

Mission:

To protect, promote & improve the health of all people in Florida through integrated state, county & community efforts.



Ron DeSantis
Governor

Vision: To be the **Healthiest State** in the Nation

Cancer Cluster and State Cancer Registry Frequently Asked Questions

What is a cancer cluster?

A cancer cluster is defined as a greater-than-expected number of cancer cases that occurs within a group of people in a defined geographical area over a specified period of time. When people learn that several friends, family members, or neighbors have found out they have cancer, cancer clusters are often suspected. Cancer clusters are also sometimes suspected when people who work at the same place or have other factors in common get cancer.

What are the criteria for a group of cancer cases to be considered a cluster?

To be a cancer cluster, a group of cancer cases must meet the following criteria:

- Include a large number of cases of one type of cancer or types of cancer scientifically proven to have the same cause or etiology, rather than several different cancer types.
- The observed number of cases is higher than one would typically observe in a similar setting (e.g., in a group with a similar population, age, race, or gender).

Other important factors in evaluating reports of cancer clusters are:

- A rare type of cancer, rather than common types.
- An increased number of cases of a certain type of cancer in an age group that is not usually affected by that type of cancer.
- The type of cancer involved is a primary (original) cancer not a metastasized (spread from another organ) cancer.

How are suspected cancer clusters investigated?

Not all community concerns of excess cancer require investigation; oftentimes, community concerns can be resolved by providing general cancer educational information, facts and resources.

When needed, a local or state health department gathers information about the suspected cancer cluster. This commonly includes the types of cancer, number of cases, age, sex, race, address, and age at diagnosis of the individuals with cancer. The department reviews this available information and determines if analysis of cancer rates and other investigative steps are needed to better understand the situation.

If the department determines that analysis is needed, this involves confirming the number and types of cancers in the community and comparing this to what might be expected based on state or county rates of cancer. Specific analysis (such as investigating just childhood rates, or just among women in the case of breast cancer) may also be needed depending upon the type of concern. The department communicates and discusses the results of the analysis with the community.

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Where do I go for additional information?

Centers for Disease Control and Prevention (CDC) Cancer Clusters

Agency for Toxic Substances and Disease Registry

National Cancer Institute (NCI) Cancer Clusters

What is FCDS (Florida Cancer Data System)?

The Florida Department of Health (DOH), Public Health Research has contracted with the University of Miami's Miller School of Medicine since 1979 for the day-to-day operations of the statewide cancer registry, the Florida Cancer Data System (FCDS). The FCDS is legislatively mandated to collect incidence data on all cancers diagnosed among residents in Florida per Section 385.202 *Florida Statute*. Since 1981, the FCDS has been collecting the number of new cancers diagnosed each year statewide (e.g., the annual incidence). The FCDS is used to observe cancer trends and provide a research base for studies into the possible causes of cancer.

The FCDS has been certified by the Centers for Disease Control and Prevention's National Program of Cancer Registries (CDC-NPCR) as a 'Registry of Excellence' for meeting all program standards. Furthermore, the North American Association of Central Cancer Registries (NAACCR) has certified the FCDS at its highest level, "Gold Certification" since 2002. Gold Certification is conferred on central registries that exceed standards for completeness, timeliness, and data quality.

What kind of cancer cases must be reported to FCDS?

Florida statute requires all malignant cancers reportable with the following *exceptions* - In situ carcinoma of the cervix (CIS), intraepithelial neoplasia grade III of the cervix (CIN III) and intraepithelial neoplasia of the prostate (PIN III) are *not reportable*. Basal and squamous cell carcinoma of non-genital skin sites are *not reportable* regardless of extent of disease at the time of diagnosis or the date of first contact with the reporting facility. *Reportable* on or after diagnosis date of 01/01/2001 are Intraepithelial neoplasia Grade III of vulva (VIN III), vagina (VAIN III) and anus (AIN III) and Myelodysplastic Syndrome (MDS). All patients with an active, benign or borderline brain or central nervous system (CNS) tumor, diagnosed on or after 01/01/2004, whether being treated or not *are reportable*. All cancer cases diagnosed and/or treated in Florida since 1981 must be reported to the FCDS.

What kind of data is collected by FCDS?

The FCDS requires that the data collected include information which indicates diagnosis, stage of disease, patient demographics, laboratory data, tissue diagnosis and methods of diagnosis or treatment for each cancer diagnosed or treated in Florida.

Who is required to report cancer cases to FCDS?

All facilities licensed under Chapter 395 and each freestanding radiation therapy center under Section 408.07; All ambulatory surgical centers as specified by Rule 64D-3.034; Any licensed practitioner in the state of Florida that practices medicine, osteopathic, chiropractic medicine, naturopathy or veterinary medicine are required to report under Chapter 381 or any laboratory licensed under Chapter 483 that diagnoses or suspects the existence of a cancer.

Are there limitations to using FCDS data for analyses?

Yes, there are limitations to using Florida Cancer Data System (FCDS) data. Although FCDS data can be provided by select geographical area, these data represent a retrospective account of the burden of cancer for an area. The FCDS collects outcome data. The case information submitted by medical reporters to the FCDS describes "who", "what", "when", and "where" of the cancer case. However, the

FCDS does not collect data as to “why” nor can analyses of FCDS data alone determine why the occurrence of cancer in a specific area or population is happening. Moreover, there is an inherent delay in collecting cancer incidence data as a reporting entity has up to six (6) months after the initial date of diagnosis to report the cancer case information to the Florida Department of Health. This six-month period permits the cancer case information to include the completed initial course of treatment. In addition, the FCDS must conduct external linkages with Department’s Bureau of Vital Statistics and the Florida Agency for Health Care Administration to ensure the completeness and accuracy for the diagnosis year. Therefore, cancer surveillance data from the FCDS is not available for official release until two years after the close of the diagnosis year.

Does this line pasted below from page 17 of the report mean that the FDOH’s conclusion is that these cancer rates in these two zip codes do not merit any further investigation, because there were only a few rates that were higher and they weren’t much beyond the norm? Or is the agency saying that any further investigation would be up to CDC/ATSDR? In other words, these rates wouldn’t merit CDC doing an extensive investigation, either?)

Commented Text:

More information, if available, would need to be gathered to determine causality. This would require a complex, extensive investigation effort of local and state resources beyond public health. The present review of cancer and environmental data does not support conducting an extensive investigation. The review of existing cancer and environmental data does not support conducting an extensive investigation. As stated in the Executive Summary of the Brevard County Cancer Assessment on page 2, “In some cases, an initial analysis can demonstrate statistical significance in the number of cancer cases occurring, but may not be linked with a statistically significant association with exposure to environmental contaminants. Also, a statistically significant excess of cancer cases can occur within a given population without a discernible cause and might be a chance or random occurrence (CDC, 2013).”

As stated in the assessment, the primary area of concern was the City of Satellite Beach zip code 32937. For the time period, 1996 to 2005, a higher than expected number of cases was found for urinary bladder cancer for both females (expected 23-24 cancers, 37 cancers occurred) and males (expected 80 cancers, 106 cancers occurred). For the time period from 2006 to 2015 there were no statistically significant cancer types found in zip code 32937. In other words, over the ten-year period from 1996 to 2005, instead of recording on average 2-3 cancers per year for female urinary bladder cancer, there were approximately 3-4 cancers per year. This increase can occur for many reasons as cancer is multifactorial in that many risk factors contribute to development of cancer. Furthermore, there is still underlying uncertainty in cancer occurrence and patterns of cancer due to changes in population (i.e., population growth, population migration, etc.) that cannot be easily addressed in statistical calculations. For completed analyses in the assessment, accurate, annual population data for zip-code level geography is not available and therefore, the U.S. census population for this zip code was used in statistical analyses. With that said, there is a likelihood that the number of estimated expected cases was underestimated.

At this time, there is not one known environmental contaminant that causes all cancer types. However, the one risk factor that increases a person’s risk for developing cancer is age. When reviewing the number of observed cancer cases in zip code 32937 for the selected cancer types, the pattern remained consistent with scientific literature that the number of cases increased with older age, with mark increases starting at age 40 (see Appendix A). Moreover, the risk for urinary bladder cancer include other risk factors such as family history and smoking.

Finally, there is no evidence of PFAS currently impacting the public drinking water of the surrounding areas of Patrick Air Force Base. Irrigation water and surface water samples did reveal detections of PFAS but levels were below their respective screening values. For a suspected cancer cluster to be

linked to an environmental contaminant, there must be an established pathway of exposure at concentrations above determined health advisory levels.

Also, can FDOH declare a cancer cluster, or is it only CDC that can do that?

Yes, the state of Florida can determine an area of concern as a cancer cluster.

Is there or will there be further investigation beyond the types of cancers this assessment looked at?

Currently, there are no further plans to review cancer types beyond what was presented in the assessment. The selected cancer types reviewed in this assessment were based on current scientific literature as to what cancers types a person may have increased risk for developing as it relates to perfluorooctane sulfonate (PFOS) and perfluorooctanoic acid (PFOA).

What are the theories as to why the overall cancer rate and several specific cancer types (see below) in Brevard are higher than the rest of Florida? Could FDOH comment on the higher countywide rates in Brevard, and whether the statistics/rates shown in FLORIDA CHARTS would at all be considered unusual or reason for concern and/or further assessment by FDOH?

Cancer can occur due to the contribution of one or many risk factors simultaneously occurring (age, gender, race, smoking, etc.). The source for annual state and county cancer data displayed on Florida CHARTS is the Florida Cancer Data System (FCDS). The age-adjusted rates calculated for Brevard County for all cancer types combined or a single cancer type may be higher or lower than the state based on statistical calculations in which there is greater statistical certainty of rates when based upon a greater number of cases. Hence the state rate has less variability in interpretation than a county rate. Although a single year of data for a local county shows a greater age-adjusted rate than the overall state rate for all cancer types combined or for a single cancer type, this does not mean that there is a cancer concern or cluster.