



# Cancer Data Management

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# Introduction to Cancer Data Management

- Cancer is a major national burden and the second leading cause of death among Americans. In the year 2006 alone, an estimated of 1,399,790 new cancer cases were diagnosed and 564,830 Americans died of cancer. Each year, cancer costs an estimated \$107 billion in health care expenditures and lost productivity from illness and death in the USA.

Reducing the nation's cancer burden is a great and noble cause that involves many people, including physicians, researchers, epidemiologists, public health planners, legislators, medical students, and others

# Introduction to Cancer Data Management

- Physicians need cancer data to learn more about the causes of cancer and to help detect cancer earlier, thereby increasing the chance of finding a cure.
- Physicians make treatment choices based on accurate cancer data from such sources as reports from pathologists and cytologists.
- After treatment, a life time follow-up is required to determine whether the treatment has worked or if the patients has disease recurrence or progression. Cancer registries provide this type of data; they are valuable research tools for those interested in the etiology, diagnosis, and treatment of cancer.

# WHAT IS A CANCER REGISTRY?

A cancer registry is an information system designed for the collection, management, and analysis of data on persons with the diagnosis of a malignant or neoplastic disease (cancer).



Cancer registries can be classified into three general types:

1. Health care institution / Hospital registries
2. Central registries
3. Special purpose registries

# WHAT INFORMATION IS MAINTAINED IN THE CANCER REGISTRY?

1. Demographic Information:
  - Age, gender, race/ethnicity, birthplace and residence.
2. Medical History:
  - Physical findings, screening information, occupation and any history of a previous cancer.
3. Diagnostic Findings:
  - Types, dates and results of procedures used to diagnose cancer.

# WHAT INFORMATION IS MAINTAINED IN THE CANCER REGISTRY?

4. Cancer information:
  - Primary site, cell type and extent of disease.
5. Cancer Therapy:
  - Surgery, radiation therapy, chemotherapy, hormone or immunotherapy.
6. Follow-up:
  - Annual information concerning treatment, recurrence, and patient status is updated to maintain accurate surveillance information.

# WHO IS A "CANCER REGISTRAR"?



**Registrars are data management experts who report cancer statistics for various healthcare agencies.**

# WHO IS A "CANCER REGISTRAR"?

Cancer registrars ensure **timely, accurate, and complete data** on all types of cancer diagnosed and/or treated within an institution or other defined population



# Cancer Registry Data Base

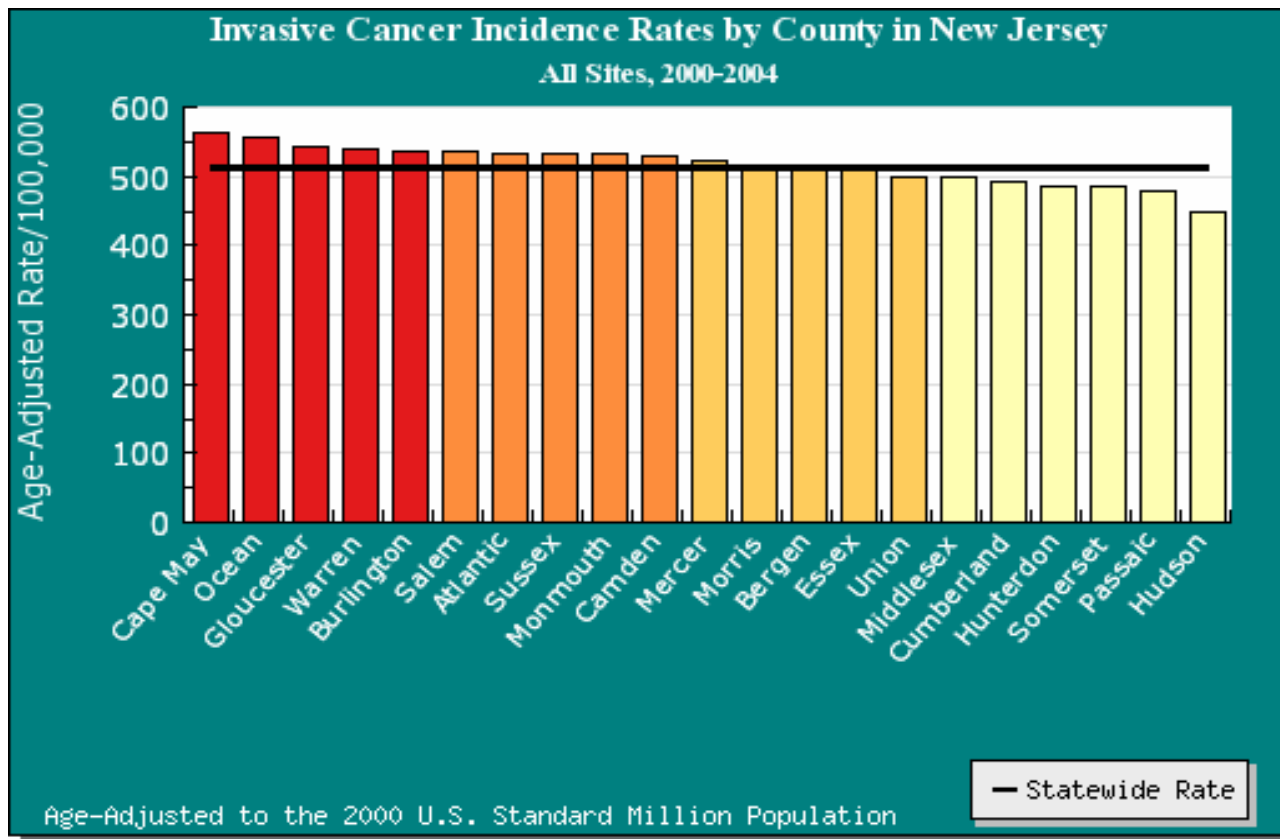
- Is maintained by trained and certified registry personnel working with federal, state, and private organizations
- Contains complete, timely, uniform medical data for each patient including diagnosis, treatment and survival information
- At the State level, is the result of data editing, merging duplicate records, running data quality reports and auditing healthcare facilities to insure reliable data

## HOW IS THE DATA USED?

- Allocate resources at the health care facility, the community, region or state level
- To determine the needs of & develop educational programs for health care providers, patients and the general public
- Report cancer incidence as required under state law
- Evaluate efficacy of treatment modalities
- Provide follow-up information for cancer surveillance

# HOW IS THE DATA USED?

- Evaluate patient outcome, quality of life, and satisfaction issues  
implement procedures for improvement
- Analyze referral patterns
- Calculate survival rates by various data items
- Provide information for cancer program activities



Note: All rates are per 100,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

Example: 1

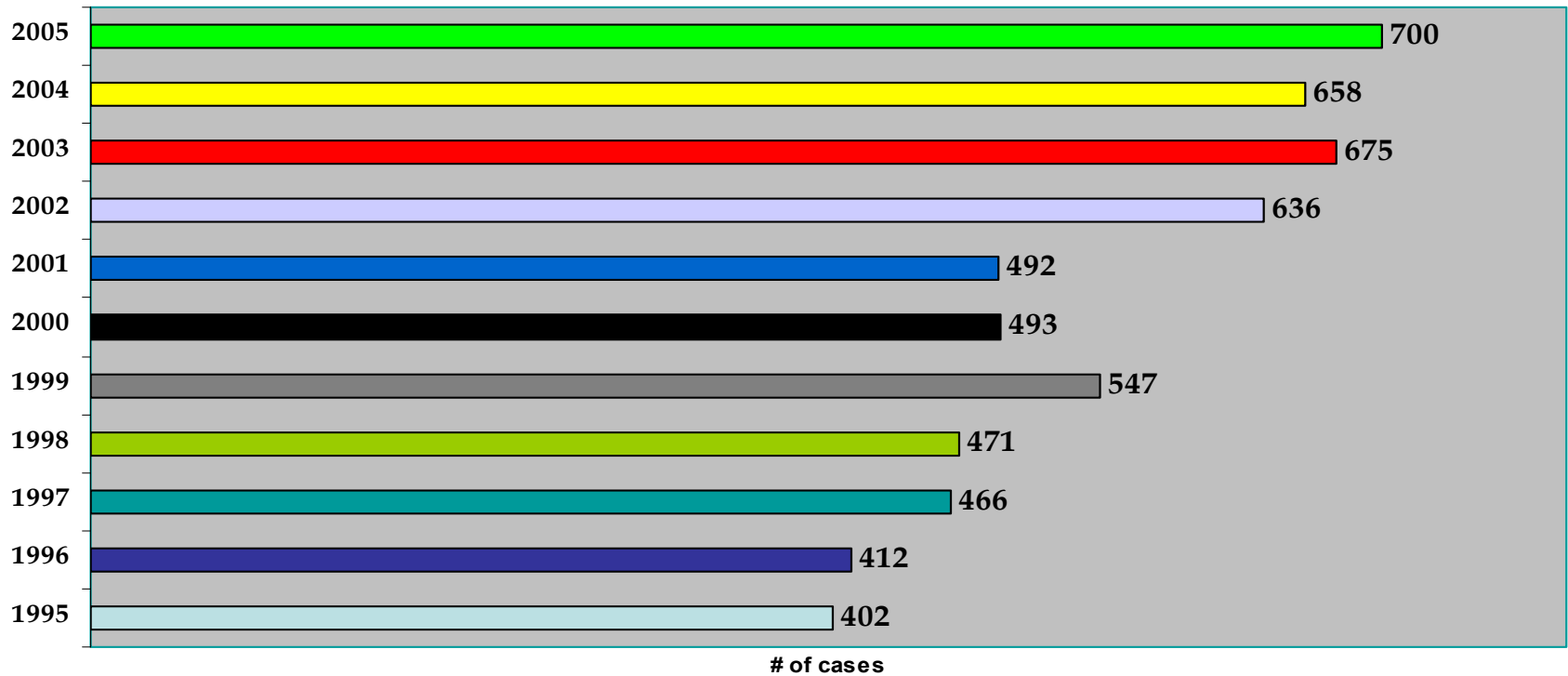
## Incidence Rates† for New Jersey, 1999 - 2003

### Breast All Races (includes Hispanic), Female, All Ages

			Rate Period	Interval Range	Interval Color
New Jersey <sup>3</sup>	133.6 (132.2 - 135.1)	6,520	1999 - 2003	N/A	N/A
Morris County <sup>7</sup>	144.3 (138.0 - 151.0)	392	1999 - 2003	143.1 - 144.3	
Bergen County <sup>7</sup>	144.0 (139.6 - 148.6)	810	1999 - 2003	143.1 - 144.3	
Monmouth County <sup>7</sup>	143.7 (138.2 - 149.4)	515	1999 - 2003	143.1 - 144.3	
Gloucester County <sup>7</sup>	143.0 (134.2 - 152.1)	201	1999 - 2003	136.7 - 143.0	
Hunterdon County <sup>7</sup>	141.2 (128.8 - 154.8)	98	1999 - 2003	136.7 - 143.0	
Ocean County <sup>7</sup>	137.3 (131.8 - 143.1)	528	1999 - 2003	136.7 - 143.0	
Warren County <sup>7</sup>	136.6 (123.7 - 150.8)	82	1999 - 2003	135.6 - 136.6	
Cape May County <sup>7</sup>	136.0 (124.0 - 149.2)	102	1999 - 2003	135.6 - 136.6	
Mercer County <sup>7</sup>	136.0 (128.8 - 143.6)	268	1999 - 2003	135.6 - 136.6	
Sussex County <sup>7</sup>	135.7 (123.8 - 148.5)	100	1999 - 2003	135.6 - 136.6	
Somerset County <sup>7</sup>	135.5 (127.6 - 143.8)	223	1999 - 2003	131.4 - 135.5	
Burlington County <sup>7</sup>	134.0 (127.5 - 140.7)	326	1999 - 2003	131.4 - 135.5	
Union County <sup>7</sup>	133.8 (128.0 - 139.8)	408	1999 - 2003	131.4 - 135.5	
Essex County <sup>7</sup>	133.6 (128.7 - 138.6)	579	1999 - 2003	131.4 - 135.5	
Middlesex County <sup>7</sup>	131.3 (126.4 - 136.4)	541	1999 - 2003	121.7 - 131.3	
Camden County <sup>7</sup>	127.6 (121.8 - 133.7)	362	1999 - 2003	121.7 - 131.3	
Salem County <sup>7</sup>	126.5 (111.0 - 143.8)	49	1999 - 2003	121.7 - 131.3	
Atlantic County <sup>7</sup>	124.3 (116.3 - 132.7)	184	1999 - 2003	121.7 - 131.3	
Passaic County <sup>7</sup>	121.6 (115.7 - 127.7)	324	1999 - 2003	107.3 - 121.6	
Cumberland County <sup>7</sup>	111.5 (101.4 - 122.6)	89	1999 - 2003	107.3 - 121.6	
Hudson County <sup>7</sup>	107.3 (102.2 - 112.6)	338	1999 - 2003	107.3 - 121.6	

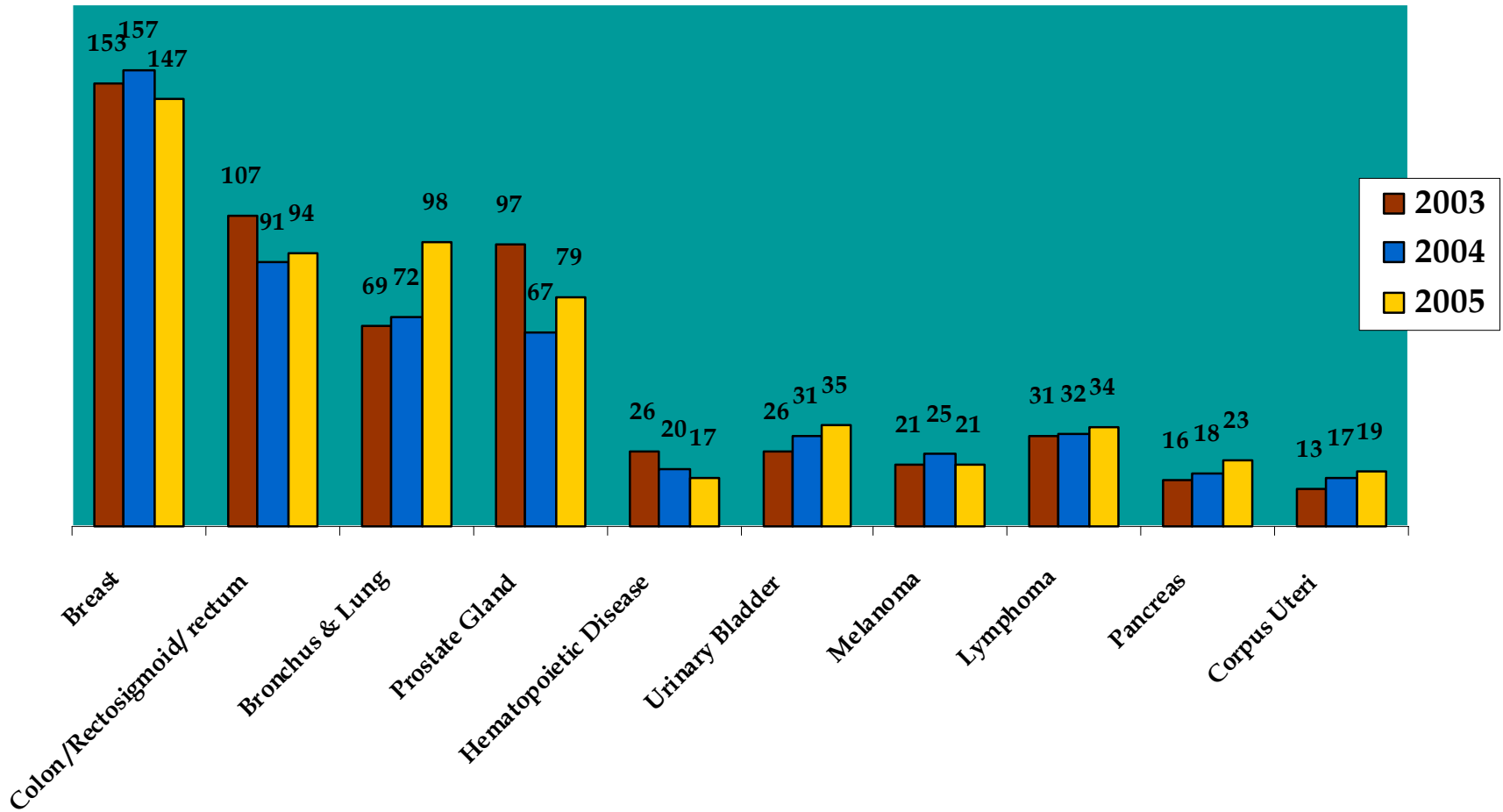
Notes:

## Newly Diagnosed and or Treated Cancer Patients Seen at CSMC



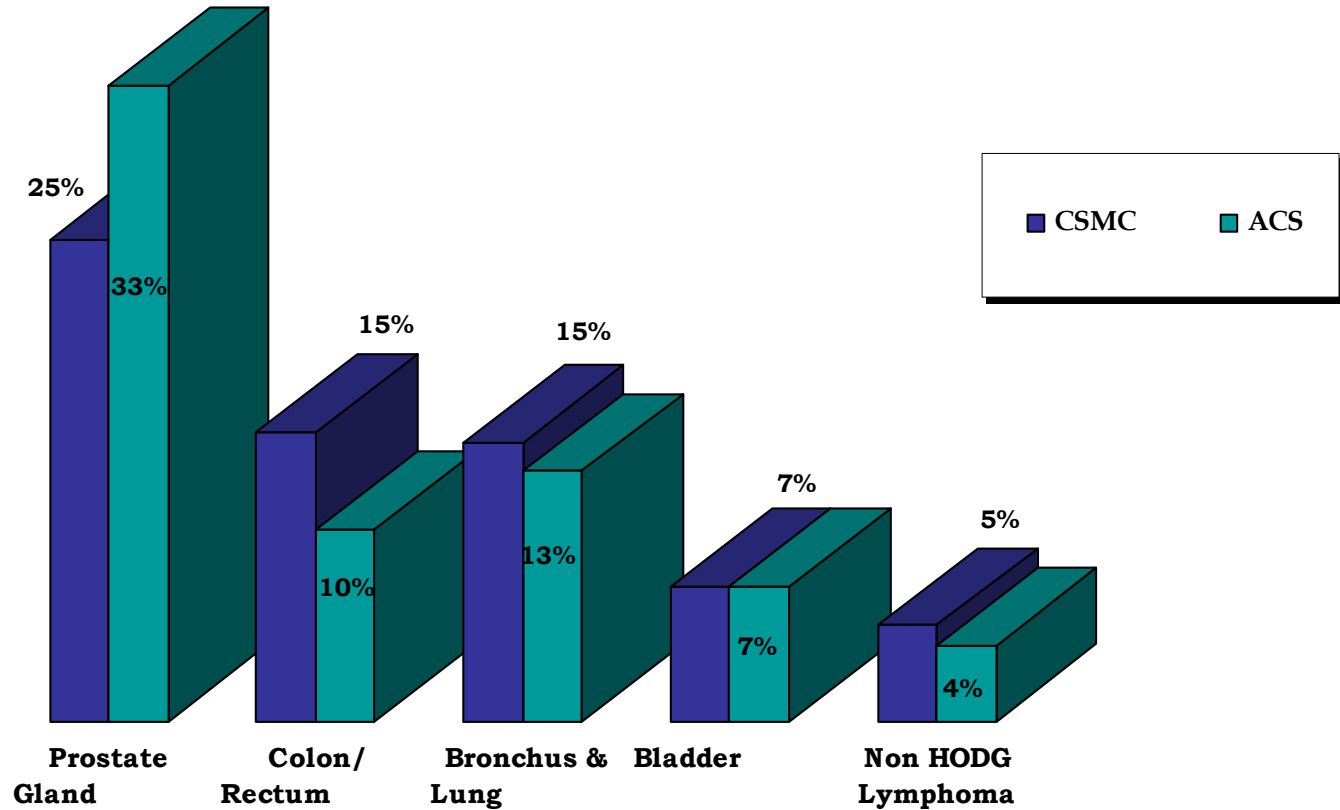
Example: 2

## Comparison of Top Ten Primary Sites Diagnosed &/or Treated at CSMC in the years 2003, 2004 & 2005



Example : 3

## COMPARISON BETWEEN TOP FIVE MALE CANCER SITES AT CSMC & ACS IN 2005



Example : 4

## Comparison Between Types of Patients

Newly diagnosed patients seen at CS	2002 Total patient = 635	2003 Total patient = 670	2004 Total patient = 659	2005 Total patient= 706
Pt did not stay with CS after CA Diagnosed	12%	11%	11%	11%
Pt stayed with CS for Dx / Rx	68%	66%	67%	67%
Pt referred to CS for part of Rx	20%	23%	22%	22%

Example ; 5

# The NEED

- In 2006 there are an estimated 7,300 Cancer Registrars nationwide and 4,272 Certified Tumor Registrars
- Expected need is 7,560 by 2010 and 8,000 in 2020.
- This shortfall does not include retiring CTR's...and the mean age is 48...

“Factors Associated with Job Satisfaction and Career Commitment for Cancer Registrars”  
Annual NCRA Educational Conference, Washington DC pp. 429-445 2006 Proceedings

# HOW DOES ONE BECOME A CANCER REGISTRAR?

Traditionally, cancer registrars were trained on the job. Today, [formal education programs](#) at colleges around the country teach cancer data management. Curricula include:

- Medical terminology, Anatomy & Physiology, Epidemiology
- Computer and information technology
- Bio-statistics
- Cancer program management
- Cancer Registry operations
- Abstracting patient records

# REQUIREMENTS TO BECOME A CTR

- Please visit <http://www.ctrexam.org/> for detailed information regarding eligibility criteria and CTR exam requirements.
- Note: The training of HIM and other allied health professionals makes them uniquely qualified to transition into the field of cancer registration with minimal additional training



# REQUIREMENTS TO BECOME A CTR

**In 2008:**

Eligibility Route 1:

- Minimum two year full-time (24 months or 3,900 hours) or equivalent experience in the Cancer Registry field and two semesters/3 quarters of college-level courses\* in Human Anatomy and/or Physiology.
- = Coursework must be completed (not audited) with a passing grade; and “college-level course” is determined as coursework eligible for college credit.



# REQUIREMENTS TO BECOME A CTR

In 2009:

## **NEW Eligibility Route 1:**

- Minimum two years full-time (24 months or 3,900 hours) or equivalent experience in the
- Cancer Registry field and the equivalent of one year (12 credits hours) of college education that includes two semesters/3 quarters of Human Anatomy and/or Physiology, one semester of Medical Science/Biology plus a college-level course in Medical Terminology.
- **= Coursework must be completed (not audited) with a passing grade; and “college-level course” is determined as coursework eligible for college credit.**



# REQUIREMENTS TO BECOME A CTR

**In 2009:**

## **Eligibility Route 2:**

- Successful completion of an NCRA-approved Cancer Information Management Associate's degree; OR successful completion of an NCRA-Accredited Formal Education Program AND successful completion of a minimum of an Associate's degree or equivalent (4 semesters/6 quarters).



# REQUIREMENTS TO BECOME A CTR

## In 2010:

- **Eligibility Route 1** will be eliminated, meaning that all candidates must apply through another route and that they have a minimum of an Associate's degree in an allied health field.



# REQUIREMENTS TO BECOME A CTR

In addition to formal college courses, training is available from programs that vary from one to two weeks in duration and provide an intensive training experience in one or more aspects of registry operations. Training courses combined with on-the-job learning remains a viable route for a career in the cancer registry profession



# The Current Path

## NCRA Accredited Programs\*

- AHIMA web-based program
- Burlington County College, NJ**
- College Ahuntsic, Montreal, QC, Canada
- Lehman College, Bronx, NY
- Minn State Community & Tech College, Moorhead, MN
- Ogeechee Tech College, Statesboro, GA
- Orange CCC, Middletown, NY
- San Jacinto College North, Houston, TX
- Santa Barbara City College-online-Santa Barbara, Ca
- Scott Community College, Bettendorf, IA
- SUNY Downstate, Brooklyn, NY
- Western Suffolk BOCES, Dix Hills, NY

<http://www.ncra-usa.org/education/formal.htm>

# The PEOPLE



- Become part of a team of dedicated, enthusiastic and self-motivated professionals
- Work closely with physicians, epidemiologists, health care experts, and administrators
- Make a difference in patient care and cancer research

# National Cancer Registrars Association (NCRA)

- NCRA is a not-for-profit association representing cancer registry professionals and Certified Tumor Registrars (CTR). NCRA's primary focus is education and certification with the goal to ensure all Cancer Registry professionals have the required knowledge to be superior in their field. Worldwide, there are over 4,500 NCRA members and nearly 4,500 CTRs.
- Cancer Registrars capture a complete summary of the history, diagnosis, treatment, & disease status for every cancer patient. Registrars' work leads to better information that is used in the management of cancer, and ultimately, cures.

# National Cancer Registrars Association (NCRA)

## •NCRA Mission Statement

Serve as the premier education, credentialing & advocacy resource for cancer data professionals.



## Oncology Registrars Association of New Jersey (ORANJ)

The **Oncology Registrars Association of New Jersey (ORANJ)** formerly known as the Tumor Registrars Association of New Jersey (TRANJ) is a non-profit professional organization that has been representing New Jersey Cancer Registrars since 1983.

The purpose of this Association is:

- To promote research and education in Cancer Registry administration and practice so that we may be of greater service to the cancer patient.
- To disseminate information to members of this Association regarding current activities, research and trends in the cancer field.
- To seek active liaison with professional and governmental organizations, which utilize data, derived from Cancer Registries.

## WEBSITES OF INTEREST:

- <http://www.ncra-usa.org>
- <http://www.seer.cancer.gov/>
- <http://www.facs.org/index.html>
- <http://www.cancer.org/>
- <http://www.ahima.org/>
- <http://oranjonline.com/>
- <http://nj.gov/health/ces/njscr.shtml>