WHAT IS THE HISTORY OF CONGRESS AND CANCER REGISTRIES?

In 1971, the National Cancer Act budgeted monies to the National Cancer Institute (NCI) for research, detection, and treatment of cancer. In 1973, NCI’s Surveillance, Epidemiology and End Results (SEER) Program established the first multi-state, population-based cancer registry system. Through the Cancer Registries Amendment Act, Congress established the National Program of Cancer Registries (NPCR) in 1992. The legislation authorized the Centers for Disease Control and Prevention (CDC) to provide funds to states and territories to enhance existing cancer registries and to plan and implement registries in states without them.

WHAT IS A CANCER REGISTRY?

Cancer registries are information systems that manage and analyze data on cancer patients and survivors. Cancer registries can be classified into three types:

- **Hospital Registries**: one of the starting points for cancer surveillance, documents diagnosis and treatment on all patients, cases are reported to the central or state cancer registry.

- **Central or State Registries**: combine and maintain data on all cancers occurring in the state’s population, collecting data from all hospitals, pathology laboratories, physicians, and other sources.

- **Special Purpose Registries**: maintain data on a type of cancer, such as brain tumors, or a special population, such as Native Americans.

Together, CDC’s NPCR and NCI’s SEER programs collect cancer data for 100% of the U.S. population. Central registries that are supported by CDC and NCI submit data to the North American Association of Central Cancer Registries (NAACCR) for certification and aggregation. Cancer registrars are data information specialists that capture the complete history, diagnosis, treatment, and health status for every cancer patient in the U.S. Over 6,000 belong to the National Cancer Registrars Association (NCRA).

WHAT INFORMATION IS INCLUDED IN THE CANCER REGISTRY?

Cancer registrars collect more than 400 data items covering a wide range of demographic and medical information:

- Patient history: physical findings, occupation, and history of a previous cancer
- Diagnostic results
- Cancer information: primary site, cell type, and stage of disease
- Treatment
- Outcomes: cancer status and cancer deaths

HOW IS REGISTRY DATA USED?

Healthcare providers, public health officials, and researchers use the data to:

- Monitor cancer trends over time
- Evaluate cancer patterns in various populations and identify high-risk groups
- Guide planning and evaluation of cancer control programs
- Help set priorities for allocating health resources
- Study cancer causes and prevention strategies

WHICH FEDERAL AGENCIES FUND CANCER REGISTRIES?

- Central registries are partially funded through the CDC’s Division of Cancer Prevention and Control and through NIH’s National Cancer Institute (NCI).
- NCI is the federal government’s principal agency for cancer research and training.
- Besides supporting central registries, the CDC also funds key prevention programs that, if adequately supported, could avert more than half of all cancer deaths over time.
HOW CANCER REGISTRY DATA ARE USED
States use the cancer registry data to develop programs to target specific cancer prevention and treatment needs. Learn how states are using cancer registry data to improve public health at: www.ncra-usa.org/Advocacy/How-Cancer-Registry-Data-is-Used.

U.S. CANCER STATISTICS: DATA VISUALIZATIONS
https://gis.cdc.gov/Cancer/USCS/DataViz.html

The United States Cancer Statistics: Data Visualizations is a user-friendly website that allows cancer surveillance data to be directly and more easily accessible by public and cancer control planners. The tool creates data visualizations to describe U.S. cancer burden, incidence, and mortality over time, and state-specific data in comparison to national rates. Data are displayed as maps and bar charts with interpretive text. Users can customize displays of overall and cancer-specific statistics, view data as a table, and share each page via social media.

EXAMPLES OF CANCER REGISTRY DATA USE

NEW YORK STATE CANCER REGISTRY DATA
To evaluate the quality of breast and colorectal cancer care, New York State Cancer Registry data were linked with Medicaid and Medicare claims and hospital discharge data. Results led to discussions with the New York Medicaid Program about policies and procedures related to adjuvant chemotherapy.

TEXAS CANCER REGISTRY DATA
CDC’s Texas Breast and Cervical Cancer Early Detection and Comprehensive Cancer Control Programs used Texas Cancer Registry data to identify counties with the greatest need and developed a plan to increase breast cancer screening, diagnosis, and patient navigation in six underserved counties. As a result, the programs increased access to breast cancer screening, mammograms, and biopsies in five counties and leveraged additional local funding to expand the program.

AMERICAN INDIANS/ALASKA NATIVES
American Indians/Alaska Natives have been misclassified leading to an underestimate of cancer incidence and deaths. CDC created the first accurate estimate of AI/AN cancer incidence by linking NPCR and Indian Health Service data. This data linkage significantly improved health agencies’ ability to identify the cancers and geographic areas with the greatest need for public health interventions targeting AI/ANs. Similar linkages were done with mortality data with linkages between enrollment records and the National Death Index.

CANCER REGISTRY RESOURCES
CDC’s National Program of Cancer Registries (NPCR) — https://www.cdc.gov/cancer/npcr

NCI’s Surveillance, Epidemiology, and End Results (SEER) Program — https://seer.cancer.gov

National Cancer Registrars Association (NCRA) — www.ncra-usa.org

North American Association of Central Cancer Registries (NAACCR) — www.naaccr.org

Phone: 703-299-6640
E-mail: info@ncra-usa.org
Website: www.ncra-usa.org

Phone: 217-698-0800
E-mail: Info@naaccr.org
Website: www.naaccr.org