

Data on cancer in the United States is collected through several systems of registries. The data collected depends on the purpose of the registry. Two types are:

- *Hospital registries*, which may be part of a facility's cancer program
- *Population-based registries*, which are usually tied to state health departments

Hospital registries provide complex data used to evaluate patient care within the hospital. This data may be focused on things like care of the cancer patient and educating health care providers. Some hospitals pool their data and use the collected information to learn more about the course of cancer. The pooled data can be used in studies that compare patterns of care among providers, population subsets, or geographic regions.

Population-based registries, such as those under state health departments, collect information on all cases diagnosed within a certain geographic area. Population-based registries in cities and states collect and pull together information from multiple reporting facilities within their geographic regions that can include:

- Hospitals
- Doctors' offices
- Nursing homes
- Pathology laboratories
- Ambulatory care facilities or clinics
- Radiation and chemotherapy treatment centers
- Other cancer care facilities

These registries provide data that can show things like new cancer cases (incidence) and death rates (mortality) across regions of the country. They can look at cancer rates in certain types of jobs, or see if cancer survival is improving. They can also watch cancer trends over time to find out if the rate of a type of cancer is going up or down. They can be used to keep an eye on which age and racial groups are most affected by different types of cancer.

Information from cancer registries helps guide cancer prevention and control programs that are focused on changing certain behaviors (like smoking) and reducing other environmental risks. Cancer registries can help identify a need for increased cancer screening in a certain region or area.

Collecting the information

Registries are usually staffed with cancer registrars who have met stringent standards of training, testing, and continuing education. The highest level is *Certified Tumor Registrar (CTR)*. These registrars compile timely, accurate, and complete cancer information to report to the registry.

Cancer registration begins with *casefinding*, or identifying people with cancer who have sought care at hospitals and other medical care settings. Most often, it's the patient's doctor who starts the data record, noting the cancer site and type, patient demographics (like sex, race, and age), and extent of disease (or stage) in the medical record. Some cancer registry programs require that the registrar summarize and record certain other information from the patient record, such as type of treatment, and follow up each year to track cancer recurrence and survival.

Confidentiality of personal information

Before any statistics or other cancer information is published, the law requires that identifying details be removed so that nothing can be traced back to any one person. This is sometimes called *de-identified data*.

Major cancer surveillance programs

The following are brief descriptions of the major cancer surveillance programs in the United States.

National Cancer Data Base

Established in 1989, the National Cancer Data Base (NCDB) is a joint program of hospital registries of the Commission on Cancer (COC) and the American Cancer Society. Its purpose is to ensure quality cancer care by providing data to:

- Evaluate patient management within hospitals and other treatment centers
- Make comparisons of cancer care and outcomes between institutions
- Set standards to help improve quality of cancer care

Groups of specialists design and monitor patient care evaluation (PCE) studies to provide timely information on patterns of care related to geographic, socioeconomic, and clinical factors. To share the results of PCE studies, the findings are presented at professional meetings and reports are published in peer-reviewed journals. More than 1,500 cancer treatment centers in the United States and Puerto Rico contribute data to the NCDB. The NCDB contains about 29 million records from hospital cancer registries.

The Surveillance, Epidemiology and End Results Program

The National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) program is a large population-based registry. It collects information from certain geographic areas which represent 48% of the US population, including:

- Cancer incidence (new cases)
- Survival
- Prevalence (number of people living with cancer during a given time period)

The NCI contracts with non-profit organizations to collect data on new cancer diagnoses in the designated geographic locations. Cases are followed up each year to determine survival. The data, along with data on cancer-related deaths from the entire US from the National Center for Health Statistics (NCHS), are analyzed and are published annually in the SEER Cancer Statistics Review.

National Program of Cancer Registries

The National Program of Cancer Registries (NPCR) of the Center for Disease Control and Prevention (CDC) supports population-based registries in state health departments. This program was established by the Cancer Registries Amendments Act in 1992 to respond to the need to collect data on larger percentages of state populations. This legislation authorizes the CDC to provide funds to states and territories to:

- Improve existing cancer registries
- Plan and set up registries where they don't exist
- Develop model legislation and regulations for states to enhance success of registry operations
- Set standards for completeness, timeliness, and quality
- Provide training for registry staff
- Help set up a computerized reporting and data processing system

State cancer registries are computerized and have many public health uses. They are designed to:

- Monitor cancer trends over time.
- Look for cancer patterns in different groups of people.
- Guide planning and evaluation of cancer control programs. For instance, look at whether prevention, screening, and treatment efforts are making a difference.

- Help set priorities for allocating health resources.
- Advance clinical, epidemiologic, and health services research.
- Provide information for a national data base of cancer incidence.

Before the NPCR was established, 10 states had no registry, and most states with registries lacked the resources and legislative support they needed to gather complete data. Today, the NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the US Pacific Island Jurisdictions. The data represent 96% of the US population.

Together, the NPCR and the National Cancer Institute's SEER Program collect data for the entire US population.

The future for registries

Future directions for cancer registries include support of more electronic information sharing. It's hoped this will allow better studies on things like access to care for people with cancer and survivorship. The CDC is already planning ways to let research be done on de-identified cancer information, which should result in doctors getting more complete information on cancer and its care.

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