

FLORIDA CANCER DATA SYSTEM (FCDS)

FAQs

April 30, 2010

Can cancer clusters be identified through the FCDS registry?

Yes, the FCDS data are sufficient to identify a cancer 'cluster.' However, disease clusters are very difficult to detect and often times, once investigated, what appeared to be a 'cluster' of cancer is not. There are many reasons for this such as miss-classification of the cancer and the population at risk (as discussed below), the length of residence in the area and possibly the most difficult of all, the cause and effect of cancer. Most cancers do not have a clear cause (etiology). The DOH relies on a variety of sources to report clusters of disease. People often detect outbreaks more quickly than the data can. For example, for the majority of our communicable diseases we rely on the public or health care providers to report outbreaks, and we estimate about 75% of our food borne outbreaks are detected that way.

Cancer data collected by the FCDS are used by the Florida Department of Health (DOH), other state agencies, federal agencies, non-governmental agencies, local coalitions, health care providers, and researchers to learn more as to the causes of cancer and the pattern of its occurrence.

Why didn't the Department of Health (DOH) surveillance systems pick up the cancer cluster, why did it take a private citizen to report the cluster?

Several factors make it difficult for the DOH to "pick up" cancer clusters. Cancer occurrence fluctuates from year to year in small areas. The number of reported cases might be higher than expected in one year or in several years, but the rates would go back to "normal" in the following years. To determine if there is a cluster, epidemiologists need to compare the cancer rates, instead of numbers, in the area of concern to either overall county rates or state rates. However, except in Census years, there is no available source for good population data in small areas for calculating cancer rates. More importantly, the Department does not have data on how long people have lived in the area of concern in order to assess if the increased cancer rates are linked to local residential history. (NOTE: The Acreage DOH in-depth study interviews will provide that specific residence information).

There are many factors affecting the data collection, analysis and reporting of 'Cancer Clusters.'

- It is imperative to define and classify the cancer correctly. A primary brain cancer is very different from a brain cancer that has spread to the brain from a different site of origin (metastatic disease).
 - The primary brain cancer is counted, the metastatic cancer is not. A primary breast cancer is very different from a primary colon cancer, and so on.
- Secondly, you must have all the cancers reported among residents in that area (completeness).
 - You cannot use a subset or a sample of these cases.
- Thirdly, you must have accurate population counts for the area and time period in question.
 - The population data must be accurate at the Census 'block group' and 'census tract' level. Using zip codes for cluster research is very difficult and can be problematic because zip code boundaries change based on the needs of the Postmaster. It is very difficult to accurately connect a cancer case to a zip code area over time.

Incomplete or inaccurate data at any one of the steps above may lead to inaccurate conclusions.

The FCDS does make data available for cancer researchers who study the epidemiology and causes of cancer for more in depth investigations. In short, zip codes and counties are too large to detect clusters. Reporting of clusters based on this level of geography is not accurate and misleading.

Cancer is very serious and frightening, and unfortunately a common disease. Current information shows that approximately one out of three Americans will develop cancer in their lifetime, and cancer will affect three out of four families. Also, the risk of developing cancer increases with age, so as the population ages, more cases of cancer in our communities are expected.

Was there a change in the law in 2004 or at any time that modified classifying a "cancer cluster" to include both benign tumors and actual cancer, when previously it was only actual number of cancer cases? How did this affect the analysis done in the Acreage?

Prior to 2004, the FCDS, by law collected information on **all malignant tumors, regardless of anatomical sites**, diagnosed among residents of the state of Florida. FCDS was not allowed to collect information on other diagnoses such as benign tumors. Please remember that the term "cancer" is defined as a **malignant tumor only**.

In 2004, the law changed, and the Florida Cancer Data System (FCDS) started collecting benign and borderline brain and central nervous system tumors as required by new federal law, the Benign Brain Tumor Cancer Registries Amendment Act, Public Law 107-260 signed by President Bush in October 2002.

In addressing the questions raised by Acreage residents, in the years 1981 through 2003, before the law changed and the Registry was only collecting information on malignant tumors, the FCDS can only calculate the expected and observed number of cases based on data reported to the registry -- malignant tumors.

Since the new federal requirements in 2004, the FCDS collects information on malignant, borderline, and benign brain and central nervous system tumors. Because of this additional data the FCDS can now calculate rates from 2004 going forward for malignant as well as for benign/borderline tumors of the brain and central nervous system combined or separately .

Some individuals have inquired if this means that the "old data changed." The answer is "No." The "old data" cannot be changed or updated to include data that were never collected by the FCDS. Borderline and benign brain and central nervous system tumors diagnosed before 2004 were not added to the registry after the fact. During the years from 1981 to 2003 there was no surveillance done by the FCDS or any other health agency on the occurrence of benign and borderline tumors. Before 2004, the FCDS collected and reported on **malignant tumors only**.

The diagnosis for a malignant tumor does not change. Also, tumors considered benign or borderline before 2004 did not change to become classified as malignant. In other words, **the law simply allowed for the collection of various types of brain tumors and there were no changes in the actual classification of these brain tumors.**

The addition of benign and borderline brain and CNS tumor cases to the registry in 2004 does not alter the finding of increased rates of pediatric brain cancers in the Acreage.

In the Tables 7 or 10 of the [Acreage Cancer Review Report of August 2009](#), pages 27 & 30, –the ratio of what we expected to see and what actually occurred was increased.

When will the data for 2009 be available for inclusion in analysis?

The reporting deadline for 2009 cases is in June 2010. There is an additional period of time for the Florida Cancer data System (FCDS) to compare reported records with multiple other sources of data for case findings and to follow back with medical facilities for record verification. The 2009 data will be provisionally available sometime in December of 2010, and will be considered a final data set later in 2012.

Are all medical facilities being asked to report new cases at time of diagnosis as we are in the middle of a vital study to save lives and make important decisions for people residing in the Acreage community?

We want to have the most current and accurate information available as we continue our investigation. We are working closely with the Florida Cancer Data Registry to speed the process of evaluation and confirmation of reported cases. We have also reached out to area physicians to remind them that it is very important that all cases are reported to the registry as quickly as possible. We have developed a secure communication link from the Neighborhood Information Center so we will be able to check and see if individual cancers have been reported to the registry. Acreage residents are able to check whether their case or a family members' case (with appropriate documentation) have been reported to the registry. If no record exists, the registry will be able to explore why this may not have occurred if the cancer is of a type that should be reported and if enough time has passed that it is likely to have been reported. If you wish to use this service, please be sure to bring a photo id and legal documentation if you are requesting this on behalf of a family member. Please call the Acreage Neighborhood Information Center at (561) 798-7082 to determine what documents are needed and if you have questions about the process. We are hoping that this will be a valuable resource to the Acreage residents concerned about the registry.

Have you used the Department of Veterans Affairs Central Cancer Registry in conjunction with our state cancer registries in order to obtain incident rates?

Presently, the rate of occurrence for new cancers diagnosed in the state of Florida does not include data from the Veterans Affairs (VA) hospitals located throughout the state.

In the past, VA hospitals were not required to report to the state cancer registries as VA medical facilities are subject to federal jurisdictions, not state. In October 2009, the Department of Veterans Affairs issued Veterans Health Administration (VHA) Directive 2009-046 providing policy on releasing VA central cancer registry data to state cancer registries to ensure a complete understanding of the national cancer burden and mortality. The FCDS is working with the Chief Medical Officer over the VA hospitals located in Florida to ensure these hospitals will report to the FCDS starting with cancers diagnosed in 2010.

FCDS web site: <http://www.fcds.med.miami.edu>