



Cancer Control and the Central Cancer Registry of North Carolina

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The North Carolina Central Cancer Registry provides core data for focused epidemiological and public health approaches to cancer control in North Carolina. Since 1946, North Carolina law has required that new diagnoses of cancer be reported. From 1970 to 1985, the state-operated cancer registry used voluntary reporting, but in 1986 concerns about environmental issues and recognition of the paucity of cancer data led to a new legislative mandate. General Statutes 130A-205 through 130A-215 address cancer registration and data based research. They established a Central Cancer Registry (CCR) as the basis of a population-based cancer surveillance system. In 1994, the National Program for Cancer Registries initiated a program to enhance the capability of registries and facilitated the establishment of national standards. The formats for all data items were brought into compliance with the guidelines of the North American Association of Central Cancer Registries.¹ The General Statutes were updated in 1999, requiring that all health care providers report cancer cases, thus giving the CCR access to more complete data.

Why Have a Central Cancer Registry?

In order to have an effective cancer registry, *all* health care providers must support the collection of necessary data. Five of the primary justifications for a CCR apply directly to medical interests.

Disease Prevention. Prevention is a complex and multifaceted issue. Primary prevention is facilitated by central cancer registries, which can identify population groups with high and low occurrence, and can identify disparities in certain aspects of cancer care and incidence between rural and urban populations, and between black and white popula-

tions. Identifying groups with high incidence allows targeted interventions aimed at reducing cancer risk. Secondary prevention relies on disease control, which requires disease surveillance. The CCR is a surveillance tool, providing information about subgroups with late stage disease and high mortality rates.² This can enhance early detection and promote access to state-of-the-art cancer care, both goals of the CCR. Tertiary prevention, long regarded as a small part of cancer prevention, is now becoming a much greater consideration. Pain management, secondary cancer risks, and quality of life are other prominent issues. Improving survival rate for cancer and the longer life expectancies of the population raise the importance of the surveillance activity of the CCR.

Medical personnel are involved at all levels of prevention, particularly secondary and tertiary. The North Carolina Central Cancer Registry actively participates in studies of the value of early detection programs, the impact of screening activities, and pain control. Doctors who work with groups like the American Cancer Society help design analyses and evaluations of specific aspects of secondary and tertiary cancer prevention. The flexibility to work with specific requests is one of the strengths of the CCR.

Treatment. Studies of cancer treatment are an increasingly important reason for having a CCR. Registries that participate in the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program have led national efforts in such studies. Central cancer registries can extend the data collected on cancer treatment into rural and medically under-served areas. Two examples of this in North Carolina involve describing the patterns of staging for lung cancer patients and the patterns of adjuvant treatment for colon cancer. The data show clearly, from the proportion of lung cancer cases not staged, that blacks are less likely than whites to be treated for primary lung cancer. They also show

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Table 1. Research studies in collaboration with the Central Cancer Registry

Subject	Focus	Research Institution	Funding Source
Breast cancer	Molecular epidemiology	UNC ^a	NCI ^b
	In situ, risk factors	UNC	NCI
	Managing uncertainty through nursing intervention	UNC	NCI
	Breast conserving surgery	Triad	State
	Mammography	UNC	Army, NCI
Cancer Prevention Study II	Prevention	NC Div Health Promotion	ACS ^c
Colon cancer	Treatment by stage and size of tumor	Triad	State
	Molecular epidemiology	UNC	NCI
Care	Care-REACH	WFU ^d	NCI
	Pathways to Care	UNC, WFU	NCI
	Patterns of Care	UNC, WFU	NCI
	Cancer Care	WFU	NCI
	Cervix cancer	Screening utilization	NC Div Health Promotion
Prostate cancer	Determinants of stage at diagnosis	Duke	State, NCI
	Men under 65	Duke	NCI
	Prognosis	UNC	Dissertation
	Managing uncertainty through nursing intervention	UNC	NCI
Malignant melanoma	Molecular epidemiology	UNC	NCI
Head and neck cancer	Molecular epidemiology	UNC	NCI
Agricultural health study	Environmental risk	Battelle	NCI
Ovarian cancer	Molecular epidemiology	Duke	NCI

^a University of North Carolina at Chapel Hill; ^b National Cancer Institute; ^c American Cancer Society; ^d Wake Forest University

that rural Appalachian patients with colorectal cancer are less likely to receive combination surgery and chemotherapy than patients who live in urban areas or travel to major medical centers. Two earlier studies in North Carolina compared breast-conserving treatment for stage II breast cancer in urban and rural populations, and assessed the combination of chemotherapy with surgery for colorectal cancer. Such analyses reveal the factors influencing patterns of care.

Research. Research is a major justification for a CCR (see examples in Table 1). Federally-funded research became prevalent through the 1990s and continues today. It is promoted by the presence of a population-based CCR. The state's three Comprehensive Cancer Centers and its four medical schools often collaborate with the CCR. Various medical societies use the CCR for directed research projects. In addition to studies that focus entirely on cancer among North Carolinians, the CCR also uses its data to study cohorts in which cancer is not the primary focus. An example of this type of activity is data linkage with the cohort of Love Canal (NY) residents.

Environmental Issues. Many people are concerned about cancer threats from the environment; this is one reason for the many reports of cancer clusters. A recent paper by Aldrich and Sinks describes the clinician's role in responding to reports of cancer clusters.³ Doctors can play a significant role in the recognition of bona fide, if rare, clusters such as the association of exposure to asbestos with mesothelioma and lung cancer, and vinyl chloride with liver cancer.⁴

Educating the Public. Cancer is a profound concern for everybody. The CCR staff responds to more than 1,000 requests a year from citizens seeking information about cancer risks. Many of these requests, as well as reports of perceived cancer clusters, provide opportunities for education about cancer risk. This was the driving force behind the National Cancer Registry legislation (Public Law 102-515: the National Cancer Registry Act of 1992). By monitoring cancer incidence and mortality across the state, the CCR can help educate the public and shape cancer control activities in the future.

Collaborations

The CCR has a legislative mandate to collaborate with medical researchers. Specifically, it is charged to support efforts to "lower the morbidity and mortality of cancer in North Carolina." This includes "consultation with public health work," and "rendering assistance to hospitals, health planning agencies, and research facilities." To facilitate research and disease-control efforts, the CCR makes specific provisions to assure patient privacy.

The CCR participates in a number of research and cancer control projects. These include clinical studies, university-based programs, environmental health assessments, and the investigation of cancer clusters. To facilitate these studies, the CCR has developed two specialized procedures.⁵ One is rapid reporting (expedited case finding), which strives for case identification within two weeks of diagnosis;⁶ the other is enhanced data collection and the collection of data items of special research interest. For each of these procedures, researchers have provided funding to the CCR and to participating hospital registries.

Table 1 lists examples of studies that depended on having a central cancer registry in place before an application for funding could be submitted, and those that required CCR staff for implementation. Several of them (mainly epidemiological studies) required rapid reporting of cases. The REACH Program was the first such study, but others using rapid reporting include studies of breast, colon, and ovarian cancer. Support for most of the listed projects came from federal funding sources, but many data analyses were carried out by CCR staff focusing on specific hypotheses of interest.

Studies of rural populations are especially challenging, but often reveal important information about barriers to getting state-of-the-art cancer care.⁷ Studies performed by the CCR staff have looked at pediatric cancer, survival from prostate cancer, the relationship between brain cancer and the environment, and the relation between pancreatic cancer and pesticide exposure. One study, on breast conserving surgery and adjuvant care, was carried out in collaboration with the American College of Surgeons, the American Cancer Society and the Association of North Carolina Cancer Registrars (one of the so-called TRIAD Studies⁸). Collaborative activities have expanded in the past few years to involve other southeastern states; these now address all of the components of cancer control. This year, the American Cancer Society is helping states across the nation develop data-supported cancer control plans. Such collaborative efforts serve the best interests of all partners in cancer control.⁹

The CCR works closely with the North Carolina Advi-

sory Committee for Cancer Coordination and Control. The Advisory Committee has sponsored studies of unmet cancer care needs in the state, and of cost of care. These evaluations will help guide planning of state resources for indigent cancer patient care.¹⁰

Conclusion

The Central Cancer Registry is an integral part of cancer prevention, detection and control activities in the state. During the past year, the CCR was awarded the highest level of certification from the North American Association of Central Cancer Registries for its high quality and complete data. The CCR's collaboration with researchers and its participation in public health efforts across the state make it a valuable asset in our efforts to control cancer. All health care providers have a share in the success of this program.

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