The Cancer Registry and the Registrar

Cancer registrars ensure that timely, accurate, and complete data are maintained on all types of cancer diagnosed and/or treated within a health care institution or within a defined population. These data are then used to inform a wide variety of public health decisions and provide rich information for cancer diagnosis and treatment education.

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:

- Healthcare institution registries maintain data on all patients diagnosed and/or treated for cancer at their facility. Healthcare facilities report cancer cases to the central or state cancer registry as required by law.
- Central registries are population-based registries that maintain data on all cancer patients within certain geographical areas.
- Special purpose registries maintain data on a particular type of cancer, such as brain tumors.

Why maintain a cancer registry?
Maintaining a cancer registry ensures that health officials have accurate and timely information, while ensuring the availability of data for treatment, research, and educational purposes:

- Local, state, and national cancer agencies use registry data in defined areas to make important public health decisions that maximize the effectiveness of limited public health funds, such as the placement of screening programs.
- Cancer registries are valuable research tools for those interested in the etiology, diagnosis, and treatment of cancer.
- Fundamental research on the epidemiology of cancer is initiated using the accumulated data.
- Lifetime follow-up is an important aspect of the cancer registry. Current patient follow-up serves as a reminder to physicians and patients to schedule regular clinical examinations and provides accurate survival information.

What information is maintained in the cancer registry and how is it used?
Cancer registries maintain a wide range of demographic and medical information, such as:

- Demographic information includes age, gender, race/ethnicity, birthplace, and residence.
- Medical history includes physical findings, screening information, occupation, and any history of a previous cancer.

Cancer Registry Timeline

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tr>
<td>1926</td>
<td>First hospital registry at Yale-New Haven Hospital in New Haven, CT.</td>
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<tr>
<td>1935</td>
<td>First central cancer registry established in Connecticut.</td>
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<td>1956</td>
<td>American College of Surgeons requires a cancer registry for approved cancer programs.</td>
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<td>1971</td>
<td>National Cancer Act budgets monies to the National Cancer Institute for research, detection and treatment of cancer.</td>
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<td>1973</td>
<td>Surveillance, Epidemiology and End Results (SEER) Program of NCI establishes the first national Cancer Registry.</td>
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<tr>
<td>1974</td>
<td>National Cancer Registrars Association (NCRA) established.</td>
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<tr>
<td>1993</td>
<td>State laws make cancer a reportable disease.</td>
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Diagnostic findings include types, dates, and results of procedures used to diagnose cancer.
Cancer information, including primary site, cell type, and extent of disease.
Cancer therapy, including surgery, radiation therapy, chemotherapy, hormone, or immunotherapy.
Follow-up, including annual information about treatment, recurrence, and patient status.

Public health and medical providers utilize these data in a wide variety of ways. Specifically, they are used to:

- Evaluate patient outcome, quality of life, and satisfaction issues and implement procedures for improvement.
- Provide follow-up information for cancer surveillance.
- Calculate survival rates by utilizing various data items and factors.
- Provide information for cancer program activities.
- Analyze referral patterns.
- Allocate resources at the health care facility, the community, region or state level.
- 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

How do cancer registries ensure confidentiality?
Confidentiality of patient identifying information and related medical data is strictly maintained at each cancer registry. Aggregate data are analyzed and published without any patient identifiers.

What is a cancer registrar?
Cancer registrars are data information specialists that capture a complete history, diagnosis, treatment, and health status for every cancer patient in the U.S. The data provide essential information to researchers, healthcare providers, and public health officials to better monitor and advance cancer treatments, conduct research, and improve cancer prevention and screening programs. Registrars 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.

How does one become a cancer registrar?
Traditionally, cancer registrars were trained on the job. Today, formal education programs at community colleges around the country teach cancer data management. Several of these programs are available online. NCRA also offers an online certificate program in cancer registry management through the American Health Information Management Association (AHIMA). Curricula include: cancer and its management, medical terminology, anatomy and physiology, biostatistics and epidemiology, cancer data abstracting, database record management, cancer program management, cancer registry procedures, among others.

How does one become certified as a cancer registrar?
The National Cancer Registrars Association’s Council on Certification administers an examination for those eligible to be Certified Tumor Registrars (CTR®). Candidates must meet eligibility requirements that include a combination of experience in the cancer registry field and educational background. After successfully passing the certification examination, the CTR credential is awarded. Persons who have successfully completed the certification exam have demonstrated that they have met or exceeded the standard level of experience and technical knowledge required for effective cancer data management. To maintain a certified status, continuing education requirements must be met.