Cancer Registrars

IMPROVING LIVES THROUGH QUALITY CANCER DATA MANAGEMENT

2017 INFORMATION AND PRIORITIES

National Cancer Registrars Association
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 and, in 1973, the Surveillance, Epidemiology and End Results (SEER) Program of NCI established the first national cancer registry. In 1992, through the Cancer Registries Amendment Act, Congress established a National Program of Cancer Registries (NPCR). 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.

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 general types:

- **Hospital registries**, the starting point for cancer surveillance, maintain data on all patients. Cases are reported to the central or state cancer registry.
- **Central 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.

Together, CDC’s NPCR and NCI’s SEER Programs collect cancer data for 100% of the US population.

What information is included in the cancer registry?

*Cancer registrars collect a wide range of demographic and medical information:*

- Patient history: physical findings, screening information, occupation, and history of a previous cancer
- Diagnostic results
- Cancer information (primary site, cell type, and stage of disease)
- Treatment
- Follow-up (recurrence and cancer status)

How is registry data used?

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

- Calculate cancer incidence
- Evaluate efficacy of treatment modalities
- Determine survival rates
- Develop targeted educational and screening programs
- Conduct research on the etiology, diagnosis, and treatment of cancer
- Monitor quality of patient care and outcomes

“SPECIALIZED POPULATION” CANCER REGISTRIES

Does creation of “specialized population” cancer registries prove helpful to fight certain cancers or cancers among certain populations?

*No, existing Central Cancer Registries are the best avenue for cancer surveillance.*

Federally mandated Central Cancer Registries already scientifically collect comprehensive patient information on all cancer patients in the US and can offer specialized population datasets and information. Occupation, patient history, pathology, demographics, as well as recurrence and survival statistics are some of the key data already recorded.

NCRA encourages the use of existing Central Cancer Registries to respond to cancer surveillance needs of special populations. For example, HR 931 and S 382 would establish a new registry of firefighters that would track cancer incidence. Rather than create a separate registry, existing registry data could be used to study this population.
This year more than 600,000 Americans—1,650 people a day—will die from the 200 diseases we call “cancer.” Cancer also takes a tremendous toll on the US economy, costing more than $216 billion annually in direct treatment and lost productivity.\(^1\)

➤ **Has cancer funding increased over the years?**

No, while the number of reported cancer cases is increasing, appropriations per patient have decreased from $32 in 2003 to $22 in 2013.\(^2\)

➤ **Which federal agencies fund cancer registries?**

- Central Registries (State/Territorial/Regional) are partially funded through the CDC’s Division of Cancer Prevention and Control and through NIH’s National Cancer Institute (NCI).
- NCI, a division of the National Institute of Health (NIH) 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 this year.\(^3\)

1. One Voice Against Cancer (OVAC)
2. Centers for Disease Control
3. OVAC

THE NATIONAL CANCER REGISTRARS ASSOCIATION ASKS CONGRESS TO:

1. Recognize the unique role that Cancer Registrars play in improving lives through quality cancer data management.
2. Understand that existing Central Cancer Registries, rather than specialized population registries, are the best avenue for cancer surveillance.
3. Adequately fund CDC cancer programs, including Cancer Registries. We’re asking Congress to reject proposed cuts to CDC cancer prevention and control programs, including a proposal to slash chronic disease funding in FY18. In fact, we’re asking that the Centers for Disease Control and Prevention cancer programs receive $514 million in a final FY17 appropriations bill and FY18, including $65 million for the National Program of Cancer Registries. The CDC’s NPCR provides critical national data to enable linkage with state surveillance data. This allows states to understand their cancer burden and prioritize cancer control and screening efforts.
4. Appropriate additional funding for the CDC’s NPCR to increase registries’ use of electronic health records to improve health programs’ ability to plan and target health care interventions designed to reduce cancer incidence and increase early detection.
5. Provide the NIH with at least a $2 billion increase in a year-end FY17 appropriations bill, for a total budget of at least $34.1 billion. Included in this amount, we’re asking for $5.9 billion for NCI.
6. Submit a FY18 appropriations request for at least a $2 billion increase above the final FY17 level for NIH, including a proportional increase for NCI and continued funding for the Cancer Moonshot and other NIH priorities as required by the 21st Century Cures Act.
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