Quality Cancer Data Saves Lives

The Vital Role of Cancer Registrars in the Fight against Cancer
Between 1990 and 2004 more than 16 million Americans were diagnosed with cancer.
The American Cancer Society estimates that approximately 1.4 million new cases of cancer were diagnosed in 2004 alone.
Virtually everyday, there is news about the efficacy of cancer drugs or reports on increased incidence of certain types of cancer or better than expected survival rates.
The current 5-year survival rate for all cancers combined is 62%. These are just a few examples of the information about cancer widely available today. This information exists and is accessible as a direct result of the work of thousands of Cancer Registries and Cancer Registrars in the United States. The information produced by Cancer Registries and Cancer Registrars form the foundation for cancer-related research, treatment advances, and prevention efforts.
Cancer Registries collect cancer information which is used in thousands of ways–including:

- producing statistics on cancer incidence and survival rates,
- improving patient care, and
- developing innovative public health initiatives, such as cancer screening programs.
Cancer Registry information in the United States is complex and changing. Diagnostic trends, treatment options, and survival rates change constantly. Readily available information from Cancer Registries allows health care providers and public health officials to make informed decisions about patient care and public health initiatives.
The ultimate goal of collecting cancer information is to prevent and control cancer and improve patient care.
Result

Assist physicians in assessing the efficacy of diagnostic and therapeutic methods

This goal is achieved by providing evidence-based information to physicians that is used to assess the efficacy of varying diagnostic and therapeutic methods and options and to plan, review, and update standards of care.
Information collected by Cancer Registries is also valuable to public health officials, policy makers, and administrators in making critical decisions about reaching populations in need of care, allocating health care resources, providing adequate staffing to care for cancer patients, and planning health care initiatives.
Cancer data collected on a local or regional basis allows those working in local health care settings to manage the flow of patients and ensure that adequate resources are available. Local health care providers also use this data to take advantage of business and fundraising opportunities, which often result in increased or better capacity for care.
Cancer Registries collect a wide range of cancer-related information; including —

- Demographics

Preventing and controlling cancer plus improving patient care begin with collecting and reporting various data beginning with basic demographic information. This enables evaluation of site/gender/age and geographic location.
Medical History:
Cancer Registries collect information on each patient’s medical histories to record risk factors and co-morbid conditions which may contribute to the development of cancer and the outcome of treatment.

Diagnosis and prognosis indicators:
Details about a patient’s cancer diagnosis, including type, anatomic location, and stage or extent of disease, are recorded using national and international coding standards.

Treatment Patterns:
Analysis of information about treatment, collected by Cancer Registries helps determine which treatment patterns are the most effective.

Cancer Recurrence:
Through annual follow-up of vital and cancer status with patients and physicians, Cancer Registries may track cancer recurrence and subsequent cancers in the same patient and calculate survival rates.

Healthcare Coverage:
Cancer Registries may track information about patients’ health care coverage and utilization of services, providing useful information to health care planners and administrators.

Patient Eligibility:
Some Cancer Registries also record the eligibility and participation of patients in various clinical trials.

As you can see, data from Cancer Registries are more than just numbers.
Different Kinds of Cancer Registries
In the United States, detailed cancer information is collected at health care facilities, such as doctors’ offices, hospitals, and clinics. The data are then compiled, and reported to central state or regional registries. The data are sent by the central registry to one or both national registries. The national population-based registries are the Surveillance, Epidemiology, and End Results Program (SEER) at the National Cancer Institute and the National Program of Cancer Registries (NPCR) at the Centers for Disease Control and Prevention. The information collected is available to the public through the publication of regular reports. The data are also made available to researchers, educators, and care providers for detailed analysis of cancer trends and development of treatment initiatives.
A hospital registry is the monitor of the cancer program at a particular health care facility. All patients diagnosed or treated at the hospital are entered into the Cancer Registry data base. The data are used to improve patient care by assessing patterns of care and outcomes relative to national norms. Registry data allows the hospital to measure their quality of care for continuing improvement. The data are aggregated with state and national data, and is used to educate staff and determine resource allocation.
A state Cancer Registry monitors cancer within the state’s boundaries. All health care facilities are mandated by legislative statute to report all cancer cases to the state Central Cancer Registry. State registries are population-based cancer registries that track the incidence and mortality of cancer within the population at risk or the state’s population.

State registry data focuses on public health rather than individual patients. The data are used for research, suspected cancer cluster investigations, public health programs, and of course state resource allocation, cancer control planning, and education.

Because state registries receive cases from all facilities in the state, a patient may be reported from more than one facility. For example, a patient may receive surgery at one facility and radiation therapy at another. Both facilities would report their information to the central cancer registry. To be able to have an accurate count of new cancer patients and new cancers, this information needs to be linked. To have the most complete information on each patient, the state registry merges or combines information from all reports that are identified as being for the same patient and for the same cancer. If a new cancer is diagnosed for a previous patient, a new cancer record is linked to that person. If there is any conflicting information reported, such as a different race or sex, the central registry contacts the reporting facilities to determine the correct information. In addition to the individual reports from the facilities, the central registry creates a consolidated record that contains the most complete and accurate data for that patient from all reporting sources.
Health care facilities that are accredited by the American College of Surgeons (ACoS) Commission on Cancer are required to submit their data to the ACoS’s National Cancer Data Base in addition to the central or regional population-based databases or registries. The NCDB is a multi-hospital database that monitors cancer care in ACoS Approved Cancer Programs. The information collected is available to the participating health care facilities for comparisons of care studies and other quality improvement initiatives. The NCDB is a nationwide oncology outcomes database and has provided the basis for many patterns of care studies.
The National Cancer Institute’s SEER Program is a national population-based cancer registry that monitors a representative sampling of certain geographic areas or about 26% of the U.S. population. The data are used to determine representative national cancer incidence, mortality, and survival rates. The SEER Program is also a data standard setting organization for cancer registries.

SEER data currently comes from the states of California, Connecticut, Iowa, Kentucky, Louisiana, New Jersey, New Mexico, Utah, and Hawaii and the metropolitan areas of Atlanta, Detroit, Los Angeles, San Francisco-Oakland, San Jose-Monterey, and Seattle-Puget Sound. Three supplemental registries provide information from 10 predominantly black rural counties in Georgia, American Indians residing in Arizona, and Alaska Native populations residing in Alaska representing 26% of the population.
The National Vital Statistics System (NVSS) is part of the National Center for Health Statistics (NCHS). NVSS provides the nation’s official vital statistics data based on the collection and registration of birth and death events at the state and local level. These data are provided through contracts between NCHS and vital registration systems operated in the all 50 States which have the legal authority for the registration of these events. The states are responsible for maintaining registries of vital events and for issuing copies of birth, marriage, divorce, and death certificates.
The Centers for Disease Control’s National Program of Cancer Registries (NPCR) provides funds and technical assistance to improve cancer registration throughout the United States. NPCR is also a data standard setting organization for cancer registries.

The NCPR is also an example of a population-based national Cancer Registry. State central cancer registries funded by NPCR submit their data to the NPCR database. The database that is maintained by NPCR is used to monitor the burden of cancer for the nation. Data are provided for research, evaluation of cancer control activities and to plan for future healthcare needs.
The CDC has administered the NPCR since 1995.

Before NPCR was established, 10 states had no registry and registries in other states were under funded. Also, there was a lack of national standards. With appropriations of approximately $50 million in fiscal year 2004, today NPCR supports central registries and promotes the use of registry data in 45 states, the District of Columbia, and the territories of Puerto Rico, the Republic of Palau, and the Virgin Islands and covers 96% of the US population.
NPCR is expanding efforts to improve and use cancer data by:

Providing technical assistance to registries to help ensure data completeness, timeliness, and quality.
Coordinating and convening meetings of registry personnel for information sharing, problem solving, and training.
Helping states and national organizations use cancer data to describe state and national disease burdens, evaluate cancer control activities, and identify populations at risk for certain cancers.

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Collaborating with federal, state, and private organizations to design and conduct research using data collected through state registries.

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CDC has established national standards to ensure the completeness, timeliness, and quality of Cancer Registry data. CDC urges central Cancer Registries to incorporate standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR). In 1997, NAACCR instituted a program that annually reviews member registries’ abilities to produce complete, accurate, and timely data. Registries that meet the highest standards receive NAACCR certification.
This map shows those NPCR and SEER state cancer registries that met the NAACCR certification standards for completeness, quality, and timeliness in 2004 based on data from 2001. Significant progress has been made since 1997 when Certification was 1st offered by NAACCR. In 1997, only 14 states achieved certification. By 1999 that number increased to 33, by 2000 37 states were certified and in 2004, 39 states were certified.
The International Association of Cancer Registries (IACR) was founded in 1966, as a professional society dedicated to fostering the aims and activities of cancer registries worldwide. It is primarily for population-based registries, which collect information on the occurrence and outcome of cancer in defined population groups (usually the inhabitants of a city, region, or country). The Association was created to foster the exchange of information between cancer registries internationally, so improving quality of data and comparability between registries. The Association is a non-governmental organization that has been in official relations with the World Health Organization since January 1979. IACR publishes *Cancer in Five Continents*. 
How Registries Collect Cancer Data
The techniques used by Cancer Registrars allows for uniform data collection

What is it that a Cancer Registrar actually collects? While we have talked generally about the kinds of information collected by Cancer Registrars, we have not looked at the techniques and language used in Cancer Registries.
The language of the Cancer Registrar is a series of codes that are uniform throughout the United States. The codes are developed by organizations known as standard setting organizations. These include NPCR, SEER, the North American Association of Central Cancer Registries (NAACCR), the World Health Organization (WHO), American Association of Cancer Research (AACR), the Systematized Nomenclature of Medicine (SNOMED) and the American College of Surgeons Commission on Cancer, (ACoS COC.)
There are three sections of each patient’s summary information or abstract that must be coded separately. Each section has from 3-15 fields that require accurate coding using national and international data standards. Each part of the body where cancer may occur has its own codes. Consequently, Cancer Registrars often have five to six reference books that they use to code each patient and each disease. In addition, Cancer Registrars make use of the Internet to research those difficult cases that require additional information in order to correctly capture the cancer information.
Cancer Registrars convert written words from a patient’s medical record to a series of codes. This activity is called “abstracting” and is a key component of a cancer data collection.
You can see the two data sources contain similar information; they differ in how the data are recorded. Why use codes instead of the written word? The act of using codes as opposed to the written word allows for data to be retrieved and compared electronically to track trends and outcomes.
Cancer Registries have embraced technology

A Cancer Registrar used to work with pen and paper in all coding. But like much of the medical field a Cancer Registrar’s job is now high tech with databases and software used to record the abstracted information thus more easily allowing the registry data to become part of the nation’s health monitoring system.
As mentioned previously, Cancer Registries exist within a national framework of health monitoring and data collection. The National Center for Health Statistics, part of the CDC, collects and manages national data on the health of Americans. In addition to Cancer Registries, national health information about HIV/AIDS, STDs, tuberculosis, other infectious diseases, workplace injuries, and those caused by exposure to toxic substances. Also every state and the U.S. territories collect vital records that track births, deaths, fetal deaths, marriages, divorces, and adoptions.
History of Cancer Information
This is one of seven papyri relating the earliest known descriptions of cancer. The seven papyri, discovered and deciphered late in the nineteenth century, provided the first direct knowledge of Egyptian medical practice. Two of them, known as the Edwin Smith and George Ebers papyri, contain descriptions of cancer written about 1600 B.C., and are believed to date from sources as early as 2500 B.C. The Smith papyrus describes surgery, and Ebers' outlines pharmacological, mechanical, and magical treatments.
A more recent history of Cancer Registries dates back almost four centuries. Cancer was first recorded as a cause of death in 1629 in England in the Bills of Mortality in 1629. The first systemized collection of information on cancer was in 1728 in London. In 1839 the implementation of death registration in the United States began. In 1842, an Italian physician surveyed the entire population of his hometown, Verona, to determine the prevalence of certain diseases, including cancer. Based upon his surveys, he reported notable differences in the rates of certain types of cancer in nuns and married women.
The Cancer Campaign Committee of the Congress of North American Surgeons in 1913 launched the first project in the United States, which successfully demonstrated the use of data collection methods to monitor and evaluate patterns of outcome of cervical cancer treatment. A decade later in 1923, the first Cancer Registry was launched in the United States—a bone sarcoma registry, followed in 1925 by registries for cancers of the breast, mouth, tongue, colon, and thyroid.
The American College of Surgeons Commission on Cancer initiated clinical surveys in 1930 and began approving cancer clinics. Though they were not required, most clinics initiated some form of cancer data collection. One of the first central state registries began in 1932 in Connecticut. In 1956, the Commission on Cancer required all approved cancer programs (located primarily in hospitals) to have registries.
In 1971 the National Cancer Act established the National Cancer Institute’s Surveillance, Epidemiology, and End Results Program (SEER). The first Population-based cancer registration officially began in 1974.
That same year, the National Cancer Registrars Association (NCRA) was chartered as the National Tumor Registrars Association. In 1983, NCRA began administering the certification examination of Cancer Registrars. In its first year, more than 350 professionals were awarded the CTR (Certified Tumor Registrar) credential.
The North American Association of Central Cancer Registries (NAACCR) was established in 1990 to set standards for data collection and reporting. NAACCR today certifies central registries in the United States and Canada. NAACCR annually publishes data that is voluntarily submitted from member central cancer registries in *Cancer in North America*.
The 1992 Cancer Registries Amendment Act created the National Program of Cancer Registries and authorized the CDC to enhance centralized cancer operations in all states and establish Cancer Registries in the 10 states where they did not previously exist.

In 1996, the ACoS CoC required health care facilities to submit data to the National Cancer Data Base.
Earlier, we looked at how information is transferred from a patient’s medical record into the Cancer Registry system. Now, let’s see how cancer information moves from diagnosis at the local level to become part of national cancer data.
Diagnosis to treatment

Jane Smith learns from her internist that she likely has breast cancer.

After feeling a lump in her breast during a breast self-exam, Jane Smith goes to her doctor who refers her for mammography. A few days later, Jane learns she likely has breast cancer. Her doctor gives her basic information about this diagnosis and refers her to a surgeon.
At a Detroit, Michigan hospital, Jane’s surgeon orders an ultrasound, blood tests, and a needle biopsy to determine the cell type of the lump found on her mammogram. The tests results prove conclusively that she has breast cancer.

Jane’s reports, along with the reports of her physician’s other patients, are sent to the hospital’s Cancer Registry. Those reports are sorted by the Cancer Registrar to determine which reports contain “reportable” information, such as Jane’s. Non-reportable cases might include lumps deemed to be benign cysts. The Cancer Registrar determines if Jane is already in the hospital’s registry. Because she is not, a new record or patient set is added to the registry database. That record includes Jane’s demographic information, her cancer diagnosis, and diagnostic services.
Jane doctor proposes a course of treatment, including a lumpectomy, radiation, and systemic therapy. She meets with a surgeon who schedules her lumpectomy, which is completed at the hospital in about three weeks. It is determined that Jane has Stage I breast cancer. She then begins a six-week course of radiation therapy, which takes place at a local cancer clinic. The oncologist meets with Jane to discuss systemic therapy and together they decide on hormonal treatment. Tamoxifen is prescribed.

The Cancer Registrar at the hospital examines Jane’s medical file to determine where she is being treated and what treatments she is receiving. The Cancer Registrar may have to contact the oncologist or surgeon to ascertain where Jane is receiving her radiation and any other treatment if the information isn’t mentioned in her chart. She then contacts each treatment source to gather complete information about Jane’s course of treatment, which is entered into Jane’s Cancer Registry record.
Her initial course of treatment now complete, Jane returns to her oncologist who orders a second mammogram and additional blood tests to see if her treatment has been successful. She learns several days later that she is now cancer free, but is to continue taking the Tamoxifen and seeing her oncologist every six months.

Jane’s record is chosen for a quality assurance audit by the Cancer Registry supervisor. The information in the Cancer Registry file is compared to the hospital’s medical record and additional information gathered from outside of the facility. After the audit review, it is noted that the data has all been coded correctly following the correct standards. Because no problems are found, Jane’s record is finalized and sent to SEER registry in Detroit, and the state NPCR registry for Michigan. Because the hospital is an ACoS approved cancer program, Jane’s data will also be sent to the National Cancer Data Base.
Diagnosis to treatment

- Jane’s data are added to other SEER and Michigan central Cancer Registry data, and the National Cancer Data Base, where it will go through more quality processes and refinement.

Because Detroit is part of SEER, Jane’s data are included in the SEER registry in Detroit, the Michigan central registry, and the NCDB where they will go through the computerized edit process and visual review. If other reports about Jane’s breast cancer from other facilities are also forwarded to these central cancer registries, they will be reconciled into one case with the most complete information. If there are data inconsistencies identified, the central registry would then return data to the hospital registry or ask for additional information. Once any outstanding issues are resolved, Jane’s data will be aggregated with other data from Michigan and ultimately with national data in the NCDB and at both SEER and NPCR.
Back in Jane’s hometown, the local Cancer Registrar will send a letter to Jane’s oncologist annually requesting information to update her disease and vital status in the Cancer Registry database. These follow-up letters are the basis for survival rates and disease recurrence rates and are unique to the cancer surveillance world. Patients are followed for a lifetime, thus providing accurate survival, recurrence, and outcomes information. In addition, the Cancer Registry’s follow-up letters often act as a prompt to the physician and the patient that it is time for a checkup.
Cancer Information is Used to Improve Prevention, Research, and Care
Cancer information is used in thousands of ways, including evaluating patient outcome, quality of life, and satisfaction issues, as well as, implementing procedures for improvement. By analyzing the effectiveness of multiple treatments, successful treatment plans can be developed for each patient.
Cancer information is also used to evaluate the efficacy of treatment modalities.
Cancer incidence data also provides cancer burden information for cancer surveillance and is used for comprehensive cancer control planning. Cancer data alerts public health officials to trends within communities and potentially dangerous environmental or workplace conditions.
Cancer data are used to report cancer incidence as required by state and federal laws.
### Trends in Five-Year Relative Survival Rates

**Trends in Five-Year Relative Survival Rates (%) by Race and Year of Diagnosis, US, 1974-1999**

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*Cancer rates are adjusted for normal life expectancy and are based on cases diagnosed between 1974-1976, 1983-1985, and 1992.*

**Trends in Five-Year Relative Survival Rates**

They are used to calculate survival rates by various data items, such as sex, race, and age.
Cancer data provide information for cancer prevention activities, such as smoking cessation programs. Accurate cancer data also allow public health experts to effectively target outreach efforts to impact affect behavior and increase early screening for certain types of cancers, such as colorectal cancer.
Cancer data can also provide information for referral pattern analysis.
Local, state, and national resource allocation is another use for cancer data. Examples of this include new locations for radiation therapy centers or new cancer screening programs.
Data can be used to develop educational programs for health care providers, patients, and the general public.
All over America, and in your community, Cancer Registrars are working to gather information from every cancer patient on all aspects of their disease. As each patient’s data becomes combined with that from other patients, and from other communities, the entire medical community can better understand more about cancer. Here are examples of how the work of Cancer Registrars has directly helped in the fight against cancer.
In the early 1990s statewide Cancer Registry data were used to identify areas of the state that had high rates of late-stage and low rates of early-stage breast cancer. As a result, Kentucky expanded mammography outreach activities in these communities. By 1996, the percentage of Kentucky women diagnosed with late-stage breast cancer had declined from 35% to 30%. By detecting these cancers early, thousands of lives were spared and an estimated $4.7 million in treatment expenditures was saved.
Arizona Cancer Registry data on the stage of cancer at diagnosis were coded and analyzed by zip code, whereby the northeastern part of the state was found to have the highest percentage of breast cancer cases diagnosed at a late stage — 42% compared to the state average of 30%. Using data from its Statewide Cancer Registry to identify areas with the highest levels of late-stage breast cancer, additional outreach efforts encouraging breast cancer screening were planned.
In Minnesota, a rare type cancer caused by asbestos exposure was identified, leading the state to look for increased state funding for occupational-related disease.

Statewide Cancer Registry Data showed a persistent excess of a rare cancer, mesothelioma, in northeastern Minnesota. This rare type of cancer has only one known cause — asbestos exposure. This revealing observation resulted in legislative funding for investigations to look for cases of other occupation-related disease.
Kansas

Cancer registry data identified a lack of cancer care facilities

Using Statewide Cancer Registry data that examined cancer care in various communities, hospital administrators and physicians concluded that people in certain locations lacked access to radiation treatment centers and clinics. Statewide Cancer Registry data were able to pinpoint communities needing cancer care facilities and as a result, new facilities were opened in some of those areas.
Cancer registry data are now used to educate New Yorkers about cancer risk factors.

Cancer incidence data were collected locally and sorted by zip code. Employing data from the statewide Cancer Registry and state-of-the-art mapping techniques, they were able to show the distribution of cancer risk factors and develop targeted Statewide public education programs.
Cancer Registrars Ensure Accuracy and Privacy

Cancer Registrars and the information they produce are essential to modern-day medicine—ensuring that patients receive accurate diagnoses, treatment, and prevention information. Cancer Registrars work diligently to ensure that the information they collect is accurate and meaningful, and that the privacy of a patient’s medical information will be assured.
Inaccurate data are useless, expensive, and often harmful

As the data collected by Cancer Registrars grow in volume and complexity, the need for accuracy significantly increases. As an example, errors in coding types of cancer, stages of disease, or even race and sex can lead researchers and public health officials to make incorrect assumptions on why cancer rates may be increasing in specific populations. As a result, resources might be allocated unwisely and public health campaigns targeted to the wrong population.
Of course, because local data are then reported to a Statewide registry and then to a national registry, it is critical that source data from the local level is accurate, complete, and timely. Data fields that are left blank or coded to unknown are virtually eliminated from analysis so it is very important that the data be complete. Also, to be of greatest use, data must be timely. To facilitate timely data, cases should be reported within six months of diagnosis.
To assure that accurate information is entered in the database, the hospital Cancer Registrar closely reviews patient's medical records. The Cancer Registry supervisor further ensures accuracy by reviewing data that has been coded by the Cancer Registrar. A quality assurance team reviews a random sample of records each year to ensure the overall accuracy of the registry.

The cancer registrars at the central registry are responsible for the accuracy of all data that they receive. In addition to the data from hospital cancer registries, some of the data received by central cancer registries come from hospitals that do not have a cancer registry or from other non-hospital sources such as doctor’s offices. The central cancer registry has quality assurance procedures that are applied to all of the data received. In addition to the complex computerized edits that are run at the local cancer registry, the same type of computerized edits are run again at the state level, and the data are audited by the Statewide registry on a random basis. These audits frequently include both case finding and re-abstracting studies.
Privacy concerns are paramount to Cancer Registrars

Because Cancer Registrars have access to virtually every piece of medical information about every cancer patient in a health care facility, ensuring confidentiality and privacy is a paramount concern. Training on local, state, and federal privacy laws and regulations, such as the Health Insurance Portability and Accountability Act (HIPAA) regulations provides an important foundation for the cancer registrar. Additional training on workplace and professional ethics helps ensure that the confidentiality of patient information is maintained.
Cancer Registrars: A challenging career requires quality education, and certification
Even with the most advanced technology and the finest physicians and doctors, health care facilities would be unable to accurately track and record cancer information without Cancer Registrars. Because the cancer information that is fed into Cancer Registries contains data from many different sources and covers a long period of time, it is essential that Cancer Registrars have the skills and resources to locate, interpret, and record hundreds of data points on each cancer patient.
Cancer Registrars not only record data, they find and interpret it.

The hospital Cancer Registrar interacts with a patient’s health care team, and sometimes patients themselves, to gather information about a patient’s medical and social background. The data are coded and recorded in the Registry. The Registrar queries the database and reports pertinent information to the cancer committee to improve patient care, indicate resource needs, and provide other needed information.
The Cancer Registrar must gather information from multiple sources, including each of the places where a patient has received care such as the hospital, free-standing radiation therapy clinics, or an oncologist’s office.

The Cancer Registrar must understand what data are useful and ensure that they are accurately and completely entered into a database.

The Cancer Registrar must have a thorough understanding of computer systems and know how data will be shared with central registries and ultimately used.

Finally, the Cancer Registrar must have a complete knowledge of the illnesses faced by patients living with cancer and the vast number of treatment options used to treat different forms of cancer.
Education for Health Information Management Professionals and Cancer Registrars are similar

The necessary education for a Cancer Registrar closely parallels that for Health Information Management (HIM) professionals. This includes Anatomy and Physiology, Database Management, Medical Coding, Medical Terminology, Writing and Communication, Statistics. Earning an HIM Degree forms a wonderful foundation for the Cancer Registry profession.
Cancer Registrars are key players in health care facilities. To do a complete job, Cancer Registrars must interact with physicians, administrators, researchers, and health care planners. They not only gather information, but also share information about specific patients’ histories and treatment results, and note trends in cancer diagnoses in health care facilities and communities.
Data collection is only one part of the duties of a Cancer Registrar.

Often the cancer registrar in a hospital is the manager of the cancer program. The Registrar may coordinate the cancer conferences where patient treatment options are discussed by a multi-disciplinary group of physicians and participate in other cancer program activities. As an active member of the hospital’s cancer committee, the registrar works with physicians and administration to improve the quality of the cancer program. The Cancer Registrar may participate in studies monitoring quality of care, and participate in system wide quality assurances programs.
The Role of Hospital-based Registrars Goes Beyond Data Collection

- Data Analysis for Studies
- Compiling Cancer Program Annual Report
- Assess referral patterns

The Cancer Registrar frequently is also responsible for analyzing data and preparing reports for special physician requests, outcomes of treatment, and for preparing the Cancer Program Annual Report. Registrars may also prepare administrative reports such as an analysis of referral patterns.
The Role of Hospital-based Registrars Goes Beyond Data Collection

- Participate in cancer prevention
- Present information to cancer committee, physicians, administration

Hospital-based Cancer Registrars may assist in developing cancer prevention and screening programs, and in educating other members of the health care team regarding cancer and its treatment.
Registrars in Central Cancer Registries are Key Players in Ensuring Quality Health Care

- Edit the data from all facilities
- Query the database for data quality reports
- Merge duplicate records
- Audit healthcare facilities to insure accurate, timely, complete data

Work in the Central cancer registry involves almost no abstracting but does require extensive data standard knowledge, knowledge of the disease process, standards of care, and new technologies–both database and medical.

There is a strong emphasis on monitoring the quality of the data received.

It is also important to assure that the data collected are complete and that all of the cancer cases diagnosed in the state within each year are identified.
Registrars in Central Cancer Registries are Key Players in Ensuring Quality Health Care

- Work with researchers
- Contribute to data analysis for cancer program planning
- Present data to the local community, schools, and others
- Provide education and training for registrars

Once the data are complete, central registrars work with researchers and epidemiologists to report the findings and provide data to community leaders to assist in cancer program planning. This extensive knowledge allows the central cancer registrar to carry out the duties of the central cancer registry, resulting in complete and accurate information on the cancer burden of the state.

Many central registrars play an active role in providing education and training to new registrars entering the profession.
How Does One Become a Cancer Registrar?
Traditionally, Cancer Registrars came from other allied health fields such as Health Information Management, or nursing, and were trained on the job. However, with the advent of national cancer reporting and an emphasis on quality assurance, formal education programs have greatly expanded over the past two decades. Today, formal education programs at colleges around the country teach cancer information management. Most formal education programs are one-year certificate programs. In 2005 there are 12 NCRA-approved formal education programs with more programs continually undergoing the approval process.
It is more important than ever to have a solid education and experience when sitting for the Certified Tumor Registrar (CTR) exam. Most applicants for the CTR exam have at least some college training under their belt, while many have an Associates or Bachelors degree. There are even some who seek the CTR credential after obtaining their Masters degree or PhD.
NCRA’s requirements for approval of formal education 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

Curricula at formal education programs include, but are not limited to, cancer and its management, medical terminology, anatomy and physiology, biostatistics and epidemiology, cancer data abstracting, database record management, cancer program management, and Cancer Registry procedures. Many formal education programs now offer distance-learning education so that prospective Cancer Registrars anywhere can take advantage of these opportunities.
Other educational opportunities:

- Intensive trainings on specific subjects
- On-the-job training
- Online resources, including NPCR and SEER training modules
  http://www.training.seer.cancer.gov
- SEER Self-Instructional Manuals
  http://seer.cancer.gov/training/manuals

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 Cancer Registries.

Additionally, SEER offers online training modules for Cancer Registrars and they maintain a set of eight free Self-Instructional Manuals for Tumor Registrars. The Web sites are listed on the slide.
Certification of Cancer Registrars
In the rapidly changing field of health care delivery, setting standards to assure the quality of care is mandatory. Certification of Cancer Registrars enhances data quality, fosters professional pride, and is nationally recognized in recruitment and retention of registry personnel.
Certification promotes excellence in the Cancer Registry field by establishing a standard of knowledge and experience required for professional registry practice. It measures the requisite knowledge of applicants for the professional credential of CTR, or Certified Tumor Registrar.

Certification promotes professional growth and individual study by Cancer Registrars which is necessary for attaining and maintaining CTR the credential. It formally recognizes Cancer Registrars who meet all the requirements for using the CTR credential; and assists employers, members of allied health professions, and public in assessing Cancer Registrars qualifications.
Cancer Registrars who meet eligibility requirements and pass the CTR examination are awarded the CTR credential.

NCRA’s Council on Certification sets the certification standards.

NCRA’s Council on Certification promotes standardization in the collecting and using of cancer data through examination and certification of Cancer Registrars and other cancer data specialists. Cancer Registrars who meet eligibility requirements and pass the CTR examination are awarded the CTR credential.
What are the eligibility requirements for certification?

- Two years of Cancer Registry experience; or
- Completion of an NCRA-approved college-level curriculum in Cancer Registry/cancer data and management; or

Eligibility for the CTR is achieved through a combination of education and employment experience. There are several eligibility routes that applicants can choose from. One route requires a high school diploma and two years of Cancer Registry experience, which can be achieved with volunteer hours, or full- or part-time employment.

A second route is the completion of an NCRA-approved college level curriculum in Cancer Registry/cancer data and management. This route requires a minimum number of clinical practicum hours.
CTR Requirements cont’d

- Completing a minimum of an associate’s degree in a NCRA-approved college-level curriculum in an allied health field and one year of Cancer Registry experience; or
- Credentialed or licensed status in an approved allied health field and one year of Cancer Registry experience; or

Education, training, and experience in a NCRA-approved allied health fields with a minimum of an associate’s degree and one year of Cancer Registry experience also provides eligibility for the CTR exam.

All approved degrees must include a minimum of two semesters of human anatomy and/or physiology.

Allied health fields include but are not limited to health information management, radiology, nursing, physical, and occupational therapy. A full listing of approved allied health fields are listed on the Council on Certification Web site.
CTR Requirements cont’d

- Completion of a Master’s level or higher college-level curriculum in an allied health field and one year of Cancer Registry experience
- Council on Certification Web site: http://www.ctreexam.org

If an applicant has a masters or higher degree in any allied health field, they only need an additional one year’s experience in the cancer registry field to be eligible to take the examination. This category includes M.D., D.O.’s and persons with a Masters in Public Health.

A full listing of eligibility criteria can also be found on the Council on Certification Web site at http://www.ctreexam.org. *
The CTR exam is offered during two 2-week testing windows each year and can be taken at more than 700 computer testing facilities around the world.

The examination covers a wide range of medical and data management principles including Cancer Registry organization and operations; anatomy, physiology, and histology of the human body related to the disease processes of cancer; abstracting and coding cancer data items using standard registry coding references.
CTR Examination Content

- Statistical and graphic concepts
- Practical application of registry principles
- Computerized data management

It also covers statistical and graphic concepts used in presenting cancer incidence, treatment, and survival information, practical application of registry principles to determine appropriate registry responses, and computerized data management.
In 1983 the National Tumor Registrars Association (now NCRA) established the first certification examination for tumor registry professionals. Since the first CTR examination, 4,400 people have attained the CTR. Today there are more than 3,700 current CTRs.
NCRA’s Council on Certification’s Mission

- To create and maintain credentialing processes whereby the public can be assured that individuals certified by NCRA have met a level of competence required to provide accurate information for cancer surveillance and research activities.

In 2002, NCRA established a Council on Certification to oversee all certification activities. It consists of seven representatives, all elected by people holding a CTR credential. The Council on Certification oversees developing and administering the professional certification examination for Cancer Registrars and establishes eligibility criteria for examination candidates. The Council also reviews proposed questions, verifies the content of upcoming examinations, and responds to questions from examination candidates regarding eligibility status.

The mission of NCRA’s Council on Certification is to create and maintain credentialing processes whereby the public can be assured that individuals certified by NCRA have met a level of competence required to provide accurate information for cancer surveillance and research activities.
Rapidly changing technology and treatment options necessitate continuing education

To maintain their CTR credential, certified Cancer Registrars must complete 20 continuing education hours every two years. Continuing education opportunities are offered by NCRA through an annual conference and through multimedia presentations. NCRA’s Credentialing committee continually develops and approves other continuing education opportunities across the United States that are sponsored and offered locally and regionally.
NCRA: Resources for Registrars
Since 1974, NCRA has represented Cancer Registry professionals and CTR’s. NCRA is based in the Washington, DC, area and currently has more than 4,000 members from local, state, national, and international Cancer Registries.
NCRA’s Strategic Management Plan is a clear agenda of NCRA’s efforts built squarely on NCRA members’ ideals. As part of a strategic management process, starting in 2003, NCRA adopted new mission and vision statements and a set of core values. The mission of NCRA is to promote education, credentialing, and advocacy for Cancer Registry professionals.
The vision statement is to serve professionals who provide data that makes a difference in the fight against cancer.
The core values that NCRA is built upon are networking, mentoring, and making a difference.
NCRA offers:

- Multiple educational and networking opportunities
- Annual national conference to build knowledge and expertise
- Promotion of professional standards and ethics

In serving its members, NCRA focuses on ensuring ongoing educational and professional support. NCRA hosts an annual educational conference that draws more than 1,100 Cancer Registration professionals. Many of the workshops from that conference are turned into multimedia presentations and available to members who were unable to participate in the conference. NCRA also manages the CTR process and supports and manages NCRA’s council on certification.

The *Journal of Registry Management* is the official journal of the National Cancer Registrars Association (NCRA). This peer-reviewed journal publishes papers on topics related to the management of health registries and the collection, management and use of cancer, trauma, AIDS and other health registry data. *The Journal of Registry Management* is published four times a year. The journal is provided free of charge to all NCRA members and by subscription to nonmembers.
NCRA offers:

- Management of the CTR process and NCRA’s Council on Certification
- Publication of a peer-reviewed scientific journal and a quarterly newsletter

*The Connection* is the official newsletter of the National Cancer Registrars Association. This member-only newsletter publishes articles on NCRA topics related to the Board of Directors, Committees, Liaisons, Council on Certification, State Cancer Registrars Associations, Executive Office, and NCRA member news. *The Connection* is also published four times a year.
NCRA offers:

- A Web site offering a wide range of publications and information about educational opportunities
- [http://www.ncra-usa.org*](http://www.ncra-usa.org*)

The NCRA web site [http://www.ncra-usa.org*](http://www.ncra-usa.org*) offers a wide range of publications, information about the Cancer Registry profession, and details on certification. It also includes information specifically for members, including the NCRA Membership Directory, educational opportunities, multimedia training opportunities and a job bank.
Cancer Registry is a Dynamic Profession
Cancer Registrars tend to love their work. To work in a registry, you must be self motivated and detail oriented, not just in data collection but also in the data analysis.
Cancer Registry is a dynamic profession

- Registry data makes a difference in patient care and cancer research
- Registrars perform a wide variety of interesting tasks, including data analysis

The work requires medical and scientific knowledge but without hands on patient care; like the Health Information Management field.
The profession offers regular work day hours with holidays and vacations. There is minimal supervision required for self-motivated registrars.

Cancer Registry is a dynamic profession

The greatest satisfaction for Cancer Registrars is knowing that their work contributes to the knowledge of cancer, the improvement in patient care and valuable research on new medical technologies.
Cancer Registrar salaries are usually commensurate with Health Information position salaries. Salaries range from an average for Registrar/Abstractor/Data Manager of about $33,600 annually to $61,600 for Administrators and Directors. Persons working for Contractor Services and in Central Cancer Registries may have slightly higher salaries.
Cancer Registrars Have Many Career Opportunities

- Hospitals and Health Care Facilities
- Software Vendors
- Government Agencies
- Pharmaceutical Companies
- Outsourcing or Contract services

Cancer Registrars have opportunities to pursue other exciting career paths, including working in hospital administration, software sales and support, and program management in government or the private sector. Many Cancer Registrars also enter the consulting fields. Many of these careers offer flexible working arrangements, including telecommuting, and many offer travel opportunities.
Cancer registrars are the intelligence officers on the front lines, collecting critical information that is used to develop the battle plan and to deliver the necessary troops to the right location at the right time in order to combat the enemy—cancer. As active members of the cancer team, registrars prepare and present data for cancer conferences, grand rounds, tumor boards, and planning meetings. Cancer registrars are the lifeblood of cancer registries and serve as the backbone of local, state, and national cancer surveillance and cancer control programs. If you want to make a difference in the fight against cancer, this may be the career path for you!