

# Cancer Surveillance and Its Use to Reduce Cancer Burden in North Carolina

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The North Carolina Central Cancer Registry (CCR) is the state agency that collects data and produces statistics on the burden of cancer among North Carolinians. The CCR works closely with the North Carolina Comprehensive Cancer Control Program to plan and evaluate programs that address prevention, early detection, treatment, and survival. This article describes the history and purpose of the CCR, mechanisms of cancer reporting and processing, and uses of cancer data in cancer surveillance, program planning and evaluation, and research.

## History and Operation of the North Carolina Central Cancer Registry

The North Carolina General Assembly established cancer as a reportable disease in 1945 for the purpose of population-based cancer surveillance. The North Carolina Central Cancer Registry was formed after the General Assembly provided funding in 1985 to collect information on the incidence of cancer among North Carolina residents to compile relevant statistics and to support “public health work.”<sup>1</sup> Funding is also provided through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR) which funds central cancer registries in 45 states, the District of Columbia, and 3 United States territories.

The CCR is a unit of the State Center for Health Statistics (SCHS) in the Chronic Disease and Injury Section of the North Carolina Division of Public Health. (Paul Buescher, PhD, director of the SCHS, reports in this issue on other public health surveillance databases.) The CCR works closely with other units in the SCHS such as the Vital Statistics Unit to monitor mortality trends and the Survey Unit to monitor

screening and prevention behaviors. The addition of prevention, screening, and mortality data to incidence information (which includes stage at diagnosis and treatment) provides a more complete assessment of cancer burden. For instance, a shift to an earlier stage at diagnosis for a highly treatable cancer, such as colon cancer, should correspond with a declining mortality rate in the following years.

*“The Central Cancer Registry is structured to ensure complete, timely, and high quality production of cancer incidence data for use in cancer control and research.”*

The CCR is structured to ensure complete, timely, and high quality production of cancer incidence data for use in cancer control and research. Standards for reporting are set by the North American Association of Central Cancer Registries (NAACCR), of which the CCR is a member. The CCR also collaborates with other standard-setting organizations including the NPCR, the National Cancer Institute’s Surveillance Epidemiology and End Results (SEER) program, the American College of Surgeons Commission on Cancer, and the American Cancer Society.

Consistent standards across central cancer registries make meaningful national statistics and comparisons possible across

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states and regions. Cancer control and research programs can trust the sources of these data when measuring outcomes in different populations. To that end, NAACCR provides evaluation for certification of central cancer registries, and the CCR submits data each December for this purpose. The CCR has achieved NAACCR certification for every diagnosis year since 1997. The cooperative agreement with CDC through the NPCR also sets additional guidance and goals for the CCR, with the CCR submitting data for evaluation and incorporation into United States statistics each January.

## Completeness of Reporting

Complete ascertainment of cancer is the first priority of the CCR. This ensures accurate detection of disparities in incidence. The legislation that established the registry requires that all health care facilities that diagnose or treat cancer report to the CCR within 6 months of diagnosis. Reporting sources include hospitals, freestanding surgery and radiation centers, physicians' offices, pathology laboratories, nursing homes, and hospice agencies. Reportable conditions include all malignancies except *in situ* cancers of the cervix, and includes benign brain and central nervous system tumors. Because the CCR is a public health entity, reporting to the CCR is exempt from the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Information collected about each case includes demographics of the patient at time of diagnosis including name, Social Security Number, race, ethnicity,<sup>a</sup> date of birth, and address, as well as information about the diagnosis including cancer site, histology, stage and grade, and first course of treatment. Over 90% of the data are reported via the CCR's secure Web-based database. CCR staff members assist small facilities and physicians' offices with reporting.

## Changes in Cancer Reporting

Ten years ago almost all cancers were diagnosed and treated in hospitals, the primary source of cancer reporting. As more, large physician practices and freestanding chemotherapy and radiology centers have opened, cancers are being diagnosed and treated more frequently outside the hospital setting. Cancers such as prostate, melanoma, leukemias, and lymphomas are most often diagnosed at physicians' offices. Cancers of other sites such as breast and colon are often treated at small facilities with chemotherapy or radiation, without the patient being admitted to a hospital. To ensure that diagnosis and first course of treatment data are completely ascertained, CCR resources have been devoted to recruiting physicians to report cases although many of these small facilities do not have the trained staff or resources to adequately report the needed information.

Electronic reporting of cancer is necessary in order to make use of the electronic medical record and to promote efficient

use of scarce resources. For example, electronic pathology reports are linked with the current database to identify cases not previously reported. CCR staff then use the information provided in the pathology report to partially abstract the case and contact the ordering physician to complete the case information. This process not only increases immediate reporting and identifies facilities that may be underreporting, but also identifies physicians' offices for recruitment and reduces the information needed from those offices.

In 2007 the General Assembly passed legislation to fund a Cancer Research Fund to be administered at the University of North Carolina (UNC) at Chapel Hill.<sup>2</sup> The administrators of the fund have been consulting with the CCR and Comprehensive Cancer Control Program for ways to support these programs as they relate to cancer research. Identified areas for partnership with the registry include enhancing cancer treatment data and enhancing geographic information systems to study patterns of care.

## Accuracy of CCR Data

Data quality standards include accuracy and consistency of case abstraction and occurrence of few missing data items. This ensures that the data are appropriate for analysis and reporting. When a case is reported to the CCR, the data fields must pass a standard set of data requirements, and 90% are reviewed by certified tumor registrars (CTRs).<sup>3</sup> If a case for the same person has been reported previously by other facilities, CTRs determine if the case is a subsequent "primary" diagnosis or a "multiple primary." If the case has been reported previously by other facilities, the best information is selected from each report and a consolidated record is maintained for analytic use. The rules for consolidating records are standardized by NAACCR. Staff conduct routine quality control audits to identify common errors and follow up to provide training for reporting facilities.

Professional certification is provided by the National Cancer Registrars Association, and reporting facilities are strongly encouraged to hire CTRs for data collection and reporting. There is a nationwide shortage of CTRs, making recruiting difficult for both reporting facilities and for the CCR.<sup>4</sup> Recruiting new people to the rewarding work of cancer registration is necessary to ensure high quality cancer data.

## Cancer Prevention and Control Activities and Data Use in North Carolina

The first major steps taken to address cancer prevention and control in North Carolina began in the mid-1940s through the joint efforts of the North Carolina Medical Society and the American Cancer Society, and resulted in the passage in 1945 of House Bill 786 which authorized the establishment of the Division of Cancer Control as part of the State Board of Health.<sup>5</sup> In 1957 the first Governor's Cancer Commission was

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a The only ethnicity captured is Hispanic.

created and continued to exist in some form for the next 2 decades. Several ad hoc study committees followed. Finally in 1992, former Senator George Daniel and the late Representative Nick Jeralds helped to create a study commission that resulted in 1993 legislation creating the North Carolina Advisory Committee on Cancer Coordination and Control.<sup>6</sup> The Advisory Committee has continued its work since then. Two 5-year State Cancer Control Plans have been developed and disseminated (1996-2001, 2001-2006). A third 5-year plan was put on hold while transitioning to a new, continually evolving “living cancer plan,” which began to be distributed for public review and comment in the fall of 2007. The current plan can be found on the cancer control Web site at <http://www.nccanceradvisory.com/cancerplan.shtml>.

The purpose of the State Cancer Control Plan is to examine the burden of cancer in North Carolina and develop a set of goals and objectives. The goals and objectives are associated with strategies for adoption and implementation by public and private organizations, thus creating a blueprint for action.

In addition to mortality and Behavioral Risk Factor Surveillance System (BRFSS) data compiled by the State Center for Health Statistics, the Advisory Committee relies heavily on the work of the CCR to determine the extent of cancer risk and burden, to provide baseline measures for establishment of targets, and to provide the basis for measurement of progress towards meeting the goals. The following describe some of the ways cancer data have been used along the continuum of cancer control:

*Prevalence Estimates.* The CCR has partnered with UNC to statistically model the state’s cancer prevalence. This will be the first time cancer prevalence statistics will be available for North Carolina.

*Prevention.* Cancer incidence data can be used to target prevention educational messages to subpopulations. Several years ago, the CCR was involved in strategic planning for tobacco control by helping to target populations. In 2007 the CCR worked with the Advisory Committee’s Melanoma Task Force to identify areas in the state with high melanoma incidence at younger ages to support efforts at addressing tanning bed use.

*Early Detection.* Each year the CCR links the incidence data with data from the state’s Breast and Cervical Cancer Control Program to identify missed cases and to determine the stage at diagnosis for cases detected through the program.

*Treatment.* The CCR has worked with researchers from Wake Forest University to link both breast and colorectal cancer data with Medicaid paid claims data to evaluate access and quality of care across the state. Currently, the CDC’s Breast and Prostate Patterns of Care study is being conducted by 8 states, including North Carolina, to better understand disparities in cancer treatment and potential barriers to treatment.

*Survivorship.* Several research studies using CCR data have examined quality of life issues among cancer survivors. Contacting patients can be difficult for these studies since physician notification is required and often physician information is not reported or the physician at time of diagnosis is no longer relevant. New standards in reporting physician information will be in effect for 2008 diagnoses, remedying the first issue.

This year, the CDC negotiated an agreement with the Social Security Death Index and the National Death Index to make these data available to central cancer registries for follow-up and calculation of survival statistics. Survival statistics currently in widespread use are produced by the National Cancer Institute’s SEER program which follows all patients until death. Although the CCR links incidence data with North Carolina death records each year, many deaths are missed because patients move and die out of state. By linking incidence data with these additional data resources, the CCR will be able to produce its own survival statistics for the first time, which will be a helpful tool for physicians, patients, and researchers.

## Other Uses of Cancer Data in North Carolina

More broadly, data use activities include investigating patterns in cancer incidence and mortality across subgroups of the population, responding to citizens’ concerns regarding cancer in their communities, supporting research addressing the causes and outcomes of cancer, and supporting the planning and evaluation of prevention, early detection, and survivorship studies in cancer control. Examples of recent projects are provided to illustrate the variety of ways cancer incidence data are used to address the cancer burden in North Carolina.

*Routine Surveillance.* Each year the CCR examines the data across the state, evaluating trends over time, racial and geographic disparities, and patterns in stage at diagnosis. The CCR also produces annual reports of cancer incidence statistics and provides more detailed statistics upon request. The latest cancer incidence statistics by race, gender, and county are available on the State Center for Health Statistics Web site at <http://www.schs.state.nc.us/SCHS/CCR/>. Refer to the section “Availability of Data” in this article for information on how to obtain additional data.

*Response to the Public.* The CCR responds to citizens’ concerns about cancer in their communities by providing opportunities for education about the causes of cancer, how to reduce risk factors, and cancer screening. The CCR also works with the Occupational and Environmental Epidemiology Branch in the Division of Public Health to investigate possible links between exposures in the community and incidence of cancer. However, because there is often a long latency period between a carcinogenic exposure and a cancer diagnosis, it can be difficult to find such associations.

*Support of Cancer Research.* The CCR works with researchers across the state and the nation to study the causes and outcomes of cancer. There are currently 32 studies in which the CCR is directly involved or releases data for epidemiologic research. Many studies ask the CCR to link incidence data to external data sources. Examples include linkages with Medicaid data in order to look at differences in treatment, as well as linkages with cohorts of employees to study links between occupational exposures and cancer. The Agricultural Health Study, funded by the National Cancer Institute, the National Institute of Environmental Health Sciences, and the US Environmental Protection Agency, has linked information with the registry data in North Carolina and Iowa for the past 15 years to study the effects of a farmer's diet, physical activity, and exposure to pesticides on the incidence of cancer.

Researchers studying the causes of cancer and treatment choices of cancer patients often need to contact patients soon after diagnosis in order to enroll them into studies. Through a partnership with the University of North Carolina's Lineberger Cancer Center's Rapid Case Ascertainment (RCA) Core, the CCR is one of a few state central registries that offer this service for epidemiologic research to research institutions across the state. These university staff members represent the CCR and obtain pathology reports from hospitals within a few weeks of diagnosis. Current and recent studies using RCA include the role of diet and genetics in racial disparities in prostate cancer, risk factors and access to care for colorectal cancer, level of screening mammography in communities, risk factors for ovarian cancer, and risk factors and quality of care for meningioma, a common brain tumor.

## Availability of Data

Cancer incidence data by gender, race, and county are provided in reports on the State Center for Health Statistics Web site at <http://www.schs.state.nc.us/SCHS/CCR/>. Additional aggregate statistics are available by request. A version of cancer incidence statistics that can be queried online is expected in 2008. CCR staff members consult with requestors to assure the best information is

provided to address the research or program questions. Some aggregate statistics, in combination with information from other sources, may provide enough information to identify a patient. To mitigate the potential identification of individuals, aggregate counts are released only when there are 5 or more cases per cell of a table. If the number of cases is fewer than 5, the director of the State Center for Health Statistics must approve the data release. If patients are to be contacted for epidemiologic research, the Advisory Committee for Cancer Coordination and Control is consulted for review of the request.

Requests for aggregate statistics not available on the Web site can be obtained by contacting the statistical staff at the CCR at 919-715-7289.

## Future of Cancer Surveillance in North Carolina

High quality population-based cancer surveillance data are important for understanding the causes of cancer, detecting demographic and geographic differentials in cancer incidence, and tracking changes in cancer treatment and health care utilization. Projects slated for the next few years to improve our cancer surveillance data include an increase in electronic reporting from pathology laboratories and physician offices, survival analysis, and increased analytic capacity for linkages with external data sources for research. In 2007 the CCR migrated its database management system to California's system, which has a greater capacity to support these projects. Increased electronic reporting in the future will allow the CCR to more efficiently provide data for studies that require patient contact soon after diagnosis and will also increase the ascertainment of cancer cases for cancer control. **NCMJ**

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