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The History and Use of Cancer Registry Data by Public Health Cancer Control Programs in the United States

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Abstract

Because cancer registry data provide a census of cancer cases, registry data can be used to: 1) define and monitor cancer incidence at the local, state, and national levels; 2) investigate patterns of cancer treatment; and 3) evaluate the effectiveness of public health efforts to prevent cancer cases and improve cancer survival. The purpose of this article is to provide a broad overview of the history of cancer surveillance programs in the United States, and illustrate the expanding ways in which cancer surveillance data are being made available and contributing to cancer control programs. The article describes the building of the cancer registry infrastructure and the successful coordination of efforts among the 2 federal agencies that support cancer registry programs, the Centers for Disease Control and Prevention and the National Cancer Institute, and the North American Association of Central Cancer Registries. The major US cancer control programs also are described, including the National Comprehensive Cancer Control Program, the National Breast and Cervical Cancer Early Detection Program, and the Colorectal Cancer Control Program. This overview illustrates how cancer registry data can inform public health actions to reduce disparities in cancer outcomes and may be instructional for a variety of cancer control professionals in the United States and in other countries.

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CONFLICT OF INTEREST DISCLOSURES

All authors other than Betsy A. Kohler are federal employees who contributed to this article as part of their official duties.

AUTHOR CONTRIBUTIONS

Mary C. White: Coordinated the writing team and led the drafting and revision of the manuscript. All authors participated in writing, reviewing and editing the manuscript and contributed in specific areas: **Frances Babcock**, NPCR; **Nikki S. Hayes**, NCCCP; **Angela B. Mariotto**, SEER; **Faye L. Wong**, NBCCEDP and CRCCP; **Betsy A. Kohler**, NAACCR; **Hannah K. Weir**, conceptualization of the paper.

Keywords

cancer registries; cancer prevention; cancer control; cancer screening program; cancer surveillance; cancer history; cancer incidence data; population-based survival public health planning; NPCR; SEER; NBCCEDP; NCCCP; CRCCP

INTRODUCTION

Public health surveillance, defined as the ongoing, systematic collection, analysis, interpretation, and dissemination of data,¹ is one of the underlying pillars of all chronic disease programs.² Among chronic disease programs in the United States, cancer prevention and control programs are unique in relying on an existing network of disease registries that collect and maintain high-quality surveillance data regarding incident cases. In fact, cancer is the only notifiable chronic condition,³ meaning that cancer data must be reported to the state. Cancer reporting is available for the entire US population, similar to the reporting of death records, because of the combined efforts of federal cancer registry programs supported by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI). The CDC and NCI have a long history of coordinating these 2 programs to build a national infrastructure for cancer surveillance.^{4,5} Since 1998, the combined data from these CDC and NCI cancer registry programs have been summarized in the *Annual Report to the Nation on the Status of Cancer*, a yearly update of cancer incidence and death rates and trends with an in-depth analysis of a selected topic, most recently featuring survival in the United States.⁶ In addition, the NCI and CDC collaborate to make nationwide data on cancer incidence, mortality, risk factors, screening, and other resources available for use in cancer control plans in the State Cancer Profiles Web site (<http://statecancerprofiles.cancer.gov>).

Because cancer registry data provide a census of cancer cases, registry data can be used to define and monitor cancer incidence at the local, state, and national levels, investigate patterns of cancer treatment, and evaluate the effectiveness of public health prevention efforts. The purpose of this article is to provide a broad overview of the history of cancer surveillance programs in the United States and illustrate the expanding ways in which cancer surveillance data are being used for cancer prevention and control. This overview may be informative for a variety of cancer control professionals in the United States and in other countries. Cancer registry data serve as the foundation for public health action to reduce disparities in cancer incidence, mortality, and survival.

CANCER SURVEILLANCE PROGRAMS

Surveillance, Epidemiology, and End Results Program

The NCI's Surveillance, Epidemiology, and End Results (SEER) program is a coordinated system of cancer registries, strategically located across the United States, charged with providing timely and accurate data regarding cancer incidence, mortality, treatment, and survival. SEER was established in 1973 in response to the National Cancer Act of 1971, which mandated the collection, analysis, and dissemination of data regarding patients with cancer to support the prevention, diagnosis, and treatment of cancer in the United States. It

grew out of 2 earlier studies, the Third National Cancer Survey⁷ and the End Results Program,⁸ which had collected cancer survival data from 1956 to 1972 regarding patients diagnosed or treated at a select number of US hospitals. Over time, SEER has expanded to increase coverage of minority, rural, and other populations. SEER currently includes the states of California, Connecticut, Georgia, Hawaii, Iowa, Kentucky, Louisiana, New Jersey, New Mexico, and Utah, and the metropolitan areas of Detroit and Seattle-Puget Sound (Fig. 1). All SEER registries are funded by the NCI and their respective states, and the registries in Kentucky, Greater California, New Jersey, Louisiana, and Greater Georgia also are funded by CDC's National Program of Cancer Registries. SEER also collects data regarding American Indians/Alaska Natives in Arizona and Alaska, and of the Cherokee Nation. Currently, SEER covers approximately 30% of the US population, and records 400,000 new cancer cases diagnosed annually.

SEER routinely collects data regarding patient demographics, primary tumor site, tumor morphology and stage at diagnosis, initial course of cancer treatment, and follow-up for vital status information. Patient follow-up data are obtained by linking with administrative databases, mainly the National Death Index, Social Security Administration, state vital records departments, and the Centers for Medicare and Medicaid Services. In addition to date and cause of death for deceased patients, registries collect a date of last contact within 22 months of the date of their annual data submission to SEER for a minimum of 90% of all registered patients with cancer, both living and deceased (http://seer.cancer.gov/tools/SEER_2015.instructions.pdf). Date of last contact for living patients allows for the identification of patients who are likely lost to follow-up due to immigration or for other reasons. In SEER survival calculations, survival is calculated from the date of diagnosis to the date of last contact for patients not known to have died. In other words, SEER does not assume patients are alive between the date of last contact and the end of study date.

SEER also plays an important role in supporting scientific and clinical research on cancer. As a research resource, SEER data are made available to researchers and the public through dissemination of reports, databases, analytical software, and linkages to other data sources (<http://seer.cancer.gov/seerstat>). SEER data also are linked to national databases to complement the registry data with other information such as risk factors, detailed treatment information from claims, and quality of life (https://seer.cancer.gov/resources/linked_databases). The SEER-Medicare data (<http://healthcaredelivery.cancer.gov/seermedicare>) have been used extensively on studies assessing the patterns of care for patients with cancer and the cost of cancer treatment.^{9,10}

National Program of Cancer Registries

The National Program of Cancer Registries (NPCR) is the CDC's largest disease surveillance system in the United States. The purpose of this program is to provide population-based cancer incidence data on which to base national, state, and local health planning. The NPCR was established in 1992 by the US Congress through Public Law (P.L.) 102-515, the Cancer Registries Amendment Act. This law authorizes the CDC to: provide funds and technical assistance to states and territories to improve existing cancer registries; plan and implement registries where they did not exist; help develop model legislation and

regulation for states to enhance the viability of registry operations; set standards for data completeness, timeliness, and quality; provide training for registry personnel; and help establish a computerized reporting and data processing system.

P.L. 102–515 provides the framework for the legal support needed to operate central cancer registries by requiring that funded states develop legislation authorizing the establishment of a central cancer registry and provide regulations as specified in the law. These regulations provide the legal basis for the following: 1) case reporting from all facilities and practitioners; 2) access to medical records; 3) reporting of uniform data; 4) protection of patient confidentiality; 5) access to data by researchers; 6) authorization to conduct research; and 7) protection from liability for individuals who abide by the law.

In 1994, the NPCR began providing financial support and technical assistance to state health departments for the operation of statewide, population-based cancer registries. State health departments or their authorized designees were eligible for 1 of 2 funding categories. The first category of funding supported the enhancement of existing cancer registries, and the second supported the planning and implementation of a new cancer registry where none had previously existed. After the first program announcement in 1994, 42 states and the District of Columbia (34 enhancement programs and 9 planning programs) were awarded funds. After the second program announcement in 1997, 3 additional states and 3 territories (2 enhancement programs and 4 planning programs) were awarded funds. Currently, the NPCR funds support 45 states, the District of Columbia, Puerto Rico, and the Jurisdictions of the Pacific Islands (Fig. 1), and all funded programs are required to match federal funds. The NPCR covers approximately 96% of the US population and records more than 1.6 million new cancer cases diagnosed annually.

NPCR-funded central cancer registries are required to collect and report information on all state residents who are diagnosed with or treated for cancer, including residents who are diagnosed and treated outside of their state of residence. P.L. 102–515 defined reportable cancer as “each form of in situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin).” Benign brain and central nervous system tumors also must be collected and reported to the CDC. Data required to be collected are similar to SEER and include: cancer incidence; demographic information; administrative information, including the date of diagnosis and the source of information; and pathological data, including cancer site, stage at diagnosis, and type of treatment. To reduce racial misclassification of American Indian and Alaska Native populations, central cancer registries have worked with the CDC and the Indian Health Service (IHS) to link registry records with IHS patient registration records.¹¹

NPCR registries record vital status information and the date of last contact as available, but the registries are not funded or required to meet follow-up standards. The NPCR arranged for linkage with the National Death Index to be available at no additional cost to its registries, to encourage the registries to comprehensively ascertain deaths within the United States. These linkages do not provide follow-up information regarding living patients or patients who moved out of the country between the time of their diagnosis and death. Despite differences in follow-up procedures, SEER and NPCR survival estimates have been

shown to be comparable,¹² and are routinely made available free of charge from the North American Association of Central Cancer Registries (NAACCR) Web site.¹³

An economic evaluation of central cancer registry operations by the CDC found that costs varied across registries and identified opportunities for improved efficiency and reduced costs.^{14–16} Similar methods have been applied to examine costs for cancer registration in low-income and middle-income countries.¹⁷

The *U.S. Cancer Statistics Incidence and Mortality Web-Based Report* (www.cdc.gov/uscs) contains the official federal statistics on high-quality cancer incidence data from the NPCR and SEER registries and mortality data from the CDC's National Vital Statistics System.¹⁸ In 2017, the CDC launched *United States Cancer Statistics: Data Visualizations*, an interactive, online tool that displays the latest official federal cancer data by cancer type, state, demographics, and year (<https://nccd.cdc.gov/USCSDataViz>). Cancer incidence data are provided to the CDC's National Environmental Public Health Tracking Network (<http://ephtracking.cdc.gov/showCancer-Main.action>). In addition, the combined data from NPCR and SEER analytic data sets are available to researchers (www.cdc.gov/cancer/public-use), and comparative effectiveness research data¹⁹ also are available to researchers.

North American Association of Central Cancer Registries

Both federally funded registry programs (SEER and NPCR) work closely with the NAACCR to promote cancer incidence surveillance in the United States and Canada. Established in 1987, NAACCR Inc. is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in enhancing the quality and use of cancer registry data. All central cancer registries in the United States and Canada are members. The NAACCR develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based cancer registries; aggregates and publishes data from central cancer registries⁶; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer.

The NAACCR works with all member cancer surveillance entities to assure comparability of data across jurisdictions by developing consensus standards. To our knowledge, these standards are the most comprehensive of any disease surveillance system, and have been in effect for more than 25 years, contributing to the foundation of consistent and reliable cancer surveillance data. The standards pertain to case definitions, coding systems in use by registries, coding rules, standardized edits, data transmission formats, and best practices for the operation of population-based cancer registries. NAACCR standards are updated annually (<http://www.naacrr.org/StandardsandRegistryOperations/VolumeII.aspx>).

In 1992, NAACCR began independent annual reviews of member registries' data for compliance of completeness, accuracy, and timeliness with NAACCR standards. In 1997, this process was formalized into a certification program, whereby NAACCR evaluates the data using standard, objective measures. Registries that meet the highest standards for data quality are recognized through NAACCR certification. Over time, the NAACCR

certification standards have provided independent and objective measures of the improved quality of cancer surveillance data in the United States and Canada. In 2017, 55 population-based cancer registries in the United States, covering 94% of the US population, met NAACCR certification levels (<http://www.naaccr.org/certified-registries/>).

CANCER CONTROL PROGRAMS

National Comprehensive Cancer Control Program

Partnerships (or coalitions) with public and private sector organizations are essential for effective public health program implementation.²⁰ The CDC's National Comprehensive Cancer Control Program (NCCCP) was established in 1998 to support a coalition-based approach to cancer prevention and control. The NCCCP brings cancer control programs, community stakeholders, and state and local organizations together to strategically plan and implement cancer control activities. State registry data are the foundation of a state's comprehensive cancer control plan. Cancer coalitions work to reduce the burden of cancer in their communities by addressing a wide breadth of cancer prevention and control issues across multiple cancer types and levels of intervention. This highly organized public health approach provides a powerful constituency of professional, political, advocacy-oriented, and lay members to set the agenda for and advance cancer prevention and control efforts. The NCCCP supports cancer control coalitions in all 50 states, the District of Columbia, 7 US-affiliated Pacific Islands and territories, and among 7 tribes and tribal organizations (<http://www.cdc.gov/cancer/ncccp/index.htm>).

The CDC first awarded NCCCP funding to 6 grantees in 1998. Since then, the number of programs receiving NCCCP funding has grown to 65. Grantees convene stakeholder meetings, assess epidemiologic data, and prepare and implement formal plans to reduce the incidence and burden of cancer in their state and local areas. The NCCCP currently focuses on 6 priorities: 1) emphasizing primary prevention; 2) coordinating early detection and treatment activities; 3) addressing public health needs of cancer survivors; 4) implementing systems and environmental changes to sustain cancer control; 5) eliminating health disparities to achieve health equity; and 6) using evidence to evaluate impact. Additional information regarding activities around these 6 priorities can be found on the NCCCP Web site (<https://www.cdc.gov/cancer/ncccp/>). The following information describes those NCCCP activities that are most strongly related to improving cancer survival.

Recommended strategies for cancer survivors were identified in the 2004 National Action Plan for Cancer Survivorship: Advancing Public Health Strategies (NAPCS), which provided nationally accepted, evidence-based interventions for individuals diagnosed with cancer (cancer survivors) and their family members, friends, and caregivers.²¹ The NAPCS recommends strategies focused on 4 core public health areas: 1) surveillance and applied research; 2) communication, education, and training; 3) programs, policies, and infrastructure; and 4) access to quality care and services. The majority (94%) of cancer coalitions supported by the NCCCP currently are working within their communities to pursue these public health strategies in support of cancer survivors.²² A recent assessment of the implementation of NAPCS revealed that 64% of NCCCP grantees include NAPCS strategies in their own program action plans.²² For example, grantees in New Mexico, South

Carolina, Vermont, and Washington state and from the Fond Du Lac tribe have each implemented activities in all 4 of the NAPCS's strategy areas.²³

Survivorship care plans were identified by the Institute of Medicine for patients and their providers.²⁴ As people can live long after a cancer diagnosis, providing a summary of each cancer patient's treatment is an essential part of developing a complete survivorship care plan. The CDC has developed a secure, Web-based application that allows providers to import previously collected cancer registry data to facilitate the development of individual survivorship care plans (http://www.cdc.gov/cancer/npcr/tools/registryplus/wp_survmodule.htm). Providers have access to the information available in the cancer registry, and can edit or add to a patient's diagnosis and treatment information. Starting with one registry,²⁵ this pilot project has expanded and is being adopted by other cancer registries through the NCCCP.

In 2015, the CDC funded a supplemental award to NCCCP grantees in Indiana, Kansas, Louisiana, Michigan, South Dakota, and Washington to implement a broad set of evidence-based survivorship strategies. Strategies focus on increasing core surveillance and communications between community-based and clinical health care organizations and include using data systems to increase the use of survivorship care plans, increasing patient navigation programs to assist cancer survivors, and using electronic learning series to increase the education of providers concerning survivor care. Together, these strategies help to specifically identify and characterize the survivor population and address survivor needs from diagnosis through treatment and after treatment. These grantees are partnering with their state cancer registries and hospital registries to link data regarding incidence and cancer stage to patient electronic health record data to improve care planning in specific health systems. NCCCP grantees are uniquely positioned to help cancer control programs plan and implement policy, systems, or environmental changes that will have an impact on the quality of life of cancer survivors.

National Breast and Cervical Cancer Early Detection Program

Through Congressional legislation passed in 1990, the CDC established the National Breast and Cervical Cancer Early Detection Program (NBCCEDP)^{26–28} to provide access to quality cancer screening for low-income women who meet program eligibility criteria (income, insurance status, and national screening guidelines).²⁹ Since then, the NBCCEDP has become the only nationwide, organized cancer early detection program in the United States,³⁰ cumulatively screening nearly 4.9 million women. In 2017, the program awarded funding to 50 states, the District of Columbia, 13 tribes and tribal organizations, and 6 US territories to maintain screening programs within their jurisdictions.

From the beginning, demographic and clinical data called Minimum Data Elements have been collected on every woman screened by the NBCCEDP.³¹ These data are used by the CDC and individual grantees to monitor the number of women screened and their screening outcomes (abnormal screening results and diagnostic tests), as well as to assess performance in achieving program quality standards³² and to conduct program studies.³³ The CDC requires grantees to link Minimum Data Elements data to their state cancer registries data and in doing so, they have created an information infrastructure with the capacity to provide

standardized data regarding the diagnosis and cancer stage for women identified by the program as having cancer. In addition, the linked data set benefits cancer registries by identifying potentially missed cancer cases and providing missing race data. For example, studies have been performed using the data set to compare stage of disease at the time of diagnosis with screening histories among women with cancer.^{34–36}

Colorectal Cancer Control Program

Beginning in 2009, the CDC awarded funds to 29 state and tribal grantees to implement the Colorectal Cancer Control Program (CRCCP).^{37,38} A second round of funding was awarded to 30 grantees (states, universities, and 1 tribe) in 2015, stipulating a decided shift in program emphasis to increase and integrate the use of recommended evidence-based interventions from the Community Preventive Services Task Force (www.the-communityguide.org/findings/cancer-screening-multi-component-interventions-colorectal-cancer) to increase colorectal cancer screening within partner health systems, such as federally qualified health centers. CRCCP priority interventions include client and provider reminder systems, provider assessment and feedback, and removal of structural barriers to screening. Among the initial CRCCP programs, there was a higher use of evidence-based interventions compared with nongrantees³⁹; however, fewer of these were implemented by CRCCP grantees than other interventions, although they potentially have a greater impact on screening rates.⁴⁰

Enhancing Cancer Genomic Best Practices

The CDC currently supports 5 state health departments (Colorado, Connecticut, Michigan, Oregon, and Utah) in developing or expanding programs that rely on education, surveillance, and policy to assist individuals who are at high risk of developing cancer based on inherited genetic factors that predispose some persons to developing certain cancers (http://www.cdc.gov/cancer/breast/what_cdc_is_doing/genomics_foa.htm). The current program began in 2014, and follows a previous 3-year program with 3 grantees and earlier genomic activities supported by the CDC. Under this program, state grantees are encouraged to take advantage of collaborations with state cancer registries and comprehensive cancer control programs. The objectives of this program are to assess the burden of cancers based on inherited genetic factors and the use of services for genetic counseling and testing, increase knowledge about such services among health care providers and the general public, and improve access to these services for persons at high risk.

DISCUSSION

In the United States, cancer claims nearly 600,000 lives each year.⁴¹ It is the leading cause of premature death,⁴² and the leading cause of death in midlife (aged 45–64 years).⁴³ In addition, well over 1.5 million individuals each year are told they have cancer.⁴¹ The nation is facing the added challenge of responding to the aging of the population and the projected increases in the numbers of people diagnosed, living with, and dying of cancer.^{44–46} It is widely accepted that much of this cancer burden could be reduced through the expanded implementation of proven prevention interventions and programs by public health agencies.^{47,48}

Cancer control planning and evaluation at the population level is a data-driven process. All major cancer control programs rely on state cancer registry data to inform planning efforts, allocate resources to specific areas or populations, or evaluate progress. Cancer registries have been used to provide compelling data documenting variations in cancer incidence and cancer mortality within and among different populations.^{49–52} Combined data from the NPCR and SEER registries have provided sufficient numbers of incident cases to examine rare cancers, specific histologic types, cancers at specific ages, and regional variations.^{53–58} In addition to contributing critical knowledge regarding patterns in cancer occurrence and a resource for cancer researchers, cancer surveillance data provide essential data with which to guide cancer prevention and control activities at the national, state, and local levels. To have the greatest impact on promoting health and improving survival after a cancer diagnosis, partnerships between public health agencies, health care providers, and across multiple other sectors will be essential to address the underlying social determinants of persistent health disparities.⁵⁹

The combination of problems and challenges are unique to each state, and local data are critical to inform local activities. Measures of cancer survival at the population level rely on our extensive surveillance infrastructure, particularly a national network of high-quality cancer registries. These cancer survival measures offer new insights into the need to address inequities in cancer diagnosis, treatment, and survivorship.⁶⁰ Together with data regarding cancer incidence and death rates, cancer survival measures provide a comprehensive picture of the burden of cancer in a population and support public health efforts to prevent new cancers, extend survival and quality of life after a cancer diagnosis, and reduce cancer health disparities.

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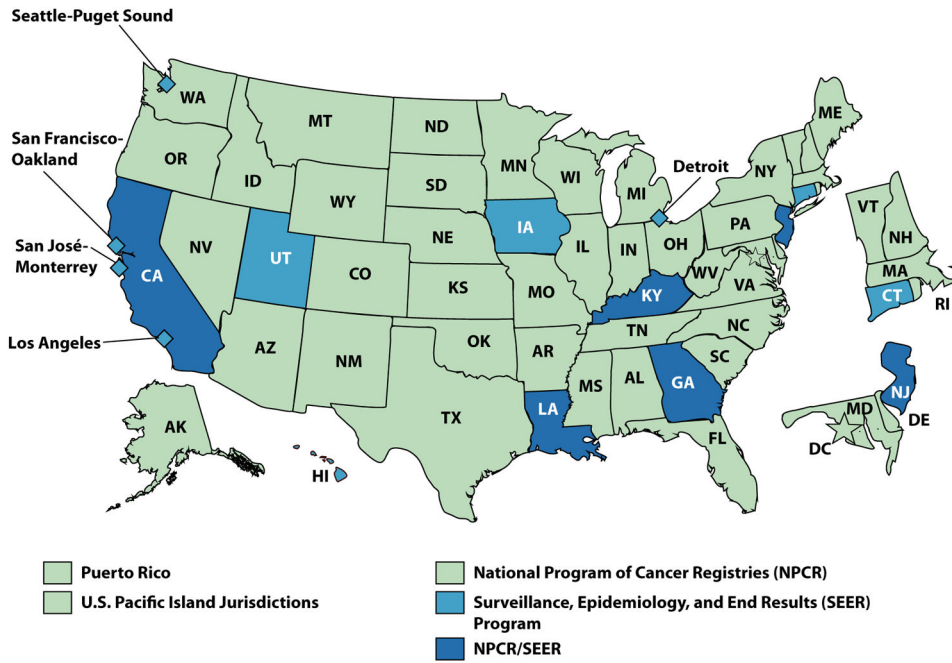


Figure 1. Funding status for cancer registries supported through the Centers for Disease Control and Prevention’s National Program of Cancer Registries or the National Cancer Institute’s Surveillance, Epidemiology, and End Results Program. Source: Division of Cancer Prevention and Control, Centers for Disease Control and Prevention (<http://www.cdc.gov/cancer/npcr/index.htm>).