER DATA SYSTEM (FCDS) PUBLICATION

Monique N Hernandez, David J Lee, Lora E Fleming, Jill A MacKinnon, Youjie Huang, Tara Hylton Florida Cancer Data System (FCDS), Sylvester Cancer Center, University of Miami, Miami, FL; Florida Dept of Health, Tallahassee, FL.

Hispanic colorectal cancer rates historically have been lower than for non-Hispanic Whites in the United States. The purpose of this paper is to understand the cancer experience of Florida Hispanics and potential differences in cancer outcomes based on the diversity of Hispanic subgroups in the state. The FCDS has created a Monograph focusing on the cancer experience of Florida Hispanics diagnosed between 1989-2006. Methods: The Hispanic Origin Identification Algorithm was applied to the FCDS data in order to reduce misclassification as to ethnic designation. Primary cancer site and histology data were categorized according to SEER site groups. Cancer incidence trends between 1989-2006 were conducted using the Joinpoint regression model. Results: In Florida, Hispanic cancer rates have historically been lower than

the leading cancers among non-Hispanic Whites. Trends in colorectal cancer (CRC), however, have been higher for Florida Hispanics compared to non-Hispanic Whites since the mid 1990’s. More troubling was a consistent significant increase in the incidence of distant stage CRC in Hispanics (annual percent change [APC] of 1.26% and 0.90% in males and females), while rates in non-Hispanics decreased significantly during the same time period (APCs= -1.36% and -1.28%, respectively). This is a particular public health concern given that CRC is a screenable cancer and could imply a concomitant increase in CRC-related mortality among Florida Hispanics Current (2008) Florida Behavioral Risk Factor Surveillance System reports document significantly lower rates of colorectal screening in Hispanic adults 50 years of age and older relative to non-Hispanic whites. Comprehensive colorectal screening programs targeting the Florida Hispanic population are warranted.



UTILITY OF HOSPITAL DISCHARGE DATA FOR REGISTRY ENHANCEMENT

R Sherman, J MacKinnon, G Levin, B Wohler, University of Miami, Miami, FL



Background: Survival analysis using cancer registry data is difficult, particularly for many NPCR registries, due to lack of active follow-up (resulting in early censoring of cases) and limited covariates for adjustments, due to incomplete treatment variables and information on co-

morbidities. Florida Cancer Registry (FCDS) historically links with state discharge data as a case-finding source. Due to a recent agreement between FCDS and Florida Agency for Health Care Administration (AHCA), FCDS data was linked with "all cause" AHCA discharge data.

Methods: This pilot study evaluated using a linked dataset between FCDS and AHCA for enhancement of FCDS data. FCDS cases (SSN known, alive, and dxed 1981-2007) were linked with AHCA with a deterministic match on SSN against three AHCA files for 2008: ambulatory surgery, ER, and inpatient encounters. The data was evaluated for accuracy of linkage and improvement of incomplete FCDS data items. Co-morbidity algorithms were developed for the AHCA data and an in-house matrix was used to identify missed treatment information.

Results: Nearly 17% of registry cases linked with AHCA, increasing by dx year to over a 50% link for dx year 2007. Of unknown FCDS data, 98% of race, 97% of ethnicity, 100% of DOB, and 100% of sex were known in AHCA.

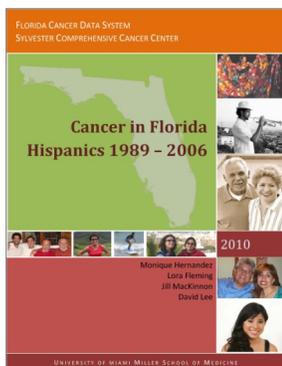
Implications: Completeness of specific demographic variables can be improved through linkage with discharge data, and survival studies can benefit by updating date of last contact. This linkage also has the potential for improving completeness of treatment data and adding co-morbidity codes. Despite issues, such as inadequate linkage capacity and years of available data, linking with hospital discharge datasets can improve registry data.

Below is a summary of each of the abstracts submitted for Posters:

THE HISPANIC MONOGRAPH – A FLORIDA CANCER DATA SYSTEM (FCDS) PUBLICATION OF HISPANIC CANCER TRENDS IN FLORIDA

Lora E Fleming, Monique N Hernandez, Jill A MacKinnon, David J Lee

Background: Hispanics are the fastest growing minority population in the US. FCDS has created a Monograph focusing on the cancer experience of Florida Hispanics.



Methods: The data were all cancer cases residing in Florida diagnosed between 1989-2006. The Hispanic Origin Identification Algorithm was applied to the FCDS data (Pinheiro 2008). Primary cancer site and histology data were categorized according to SEER site groups. The top 10 cancers among all Florida residents for 2006 were selected, as well as additional cancers traditionally elevated in Hispanics. Cancer incidence trends between 1989-2006 were conducted using joinpoint regression model.

Results: Cancer rankings among Hispanic and on-Hispanic white males were similar for the top four cancers. Proportionally, male Hispanics had lower melanoma and bladder rates and higher proportions of on-Hodgkin lymphoma, liver and stomach cancers. For Hispanic females, the top five were breast, colorectal, lung and bronchus, uterus, and thyroid, with a higher proportion of cervical cancer, but lower of melanoma. Although Hispanics and non-Hispanic whites had decreasing trends in overall cancer rates, the decrease was greater for non-Hispanic whites.

Implications: Rates for cervical, liver, stomach, non Hodgkins' lymphoma, and thyroid cancers are elevated in the Hispanics. Cancer rate trend decreases were greater for non-Hispanic white population indicating the existence of health disparities between the two groups.

NATIONAL HEALTH INTERVIEW SURVEY (NHIS) FLORIDA CANCER DATA SYSTEM (FCDS) DATA LINKAGE PROJECT

D Lee, JA MacKinnon, CS Cox, H Huang, DM Miller, B Wohler, T Hylton, G Levin, LE Fleming

Background: This Pilot Demonstration Project is designed to demonstrate and evaluate the feasibility of performing a record linkage between the National Health Interview Survey (NHIS) of the National Center for Health Statistics (NCHS) and the Florida Cancer Data System (FCDS) databases.

Purpose: The Project will assess the feasibility of linking NCHS national population-based survey data with individual state cancer registries and to establish the logistics involved in conducting such linkages with individual state cancer registries. This linkage will provide highly enriched data for incident cancer cases who participated in the NHIS. Linking the NHIS survey participants' demographic, socio-economic, health conditions, health care utilization, health insurance and health behaviors with the FCDS cancer incidence cases.

Methods: Human Subjects clearance has been obtained and procedures for secure data linkage and secure transfer of data to the NCHS Research Data Center (which will serve as the data repository) have been developed. The initial linkage will use 1987 NHIS data with the entire FCDS database and will be completed by Spring 2010, with plans to expand the linkage to the other NHIS Survey years.

Implications: The ultimate goal of the proposed Pilot Study is to develop a model for conducting linkages between NCHS population-based Surveys, and the CDC National Program of Cancer Research and the National Cancer Institute-supported SEER Cancer Registries within the US.

(Continued from page 6: NAACCR 2010 Annual Conference)

CO-MORBIDITIES AMONG FEMALE BREAST CANCER PATIENTS IN FLORIDA, 2000-2008

A Surendera Babu, J MacKinnon

Background: Breast cancer is the most common cancer among females in Florida. Though the incidence and mortality rates are decreasing, it remains a threat among blacks. Co-morbid conditions are an important factor of determining treatment and the prognosis and are understudied.

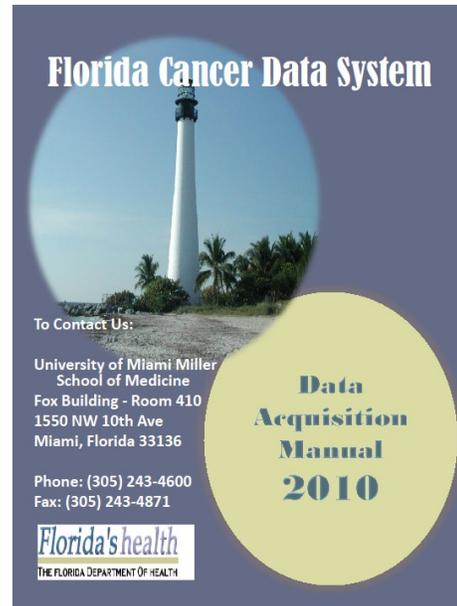
Purpose: The study explores the co-morbid conditions among female breast cancer patients between 2000 and 2008. Disparities in co-morbidity will be examined.

Methods: Florida data from the AHCA for the years 2000 to 2008 were analyzed. Females were grouped into: <40 years, 40-64 years, and 65+ years, whites and blacks. The frequently reported co-morbid conditions were identified. The sums of co-morbidity were calculated and were grouped into: no co-morbidity, 1 to 3 conditions, and over 4 conditions. Cross tabulations were performed by age and race groups.

Results: Between 2000 and 2008, 43,787 females were hospitalized for breast cancer. The commonly reported co-morbid conditions in Florida were hypertension, diabetes, lipid metabolism disorders, hypothyroidism, CVD, and COPD. The percentage of having one to three co-morbid conditions was higher among the older age groups and among blacks. The percentage of having hypertension and diabetes was significantly higher among blacks and having hypothyroidism was significantly higher among whites.

Conclusion: The percentage of having higher co-morbid conditions could be a possible explanation for the threat among blacks. ❖

DAM 2010



FCDS is pleased to announce the availability of the 2010 FCDS Data Acquisition Manual (FCDS DAM). The manual includes important information about Florida cancer reporting requirements for 2010, instructions for coding new and changed data items, and has links to references and resources used daily when abstracting cancer cases. Download a copy to your computer desktop for easy reference or for printing at <http://fcds.med.miami.edu> under What's New. ❖

Cancer Awareness

JULY

UV SAFETY MONTH
SARCOMA AWARENESS MONTH

SEPTEMBER

CHILDHOOD CANCER MONTH
LEUKEMIA & LYMPHOMA AWARENESS MONTH
GYNECOLOGIC CANCER AWARENESS MONTH
OVARIAN CANCER AWARENESS MONTH
PROSTATE 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."



The art of
being wise is
the art of
knowing
what to
overlook.

William James

Security Awareness Tips

Warning: Your Computer May Not Be Infected

By now, most of us know better than to open email attachments from unknown sources or download software from untrusted sites. Likewise, we should already have an antivirus program and maybe even other software on our computers to stop malware.



We depend on those programs to protect our vital information. But if you are like most people, you have installed your antivirus and forgotten about it. Good security software is supposed to work behind the scenes, with as little intervention from you, the user, as possible. Hopefully, you have remembered to set your antivirus to automatically download updates on a regular basis or you do so manually.



Now, a new trend — *malvertising* — takes advantage of your security knowledge. Online advertisements are posing as antivirus software to make you believe your computer has been infected. So while you are browsing

the Web, a message will display, like "Warning, your PC is infected," and inviting you to click a link to download bogus software. The image above contains samples of what may appear in one of these scams. These advertisements often lead to harmful or deceptive content, redirect to a website that advertises rogue security software (*scareware*), infect a computer with programs that can damage or steal information, or even allow a remote attacker to fully control the computer.

"The fake [antivirus] threat is rising in prevalence," according to Google. Fake antivirus programs recently accounted for 15 percent of malicious software they found online. Malvertising can even be found on reputable sites. The New York Times, Fox News, and other leading websites have already fallen victim to malware ads.

Not only do these fake antivirus programs pose a security threat to your computer, but "many users ... pay to register the fake [antivirus]." Google said in a report last week. So these users are providing their credit card information as well as other personal information to online hucksters — a recipe for identity theft and fraud.

A few good habits can help you avoid online scams and ensure the safest computing experience possible:

- Make sure you use legitimate and up-to-date antivirus, firewall, and anti-malware tools.
- Get to know your security software and be extra cautious about offers to scan your computer with programs you do not recognize.
- Do not give out personal information unless you know the website is secure.
- Do not enter your credit card on websites you do not trust.

For more information

- Anti-Malvertising.com
- Fake anti-virus software a growing online threat
- Deloitte: The rise of malvertising and its threat to brands
- Internet companies face up to 'malvertising' threat
- Microsoft: Bad Ad - Going After The Malvertising Threat

Source: Office of HIPAA Privacy & Security University of Miami Miller School of Medicine

CALENDAR OF EVENTS

CALENDAR OF EVENTS

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 mherna@med.miami.edu
- **To Register:** <http://fcds.med.miami.edu>

Date	Topic
08/05/2010	Collecting Cancer Data: Lip and Oral Cavity
09/02/2010	Coding Pitfalls

FCDS 2010 EDUCATIONAL WEBCAST SERIES

- **Time:** 1:00 pm—3:00 pm
- **Dial-in Number:** 877-807-5706
- **Participant Code:** 261452
- **Link to web session:** <https://webmeeting.med.miami.edu/fcfs2010educationseries>

Date	Topic	CE Hours	NCRA Program Recognition Number
7/29/10	Collaborative Stage: Lung <i>* Recorded & posted on the FCDS website*</i>	2	2010-105A
08/12/2010	Collaborative Stage: Breast <i>* Recorded & posted on the FCDS website*</i>	2	2010-105B
08/26/2010	Collaborative State: Prostate	2	2010-105C
09/09/10	Collaborative Stage: Colon	2	2010-105D
09/23/10	Hematopoietic and Lymphoid Part I	2	2010-105E
9/30/10	Hematopoietic and Lymphoid Part II	2	2010-105F

CTR EXAM PREP WORKSHOP BY AFRTZ AND ASSOCIATES

- **Date:** August 12-14, 2010
- **Location:** Reno, NV
- **Website:** <http://www.afritz.org>

CTR EXAM PREP WORKSHOP BY NCRA

- **Date:** August 21-22, 2010
- **Location:** Baltimore, MD
- **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%
January 2010	45%	58%
February 2010	54%	66%
March 2010	61%	75%
April 2010	70%	83%
May 2010	80%	91%
June 2010	100%*	100%

*Caseload has increased this year. We are still expecting more cases to be reported.

COMPLETENESS REPORT—2010 CASE REPORTING

Month	Complete	Expected
July 2009	0%	8%



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.

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

FLORIDA CANCER DATA SYSTEM
 SYLVESTER COMPREHENSIVE CANCER CTR AT THE
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SYLVESTER
 COMPREHENSIVE CANCER CENTER
 UNIVERSITY OF MIAMI HEALTH SYSTEM

MILLER
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 UNIVERSITY OF MIAMI