Florida Cancer Data System
Overview
FCDS is the legislatively mandated, population-based central cancer registry for the state of Florida.

Data in the FCDS are collected from patient medical records.

Cases in the FCDS database are submitted from hospitals, freestanding ambulatory surgical facilities, radiation therapy facilities, private physicians, and death certificates.
FCDS is an incidence registry, a joint project of the University of Miami Miller School of Medicine and the Florida Department of Health.

FCDS is part of the Centers for Disease Control National Program of Cancer Registries (CDC/NPCR) and is nationally certified by the North American Association of Central Cancer Registries (NAACCR) at its highest level, ‘gold certification’.

Gold certification is conferred on central registries that meet or exceed all standards for completeness, timeliness, and quality.

Data collected and coded by FCDS are in accordance with national standards as put forth by the North American Association of Central Cancer Registries (NAACCR).
Who is required to report?

Florida Statute 385.202 provides for the establishment of a statewide cancer registry.

All facilities licensed under Florida Statute 395 and each freestanding radiation therapy center as defined in Florida Statute 408.07 shall report to the Department of Health, through FCDS, such cancer incidence information as specified by Rule 64D-3 which includes, but is not limited to, diagnosis, stage of disease, medical history, laboratory data, tissue diagnosis, radiation, or surgical treatment and either method of diagnosis or treatment for each cancer diagnosed or treated by the facility or center.

Failure to comply with this requirement may cause for registration or licensure suspension or revocation.
Who is required to report?

Any licensed practitioner in the state of Florida that practices medicine, osteopathic, chiropractic, naturopathy or veterinary medicine is required to report under Florida Statute 381.0031 or any laboratory licensed under chapter Florida Statute 483 that diagnoses or suspects the existence of a disease of public health significance shall immediately report the fact to the Department of Health.
The Need

Cancer surveillance serves as the foundation for a national, comprehensive strategy to reduce illness and death from cancer.

Such surveillance is the indispensable tool that enables public health professionals at the national, state, and local levels to better understand and tackle the cancer burden.
Information derived through surveillance is critical for directing effective cancer prevention and control programs focused on preventing risk behaviors for cancer, such as tobacco use and poor diet, as well as reducing environmental risk factors.

Such information is also essential in identifying when and where cancer screening efforts should be enhanced.
The Need

Cancer is the second leading cause of death among Americans.

One of every four deaths is from this disease.

Annually approximately 600,000 Americans die of cancer—more than 1,500 people a day.

Advances in treatment and detection techniques have resulted in a drop in the overall cancer death rate by 16% (215.1 per 100,000 in 1991 to 180.7 in 2006).

2009 Estimated US Cancer Deaths*

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung &amp; bronchus</td>
<td>30%</td>
<td>26%</td>
</tr>
<tr>
<td>Prostate</td>
<td>9%</td>
<td>15%</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Liver &amp; intrahepatic bile duct</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Esophagus</td>
<td>4%</td>
<td>3%</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Kidney &amp; renal pelvis</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>All other sites</td>
<td>25%</td>
<td>2%</td>
</tr>
</tbody>
</table>

The FCDS is an ‘incidence’ registry.

This means Florida captures basic information about the patient at time of diagnosis including the initial course of treatment.

Records in an incident record undergo annual ‘passive follow-up,’ meaning cancer records are passively linked to mortality record to record the occurrence of death.

The ‘living’ patient is not actively followed to ascertain a date of last contact; that indicates the patient is still alive.
An end-results registry is one that collects active annual follow-up on all patients in their catchment area.

In addition to patient status (dead or alive), an end-results registry may actively collect subsequent treatment given to the patient.

End-results registries may be population based which means they cover a defined geographic population (a county, region or entire state) or may be hospital-based.
Hospital based registries are responsible for gathering cancer data from a single hospital or multiple facilities under one hospital umbrella.

Most hospitals with in-house registries are approved and accredited by the American College of Surgeons (ACoS).

To become accredited by the ACoS, a facility must satisfy several criteria.
Different Types of Cancer Registries

Maintenance of a quality cancer registry is one of the criteria.

The registry is not only responsible for gathering specific data on all the cancer patients in the facility.

The registry must also perform lifetime annual follow-up on their patient population.
The FCDS collects approximately 150,000 abstracts annually and once duplicates and non-Florida residents are removed, translates into approximately 100,000 newly diagnosed cancers among Floridians.
Different Types of Cancer Registries

FCDS also conducts annual linkages with the State of Florida’s Vital Statistics mortality data.

Approximately 150,000 mortality are linked to the FCDS cancer files to identify patients that have expired (passive follow-up) and to identify any cancer deaths that are not in the FCDS files (retrospective casefinding).
Finally, FCDS links the cancer files with the State of Florida’s discharge database from the Agency for Health Care Administration as part of the year end retrospective quality control casefinding.

If a case is contained in the discharge database that is not in the registry, the case is followed-back to the discharging facility to obtain a complete abstract on the ‘missed’ cancer.

The FCDS database contains over 2 million incident records, approximately 1.5 million mortality records and over 3 million discharge records.
The FCDS computes annual incident and mortality rates based on the data received.

The criteria for a record to be included in the Florida rates are: resident of one of the 67 Florida counties at time of diagnosis; the diagnosis took place in the respective incident year; and the cancer is a reportable cancer.

Adult incident rates are expressed in per 100,000 population whereas pediatric incident rates are expressed in per million population.
There are three types of rates calculated which express very different information.

- Crude Rate
- Age Specific Rate
- Age Adjusted Rate
First is the ‘crude’ rate.

A crude rate is simply the number of incident cases for a particular geographic area divided by the population of that same area.

This gives the health professional the opportunity to assess the burden of disease.
The second is an ‘age specific’ rate.

The age specific rate computes the number of incident cases for a specific age group (0-4, 5-9... 85+) within a particular geographic area divided by the same age specific population of that same area.
Age Adjusted Rate

The third rate is an ‘age adjusted’ rate.

The age adjusted rates adjusted the age specific rates to a ‘standard population’ to remove any age bias.

Age adjusted rates can be compared between regions.

Age adjusted rates are usually the rate epidemiologists use to indicate areas where there may be an excess of cancers.
Comparing rates over time can give the researcher important information regarding trends in cancer.