CANCER REGISTRY

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New Jersey State Cancer Registry

OVERVIEW

- Introduction to the Cancer Registry
- Cancer Reporting Laws in New Jersey
- The CTR as a Profession
HISTORY OF CANCER DATA COLLECTION

Cancer was first described by the Greek physician Hippocrates in 400 B.C. He referred to the resection of a “karkinoma” (carcinoma) from the breast of a patient. It was more than two centuries before cancer data collection began with the creation of the “General Census of Cancer” in London in 1728.

HISTORY OF THE CANCER REGISTRY

In 1775, the English surgeon Sir Percival Pott recognized an association between soot exposure and scrotal cancer among chimney sweeps in London. He published his findings in Chirurgical Observations Relative to the Cataract, the Polypus of the Nose, the Cancer of the Scrotum, the Different Kinds of Ruptures, and the Mortification of the Toes and Feet. This was among the first documented uses of cancer data collection.
### OVER 250 YEARS OF CANCER SURVEILLANCE

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1728</td>
<td>First known cancer registry begins in London: “General Census of Cancer”</td>
</tr>
<tr>
<td>1775</td>
<td>Sir Percival Pott uses cancer registry data to identify the cause of scrotal cancer in chimney sweeps</td>
</tr>
<tr>
<td>1785</td>
<td>Factory Act establishes first mandatory reporting of diseases</td>
</tr>
<tr>
<td>1856</td>
<td>Cancer registry included in ACoS hospital approval process</td>
</tr>
<tr>
<td>1921</td>
<td>First U.S. cancer registry: bone sarcoma registry</td>
</tr>
<tr>
<td>1926</td>
<td>First hospital cancer registry (Yale, New Haven, CT)</td>
</tr>
<tr>
<td>1926</td>
<td>First hospital cancer registry (Yale, New Haven, CT)</td>
</tr>
<tr>
<td>1936</td>
<td>First central/state registries CT &amp; DE</td>
</tr>
<tr>
<td>1971</td>
<td>National Cancer Act funded first national cancer registry</td>
</tr>
<tr>
<td>1983</td>
<td>First CTR Exam offered by NCRA</td>
</tr>
<tr>
<td>2016</td>
<td>“Medical Registrar” recommended as a new Standard Occupational Classification.</td>
</tr>
<tr>
<td>2012</td>
<td>ACoS requires abstracting be done by a CTR</td>
</tr>
</tbody>
</table>

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**cancer registry** \( \text{ˈkān(t)-ər ˈrēj-ə-strē} \) *n*, *pl* -tries: An information system for the collection, management, and analysis of data on persons with the diagnosis of a malignant or neoplastic process.
WHAT IS A CANCER REGISTRY?

TYPES OF CANCER REGISTRIES

- **Hospital-based registries**
  - Collects cancer cases from a single facility or a network of facilities
- **Central/Population-based registries**
  - Usually state or regional
  - Collect cancer cases from an entire geographic region
- **Specialty registries**
  - Collect data on specific types of cancers for a specific reason
### DATA COLLECTION

- Medical record number
- Social security number
- Name
- Address
- Birthdate
- Race/ethnicity
- Sex
- Insurance
- Comorbidities
- Date of diagnosis
- Location of diagnosis
- Primary site
- Laterality
- Histology & behavior
- Grade/differentiation
- Diagnostic confirmation type
- Clinical Staging
- Pathologic staging
- Tumor size
- Tumor extension
- Number of lymph nodes removed
- Number of lymph nodes positive
- Metastatic disease
- Date & type of diagnostic procedure
- Date & type of all surgery
- Surgical margins
- Lymph node surgery
- Surgical approach
- Date & type of chemotherapy
- Date & type of radiation therapy
- Date & type of hormone therapy
- Reason for no treatment
- Palliative care
- Disease status
- Date of first recurrence
- Type of first recurrence
- Subsequent treatment
- Date of last contact
- Date of death
- Referring physician
- Surgeon
- Medical Oncologist
- Radiation Oncologist
- Following physician
- AND MANY MORE!

### WHY COLLECT CANCER DATA?

1. It’s the law
2. Improve patient outcomes
3. Identify groups at high risk of developing cancer
4. Allocate resources to prevention and early detection programs
5. Research into the causes and treatments of cancer
WHY COLLECT CANCER DATA?

HOSPITAL CANCER REGISTRY

- May be based out of a single hospital or might be part of a network or multi-facility health system.
- Collects data on all the reportable cancers that come to that facility as well as any reportable-by-agreement cases.
- Data collected comes directly from medical records at that facility.
- A registrar at one facility may contact registrars at other facilities to obtain information about a shared patient.
- Data is used to evaluate and improve patient care as well as for administrative purposes (i.e. staffing, certificate of need, etc.)
HOSPITAL CANCER REGISTRIES

- Data Sources:
  - History & physical
  - Pathology report(s)
  - Operative report
  - Medical oncology
  - Radiation oncology
  - Consults
  - All inpatient/outpatient medical records
  - Combined into a single abstract for each primary cancer diagnosis.

HOSPITAL CANCER REGISTRY

Number of FTEs

Source: NCRA Workload and Staffing Study, 2011.
PRIMARY FUNCTIONS

The primary functions of the hospital cancer registry are:

• Case identification ("casefinding")
• Abstracting identified cases
• Conducting follow-up of all abstracted cases
• Conducting quality control to ensure accuracy
• Reporting to state and other databases

OTHER FUNCTIONS

Depending on staffing levels of a hospital registry, registrars are often involved in (or in charge of) other tasks related to wider programmatic activities, including:

• Cancer conference/tumor board
• Cancer Committee
• Accreditation(s)
• Quality assurance activities/studies
• Data requests/analysis
• Research
• Annual reports
• Community outreach
CENTRAL/POPULATION-BASED REGISTRY

- Collect information on all cancers diagnosed in a particular population (usually by geographic region).
- May be statewide or regional
- Reports de-identified data to federal databases (CDC, NCI)

CENTRAL REGISTRIES
NPCR

• Established by Congress through the Cancer Registries Amendment Act in 1992
• NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the U.S. Pacific Islands, representing 96% of the U.S. population
• Biannual reporting to CDC on implementation of standards
• CDC site visit every 3-5 years

NPCR STANDARDS

I. Legislative Authority
II. Administration
III. Data Collection, Content and Format
IV. Electronic Data Exchange
V. Data Completeness/Timeliness/Quality
VI. Linkages
VII. Data Quality Assurance and Education
VIII. Data Use and Data Monitoring
IX. Data Submission
X. Collaborative Relationships
NAACCR

- “Established in 1987, NAACCR, Inc. is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in enhancing the quality and use of cancer registry data. All central cancer registries in the U.S. and Canada are members.”


NAACCR

- Publishes Cancer in North America (CiNA) annually – 4 volumes
- Certifies central registries annually to identify registries that have complete and accurate data to compute complete and accurate incidence statistics.
- Provides education and training
- NAACCR Standards (Volumes I-V)
- www.naaccr.org
SEER

- “Works to provide information on cancer statistics in an effort to reduce the burden of cancer among the U.S. population.”
- Collects incidence and survival data from 20 population-based registries covering approximately 28% of the U.S. population.
- Actively engaged in research and quality improvement.
- Develops coding manuals (SS2000, MPH), online tools (Heme Database) and training (SEER*Educate)

CENTRAL CANCER REGISTRIES

- State Health Department: 79%
- Non-State Health Department: 21%
Records from multiple sources for the same patient are matched based on identifiers (i.e., name, DOB, SSN).

Consolidation is the process of merging multiple records for the same diagnosis into a single abstract (CTC). Consolidation may be automated based on established algorithms, or conducted manually.

Automated and visual edit checks are conducted on every manually consolidated case. Auto-consolidated cases that fail edit checks are manually reviewed.

Additional facilities reporting on paper:
- NAACCR Abstract format
- HL7 format

OTHER DATA SOURCES

- Interstate Data Exchange Agreements
- Follow up data linkages
- NJ Vital Statistics
- National Death Index
- NJ Immunization Information System
- NJ Motor Vehicle Commission
- Social Security Administration
- Death clearance
- Follow back
Some of the primary functions of the central cancer registry are to:

- Consolidate cases from multiple sources
- Run central registry edits
- Abstract cases from physician offices
- Conduct death clearance activities
- Monitor reporting facilities for completeness, timeliness and accuracy
- Conduct audits of reporting facilities
- Report to national databases

Some central cancer registries may also be involved in other activities:

- Epidemiological research
- Cancer control
- Educational programs for cancer registrars
- Rapid case ascertainment for special studies
NAACCR INTERSTATE DATA EXCHANGE AGREEMENT

- Identifies cases of cancer diagnosed out of state for NJ residents.
- Obtains treatment information for NJ residents treated out of state.
- Follow-up for patients who have moved out of state.

FOLLOW-UP DATA LINKAGES

- National Death Index (NDI)
- Social Security Administration (SSA)
- NJ Immunization records (NJIS)
- Centers for Medicare & Medicaid (CMS)
- NJ Cancer Education & Early Detection (NJCEED) program
- NJ Motor Vehicle Commission (MVC)
- Indian Health Services (HIS)
DEATH CLEARANCE

“The process of matching registered deaths in a population against reportable conditions in the registry database for two purposes: (1) ascertainment of death information for persons in the registry, and (2) identification of all deaths with a reportable condition mentioned as a cause of death that are not found in the registry.”


FOLLOW BACK

• “The process of contacting a physician, abstractor or reporting facility to obtain missing information or to resolve inconsistencies in data.”
• Conducted as needed for coding clarifications and special projects.
• Conducted annually for race & treatment information.

Source: SEER*DMS User Manual, Chapter 22.
CANCER REPORTING IN NEW JERSEY

N.J.S.A. 26:2-104 et seq. (1977)

“The legislature hereby finds and declares:

- That New Jersey is currently suffering from the highest overall mortality rates for cancer in the Nation;
- That certain forms of cancer are now believed to be attributable to environmental factors which, if controlled, can significantly reduce cancer incidence in this State;
- That more complete and more precise statistical data are necessary to determine the correlations between cancer incidence and possible environmental factors and to evaluate cancer treatment and prevention measures that are currently in progress; and,
- That a cancer registry would thus provide a vital foundation for a concerted State effort to reduce the incidence of environmentally related cancer in this State.”

Source: NJ Office of Legislative Services, www.njleg.state.nj.us
N.J.S.A. 26:2-105

“The Department of Health shall establish and maintain an up-to-date registry which shall include a record of cases of cancer and specified cases of tumorous or precancerous disease that occur in New Jersey, and such information concerning these cases as it shall deem necessary and appropriate in order to conduct thorough and complete epidemiologic surveys of cancer and cancer-related diseases in this State and to apply appropriate preventive and control measures.”

Source: NJ Office of Legislative Services. www.njleg.state.nj.us

N.J.A.C. 8:57A-1.4

“Every New Jersey health care facility, physician, dentist, other health care provider and independent clinical laboratory shall report all cases of cancer and other specified tumorous and precancerous diseases to the Department in accordance with the list of reportable diseases and conditions…within six months of the date of diagnosis…”
N.J.A.C. 8:57A-1.13

“For failure of a health care facility, physician, dentist or other health care provider to report pursuant to the provisions of this chapter, up to $500 per unreported case of cancer or other specified tumorous and precancerous disease.”

NJSCR

- Approximately 55,000 cancers are diagnosed each year among NJ residents.
- From January 1, 2016 – December 31, 2016, NJSCR received 291,460 case reports.
CONSOLIDATION PROCESS

MATCHING

Existing Case

<table>
<thead>
<tr>
<th>Last</th>
<th>First</th>
<th>Middle</th>
<th>SS#</th>
<th>DOB</th>
<th>Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Simpson</td>
<td>Homer</td>
<td>J</td>
<td>999-99-9999</td>
<td>12-1-64</td>
<td>742 Evergreen Ter</td>
</tr>
</tbody>
</table>

Incoming Records

<table>
<thead>
<tr>
<th>Last</th>
<th>First</th>
<th>Middle</th>
<th>SS#</th>
<th>DOB</th>
<th>Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Simpson</td>
<td>H</td>
<td>Jay</td>
<td>123-45-6789</td>
<td>12-1-54</td>
<td>Evergreen Ter</td>
</tr>
<tr>
<td>Simpson</td>
<td>Homer</td>
<td></td>
<td>023-45-6789</td>
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<td>Green St</td>
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<tr>
<td>Simpson</td>
<td>A</td>
<td>Jay</td>
<td>999-99-9999</td>
<td>6-15-32</td>
<td>742 Evergreen Ter</td>
</tr>
<tr>
<td>Sampson</td>
<td>Homer</td>
<td>S</td>
<td>999-99-1234</td>
<td>7-12-64</td>
<td>132 Evergreen Ave</td>
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</table>
### CONSOLIDATION

<table>
<thead>
<tr>
<th>Date of Dx</th>
<th>Primary Site</th>
<th>Laterality</th>
<th>Histology</th>
<th>Reporting Facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>03-21-2014</td>
<td>Breast</td>
<td>Left</td>
<td>Invasive ductal carcinoma</td>
<td>A</td>
</tr>
<tr>
<td>04-16-2014</td>
<td>Axillary lymph node</td>
<td>N/A</td>
<td>Ductal carcinoma</td>
<td>C</td>
</tr>
<tr>
<td>03-19-2014</td>
<td>Breast</td>
<td>Unknown</td>
<td>Carcinoma, NOS</td>
<td>B</td>
</tr>
<tr>
<td>08-02-2004</td>
<td>Breast</td>
<td>Left</td>
<td>Ductal carcinoma</td>
<td>A</td>
</tr>
<tr>
<td>03-21-2014</td>
<td>Breast</td>
<td>Right</td>
<td>Invasive ductal carcinoma</td>
<td>A</td>
</tr>
</tbody>
</table>

### CONSOLIDATION

<table>
<thead>
<tr>
<th>Date of Dx</th>
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<th>Histology</th>
<th>Stage</th>
<th>Reporting Facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>03-21-2014</td>
<td>Breast</td>
<td>Left</td>
<td>Invasive ductal carcinoma</td>
<td>T1 N0 M0</td>
<td>A</td>
</tr>
<tr>
<td>03-19-2014</td>
<td>Breast</td>
<td>Unknown</td>
<td>Carcinoma, NOS</td>
<td>T2 Nx M0</td>
<td>B</td>
</tr>
<tr>
<td>04-01-2014</td>
<td>Breast</td>
<td>Left</td>
<td>Invasive ductal carcinoma</td>
<td>T1 N2 M1</td>
<td>C</td>
</tr>
</tbody>
</table>
RESEARCH

- Patient Contact Studies
- Data Linkages
- Surveillance
- Secondary Data Analysis
- Data Requests
- Cancer Control & Prevention

NJSCR RESEARCH

OUR 2015-2016 STUDIES COVER 13 CANCER TYPES OVER 8 STUDIES...

- Medullary Thyroid
- Osteosarcoma
- Oral & Pharyngeal
- Ovarian
- Peritoneal
- Fallopian Tube
- Prostate
- Breast
- Colorectal
- Cervical
- Liver
- Childhood
- Melanoma
OTHER OPERATIONS

• Meaningful Use reporting
• Medical oncology claims data
• Steering committee
• Cancer cluster investigations
• Collaboration with cancer control programs

NJSCR RECOGNITION

• NPCR Registry of Distinction
• NAACCR Gold Certification
• SEER 1st Place Recognition
HOW TO REPORT TO NJSCR

- Web Plus
  - Free, secure web-based application developed by the CDC for physician offices, ambulatory care center and radiation treatment facilities.
  - Go to http://www.nj.gov/health/ces/reporting-entities/non-hospital/ for more information and to register.

- Meaningful Use*
  - NJSCR is currently accepting MU Stage 2 and Stage 3 data.
  - Go to http://www.nj.gov/health/meaningfuluse/cancer.shtml for more information and to register.

*Meaningful Use reporting does not currently satisfy cancer reporting requirements under New Jersey state law.

WHAT IS A CTR?
WHAT IS A CANCER REGISTRAR?

- “Date information specialists that capture a complete history, diagnosis, treatment, and health status for every cancer patient in the U.S.”
- “Work closely with physicians, administrators, researchers, and healthcare planners to provide support for cancer program development, ensure compliance of reporting standards, and serve as a valuable resource for cancer information with the ultimate goal of preventing and controlling cancer.”

-NCRA, The Cancer Registry and the Registrar Fact Sheet

WHAT IS A CERTIFIED TUMOR REGISTRAR

- Highly-trained information specialist
- Demonstrated (by passing certification exam) the level of experience and technical knowledge required for effective cancer data management.
- Recognized by NCRA.
<table>
<thead>
<tr>
<th>WHERE DO CANCER REGISTRARS WORK?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hospital cancer registries</td>
</tr>
<tr>
<td>• Central/population-based cancer registries (i.e. state health departments)</td>
</tr>
<tr>
<td>• Public health agencies (i.e. CDC)</td>
</tr>
<tr>
<td>• Accrediting bodies (i.e. Commission on Cancer)</td>
</tr>
<tr>
<td>• Cancer Registry Software Vendors</td>
</tr>
<tr>
<td>• Research institutions</td>
</tr>
<tr>
<td>• International agencies (i.e. NAACCR)</td>
</tr>
<tr>
<td>• Independent consulting companies</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AS A CANCER REGISTRAR, WHAT WILL I DO?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• <strong>Abstracting</strong> – consolidating and coding all demographic, diagnostic, treatment and outcomes information into a single record housed within the registry database.</td>
</tr>
<tr>
<td>• <strong>Casefinding</strong> – the process of identifying reportable cancer cases from medical records systems (there are usually multiple casefinding sources).</td>
</tr>
<tr>
<td>• <strong>Follow-up</strong> – patients are following throughout their lifetime for disease status and recurrence information.</td>
</tr>
<tr>
<td>• <strong>Reporting</strong> – cancer registrars regularly report data to the central registry and other national databases (i.e. NCDB).</td>
</tr>
<tr>
<td>• <strong>Cancer conferences</strong> – usually held weekly, these are multidisciplinary meetings where treatment decisions are made.</td>
</tr>
<tr>
<td>• <strong>Cancer committee</strong> – the leadership body of the cancer program. The cancer registrar may be responsible for preparing data for the meeting and often works closely with members of the committee.</td>
</tr>
<tr>
<td>• <strong>Quality Assurance</strong> – activities conducted to ensure abstracting is complete and accurate.</td>
</tr>
<tr>
<td>• <strong>Research</strong> – cancer registry data is used to answer questions about the causes of cancer as well as the effective of treatments on patient outcomes.</td>
</tr>
</tbody>
</table>
HOW MUCH DO CANCER REGISTRARS MAKE?

<table>
<thead>
<tr>
<th>Employer Type</th>
<th>Mean Hourly Wage</th>
<th>Mean Annual Salary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>$23.05</td>
<td>$63,099</td>
</tr>
<tr>
<td>Federal/State/Other</td>
<td>$24.82</td>
<td>$59,794</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years in Field</th>
<th>Mean Hourly Wage</th>
<th>Mean Annual Salary</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 or fewer</td>
<td>$19.50</td>
<td>$53,299</td>
</tr>
<tr>
<td>6 to 10</td>
<td>$23.38</td>
<td>$56,559</td>
</tr>
<tr>
<td>11 to 20</td>
<td>$25.61</td>
<td>$61,251</td>
</tr>
<tr>
<td>21 or more</td>
<td>$30.07</td>
<td>$70,339</td>
</tr>
</tbody>
</table>


WHAT ABOUT THE LONG-TERM?

More cancer = More cancer registrars needed

- As the U.S. population grows, the number of new cancer cases diagnosed (and abstracted by CTRs) each year grows.
- Age is the #1 risk factor for developing cancer.
- As the population ages, the number of new cancer cases will increase at an even faster rate.
“BABY BOOMERS”

- According to the ACS, 77% of all cancers occur in people age 55 and older.

What about the long term?

- 30% of NJ Cancer Registrars are over the age of 55.
- In the U.S., >60% of cancer registrars are 50+.
- Only 16% of NJ Cancer Registrars are under the age of 45 — these are the future!
- Nationwide 14% of Cancer Registrars are under age 40.

Source: 2012 NCRA Salary Survey
WHY SHOULD I BECOME A CTR?

Commission on Cancer Standard 5.1:

Beginning January 1, 2012, all cancer registry staff who perform case abstracting at a CoC-accredited program must either:

- Hold a current CTR credential…
- Work under the supervision of a CTR and pass the CTR exam by January 2015 (existing employees)
- Pass the CTR exam within 3 years of hire date (new employees)

WHY SHOULD I BECOME A CTR?

Source: 2012 NCRA Salary Survey

Mean Annual Salary of CTRs and Non-CTRs in the Cancer Registry Field

Source: 2012 NCRA Salary Survey
HOW DO I BECOME A CTR?

FOR MORE INFORMATION

- New Jersey State Cancer Registry [www.nj.gov/health.ces](http://www.nj.gov/health.ces)
- National Cancer Registrars Association [www.ncra-usa.org](http://www.ncra-usa.org)
- Council on Certification [www.ctrexam.org](http://www.ctrexam.org)
- Oncology Registrars Association of New Jersey [www.oranjonline.com](http://www.oranjonline.com)
- Surveillance, Epidemiology and End Results (SEER) Program [https://seer.cancer.gov](https://seer.cancer.gov)
THANK YOU!

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New Jersey State Cancer Registry
Stephanie.hill@doh.nj.gov

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Meaningful User: njscr.muz@doh.nj.gov