Introduction

Cancer is a group of diseases in which there is an uncontrolled growth of abnormal cells in a part of the body. One out of every two men and one out of every three women in the United States will develop cancer during their lifetimes.[1] In 2011, cancer was the leading cause of death in North Carolina.[2] In order to determine the effect cancer has on the state's population, the North Carolina Central Cancer Registry (CCR) collects, compiles and tabulates data regarding the occurrence of cancer and reports the deaths due to cancer within the state. This report is a summary of the incidence and mortality due to cancer with the most complete and recent data the CCR has available.

Background

The CCR, located in the State Center for Health Statistics (SCHS), was established in 1986. The CCR operates under the authority granted in North Carolina General Statute 130A-208.[3] Legislation declaring cancer reporting to be mandatory in North Carolina became effective in 1947. Authorized funding for establishing a registry, however, was not appropriated until 1986. Between 1986 and 1989, only 50-60 percent of the cases were reported each year. The first year for which relatively complete statewide reporting was achieved was 1990. In 1999, new legislation was passed that requires every healthcare provider that detects, diagnoses or treats cancer cases to report all cases to the CCR.[3]

On a national level, the CCR reports data to the North American Association of Central Cancer Registries (NAACCR) [4] and the Centers for Disease Control and Prevention National Program of Cancer Registries (NPCR).[5] Both organizations annually review the data the CCR submits for its completeness, quality and timeliness. Completeness is the percentage of cases reported. Having high quality data ensures that there are not duplicate records per case and that certain data variables are accurate and complete. In order to meet the timeliness requirement, the data must be submitted within 23 months of the completion of the diagnosis year under review. For the last five years, the CCR has achieved the NAACCR Gold Standard for Registry Certification. This certification is the highest NAACCR standard awarded for completeness, quality and timeliness of data. The CCR continues to meet the requirements for NPCR in order to receive funding and to have data publicized nationally.

Purpose

As a population-based registry, the CCR collects, analyzes and disseminates information on the occurrence of cancer in North Carolina. The data collected include patient demographics (e.g., race, gender and age) and medical information on each cancer diagnosis (e.g., primary site, morphology, stage and first course of treatment). This information is used to improve cancer treatment and identify groups that have higher incidence and mortality from cancer.[6] The CCR preserves the confidentiality of information obtained for medical, educational, research and statistical purposes. No identifying information regarding patients, hospitals or physicians is released except under the conditions specified in General Statute and North Carolina Administrative Code.[3]

2011 Cancer Incidence and Mortality in North Carolina is the 18th annual report of the CCR. The contents of this report represent a summary of the information collected on cancer diagnoses and deaths in 2011. The information includes incidence and mortality counts and rates for all

cancers by county, race, gender and age. The primary goal of this report is to provide cancer data to healthcare planners, researchers and the general public.

Data Sources and Collection

Healthcare providers who detect, diagnose and treat cancer report cases to the CCR. The CCR receives data on death due to cancer from the Vital Records (VR) Branch, also located in the SCHS. The data are coded according to standard procedures and guidelines.

Cancer Incidence

Cancer incidence is the number of newly diagnosed cancer cases, not including recurrences, during a particular time period within a certain population. With each cancer diagnosis or treatment, the healthcare providers report the case to the CCR within six months. The CCR releases data approximately two years after the end of the diagnosis year, due to reporting delay, consolidation of records and cleaning of files.

From each case, the CCR collects patient demographics and medical information on the cancer diagnosis. Some demographics the CCR receives regarding an individual diagnosed with cancer include race, ethnicity, gender, age and residence. In addition, the CCR gathers data such as the first location of the cancer (primary site), the form of cancer (morphology), tumor size and the spread of the cancer (stage). Data regarding first course of treatment and vital status are also collected.

The CCR receives the majority of the cancer incidence data from healthcare facilities (hospitals, cancer centers, dermatology centers, urology centers and surgical oncology centers). Incidence data also come from physician offices, pathology reports, interstate data exchange, nursing facilities and death clearance cases. At present, there are 120 hospitals which routinely diagnose and treat cancer patients. Of these, 70 have tumor registries where the data are abstracted and submitted to the CCR. Also, there are 111 physician offices and clinics in North Carolina that report to the CCR. Death clearance cases are cancers reported in death certificates that were previously unreported cancer cases. The CCR received over 67,000 reports from 231 facilities in 2011.

Cancer Mortality

Cancer mortality is the number of deaths due to cancer during a specified time period within a certain population. Death certificates are filed to a county health director within five days. The death certificate is then passed on to VR on the fifth day of the following month.[3]

Once a year, VR provides the CCR with data on the deceased whose primary cause of death is cancer. This information includes demographics on the deceased including race, ethnicity, gender, age and residence. In addition to demographics, a primary cause of death and date of death are also collected.

Differences in Collecting Incidence and Mortality

For many studies, the CCR examines both incidence and mortality. Therefore, it is important to note differences in obtaining incidence data and mortality data. These differences include, but are not limited to, timeliness in reporting (both in state and out-of-state cases) and case finding.

There is a difference in the timeliness of reporting incidence and mortality data of cases reported in the state for North Carolina residents. For incidence data, the healthcare facility is supposed to report the case to the CCR within six months. However, with mortality data, a report of each death is submitted to the VR within two months.

Some people living near neighboring states go outside North Carolina for health care. Also, people may get diagnosed with or die of cancer outside of the state. North Carolina has an exchange agreement for cancer incidence data with 25 states and Washington, D.C., including its border states of Virginia, Tennessee and South Carolina. In addition, North Carolina has an exchange agreement with the other 49 states, as well as with Washington, D.C., and United States territories, for exchanging death certificates. Typically, incidence data are exchanged twice a year while mortality data, monitored by the National Center for Health Statistics (NCHS), are exchanged between states within two months of a death. However, even with these exchange agreements in place, delays or omissions can occur in the interchange of incidence and mortality records.

Although new cancer cases are required by law to be reported to the CCR, there are many that are not. Cases diagnosed in small hospitals that do not have a cancer registry may be under reported. Physicians associated with a large hospital will often report cases via a hospital registrar, but those not affiliated with a hospital may not have ample staff to report cases to the CCR. In the last few years, more cases are being diagnosed and treated in physician offices or surgical oncology centers and may never be referred to an oncologist nor be reported. The CCR has improved the completeness of reporting by recruiting physician offices and pathology laboratories as well as sending staff to smaller facilities to collect the required data. Despite the efforts of the CCR, incidence data are considered to be incomplete. On the other hand, death data are regarded as complete. Therefore, there may appear to be an excess of deaths compared to the number of cases for some cancers in rural counties.

Cancer Classification

The CCR receives an abstract of each medical record from a reporting facility. Each abstract contains specific medical information about the cancer. The cancers are categorized using codes according to the *International Classification of Diseases for Oncology, Third Edition.*[7] Each code is comprised of two pieces: topography and morphology. The topography code tells where the tumor began (primary site). The morphology code tells the type of cell (histology), the way it behaves within the body (behavior) and supplementary information about the tumor (grade). Care must be taken when coding lymphomas and leukemia.

The medical record also contains data regarding the cancer stage. The stage at diagnosis indicates how far the cancer has spread when it is first diagnosed. Knowing the extent of the cancer is important in treatment and prognosis. The CCR commonly uses National Cancer Institute's Surveillance, Epidemiology and End Results Program[8] definitions for staging and groups cancers as in situ, local, regional, distant and unknown.

In the data collected by the CCR, only malignant tumors are included with one exception. Data on benign brain and central nervous system tumors are also reported to the CCR. Only malignant tumors are included in this report. In situ cases are generally reportable to the CCR. However,

these tumors, with the exception of in situ breast and bladder cases, are not used in cancer surveillance or in cancer incidence statistics. Data on basal and squamous cell skin cancers are not collected by the CCR unless they have spread to tissue beyond the original site. Malignant melanoma may occur at many different body sites; however, this report focuses on melanoma of the skin.

Statistical Methods

Populations not only vary in size, but also in their racial, gender and age breakups. Thus, the counts of cancer incidence and mortality have limitations when comparisons are needed.

Rates are used to show the risk of an event occurring in a population and the CCR presents rates per 100,000 persons. The CCR calculates rates for both incidence and mortality data. A crude rate is found by dividing the number of events (e.g., cancer cases or deaths) for a population of interest in a specified time period by the population of interest at risk during the same time period. This ratio is then multiplied by 100,000 to express it as a rate per 100,000 persons. A crude rate can be expressed as

$$crude\,rate = \frac{count\ of\ events\ for\ a\ population\ of\ interest}{population\ of\ interest\ at\ risk} \times 100{,}000.$$

Crude incidence and mortality rates for 2011 used the population estimates obtained from the NCHS. Incidence reports published by the CCR prior to 2006 were calculated using the State Demographer's population estimates. Hence, rates from reports prior to 2006 are not comparable to rates in this report.

Age-Specific Rates

An age-specific rate is an example of a crude rate where the population of interest is a specific age group. For age group *i*, an age-specific rate can be calculated as

$$age\text{-}specific\ rate_i = \frac{count\ of\ events\ for\ age\ group_i}{population\ of\ age\ group_i\ at\ risk} \times 100{,}000.$$

A typical way to divide age groups is in five year increments (0-4, 5-9, …, 80-84, 85+). In this report, the ages are grouped as 0 to 19 (pediatrics), 20 to 44 (young adults), 45 to 64 (middle-aged adults) and 65 and older (senior adults).

Age-specific rates are used to examine the burden cancer has on a particular age group and to determine the need for services for a given population. In addition, they can be used to compare different population groups of the same age and notice the effect that cancer has on the various populations. Within a population, age-specific rates can be used to examine how cancer burden differs between age groups.

Age-Adjusted Rates

The occurrence of an event may vary with age, and the age structure of a population can vary as well. Therefore, age-specific rates are not always useful for comparisons and as a result must be adjusted to account for these differences. An age-adjusted rate is a weighted average of the age-specific rates expressed as a rate per 100,000 persons. Age-adjusted rates should be used only if the same standard population is used for computing weights. The standard population provides the proportion of the population in specific age groups and includes information regarding age,

but not race, sex or geographic location. The standard population the CCR uses is the 2000 United States Census population.

To calculate age-adjusted rates, multiply each age-specific rate by the proportion of individuals in that age group in the standard population. For example, for age group *i*,

$$weighted\ rate_i = age\text{-}specific\ rate_i \times \frac{standard\ population\ in\ age\ group_i}{total\ standard\ population}.$$

The age-adjusted rate is the sum of all the weighted age-specific rates. For *n* age groups the age adjusted rate is

$$age\text{-}adjusted\ rate = weighted\ rate_1 + weighted\ rate_2 + \cdots + weighted\ rate_n$$

An age-adjusted rate allows comparison between populations of different age groups, time periods and/or geographic areas. Age-adjusting ensures that discrepancies in rates of various populations are not a result of differences in age distributions.

Gender-Specific Rates

In addition to computing rates by age, rates can be computed by gender. For both incidence and mortality, gender data are collected by the CCR and VR, respectively. Gender-specific rates are used for comparison between different population groups of the same gender and to examine how cancer tendencies differ between males and females. Gender-specific rates are also used when calculating rates that only affect males (e.g., prostate and testes) or females (e.g., ovary and cervix).

Race-Specific Rates

Rates can also be calculated by race. Race-specific rates are used for comparison between different population groups of the race and to examine how the cancer burden varies between racial groups.

Both race and Hispanic ethnicity are collected by the CCR. Race information can be classified as one of the following: white, black, Asian/Pacific Islander, American Indian and other. Although the CCR has five race fields to account for people who are multi-racial, only the primary race is used. Often the CCR reports rates for whites and minorities. Minorities are defined to be blacks, Asian/Pacific Islanders, American Indians and others. To assist in identifying Hispanic ethnicity, the CCR uses the NAACCR Hispanic Identification Algorithm (NHIA). This algorithm uses name, birthplace, gender and race to determine Hispanic ethnicity.[9] Thus, the CCR can report rates on white non-Hispanics, black non-Hispanics, other races non-Hispanics and Hispanics.

Reliability of Rates

Precautions should always be taken when comparing rates. Rates are not a measure of actual risk. They are used to compare cancer burden between time periods, age groups, gender groups and racial groups. Both the size of the numbers and the characteristics of the population are important indicators of the real value of the rate. Rates based on a small number of cases or for sparsely populated geographic areas should be viewed with caution. Small fluctuations can lead to drastic changes. Therefore, sometimes it is more appropriate to look at the number of cases instead of the rates. When the number of events is small, multiple-year summary rates will

provide a much better measurement of risk. Expanding the period of time studied enlarges the absolute numbers and adds more credence to a statement regarding a rate.[10]

Limitations of Data

When comparing rates between two populations, the user should note that age structure is the only difference between the populations for which rates have been adjusted. Since county demographics can vary considerably, one needs to be careful not to misinterpret rates. Racial composition, for example, can have a marked influence on the patterns of cancer incidence and mortality. Under-reporting, due to out-of-state cases or poor case-finding in some non-hospital situations, also needs to be taken into account when making comparisons of cancer data.

Summary of 2011 Cancer Data

The CCR collected approximately 50,764 cases of newly diagnosed cancers and 18,201 deaths due to cancer in 2011 (Table 1). Female breast, prostate, lung and bronchus, and colon and rectum cancers were the leading diagnosed cancers among all gender and races combined. The CCR often refers to these as the top four cancers (Table 2).

Cancer risk is strongly associated with lifestyle and behavior. Dietary patterns, alcohol use, and sexual and reproductive behaviors, which vary by demographic groups, are risk factors of cancer. Cancer is diagnosed more often among older North Carolinians than younger ones. In general, males have a higher burden of cancer compared with females. Overall, non-Hispanic blacks and non-Hispanic whites had the highest incidence and mortality rates when compared with non-Hispanic other races and Hispanics. Lung and bronchus cancer was the most common cause of death due to cancer.

Age

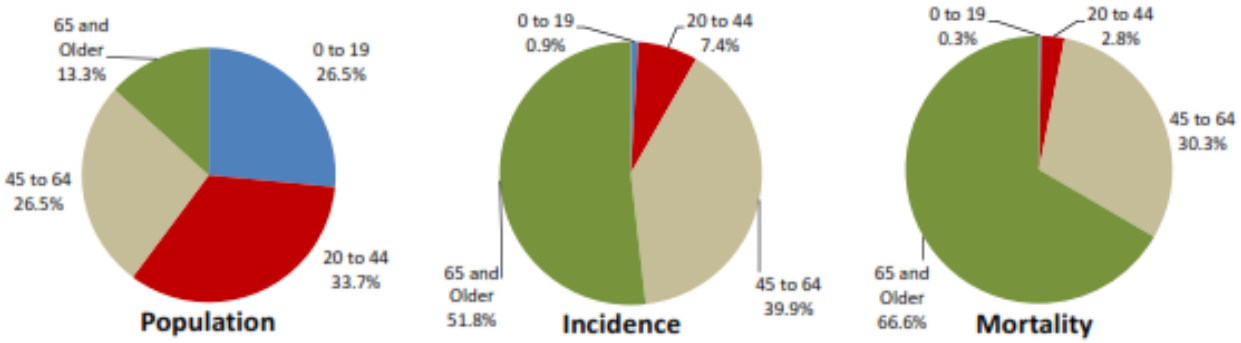
More adults are directly affected by cancer than children. Senior adults (ages 65 and older) made up about 13 percent of the population in 2011,[11] but accounted for over 50 percent of newly diagnosed cancer cases and two-thirds of deaths due to cancer. Children (ages 0 to 19) were the second largest age group, but made up less than 1 percent of both newly diagnosed cancers and deaths due to cancer (Chart 1). In 2011, the median age at which cancer was diagnosed was 65, but people ranged in age from 0 to 104. People who died of cancer ranged in age from 0 to 104 with the median age being 71. The median age of incidence and mortality for each age group as well as the percentage of cases and deaths the top four cancers comprise are shown below. In both middle-aged and senior adults, the top four cancers combined accounted for over half of the cancer cases and cancer deaths (Chart 2).

Children had a very different pattern of cancer than adults. Leukemia, brain cancer, endocrine cancer and Non-Hodgkin lymphoma accounted for over 45 percent of cancers diagnosed in people under age 20. Leukemia, brain, bone and soft tissue cancers made up over 75 percent of pediatric cancer deaths (Tables 5 and 6).

Young adults (ages 20 to 44) had a different pattern of cancer than children. In this age group, there was a greater incidence of female breast, cervical, uterine and prostate cancers than in the pediatric age group. On the other hand, the proportion of leukemia, bone, brain and liver cancers was lower. Female breast cancer accounted for over 15 percent of all cancer deaths and had the

highest mortality rate within this age group. The mortality rate for female breast cancer was more than 2.5 times higher than the next highest cancer rate, colon and rectum (Tables 5 and 6).
Cancer patterns were different in middle-aged adults (ages 45 to 64) compared with young adults. In this age group, there was a higher frequency of prostate cancer. The percentage of testicular cancer and Hodgkin disease was lower. In addition, the number of deaths due to testicular cancer was lower. The frequency of prostate cancer deaths was higher for middle-aged adults than young adults (Tables 5 and 6).

Chart 1: 2011 Percentages of N.C. Population, Cancer Incidence and Mortality by Age



In senior adults, cancer patterns were similar to middle-aged adults. The incidence of testicular cancer continued to be lower. Lung and bronchus cancer accounted for more deaths than colon and rectum, female breast and prostate cancers combined (Tables 5 and 6).

Chart 2: 2011 Median Age and Percentage of Top Four Sites for Cancer Incidence and Mortality by Age Group

	Incidence		Mortality	
	Median Age	Top 4 Sites	Median Age	Top 4 Sites
Children (ages 0-19)	8	2.5%	11	0.0%
Young Adults (ages 20 to 44)	39	35.3%	39	37.7%
Middle-Aged Adults (ages 45 to 64)	57	55.7%	58	49.6%
Senior Adults (ages 65 and older)	74	56.4%	77	51.3%

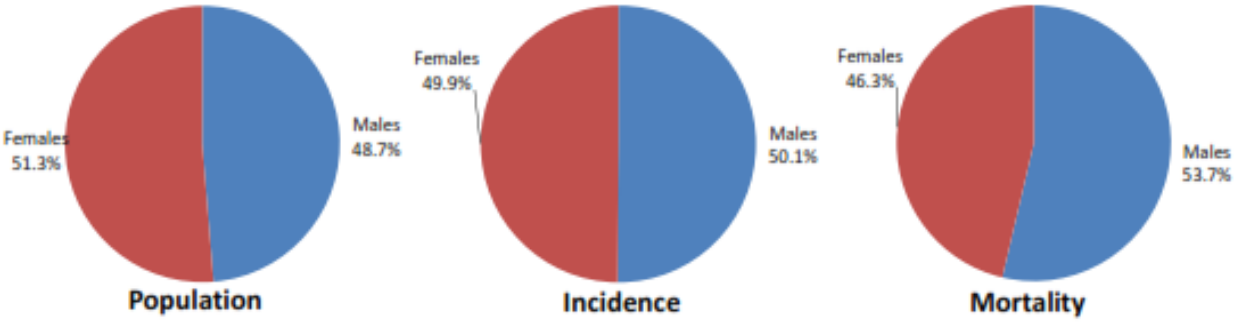
Gender

In 2011, slightly more than 50 percent of the state population was female. However, about half of all cancer cases were diagnosed in males and more than half of deaths due to cancer were in males (Chart 3). The median age of diagnosis for females was slightly younger than males, but the median age of mortality was similar between the genders. The top four sites comprised more than half of both cancer incidence and mortality (Chart 4).

The most frequently occurring cancers among males were prostate, lung and bronchus, colon and rectum, bladder and melanoma. Lung and bronchus, prostate, colon and rectum, pancreatic and leukemia were the leading causes of death due to cancer (Table 8).

Among females, the most frequently occurring cancers were breast, lung and bronchus, colon and rectum, uterine and endocrine. Lung and bronchus, breast, colon and rectum, pancreatic and ovarian were the leading causes of death due to cancer (Table 8).

Chart 3: 2011 Percentages of N.C. Population, Cancer Incidence and Mortality by Gender



Differences between genders could provide clues to factors involved in the development of cancer. Esophageal, laryngeal, bladder, liver and oral cavity cancers had a higher frequency among males compared with females. However, females had a higher frequency of endocrine cancer compared with males. In males, one third of deaths due to cancer came from lung and bronchus cancer, whereas in females, lung and bronchus cancer constituted one quarter of cancer deaths (Table 7).

Chart 4: 2011 Median Age and Percentage of Top Four Sites for Cancer Incidence and Mortality by Gender

	Incidence		Mortality	
	Median Age	**Top 4 Sites**	**Median Age**	**Top 4 Sites**
Males	66	52.1%	70	49.6%
Females	64	56.1%	71	51.0%

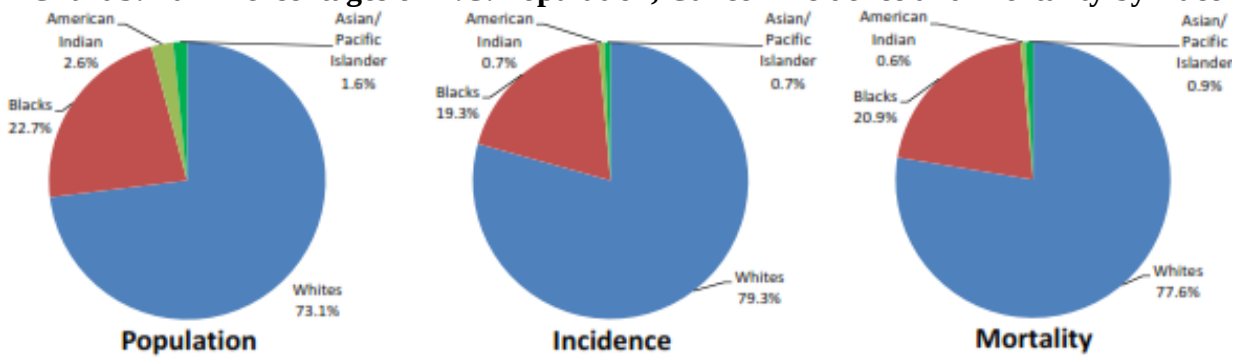
Race and Ethnicity

In 2011, about 73 percent of the North Carolina population was white. Blacks comprised more than one-fifth of the population. Almost 80 percent of cancer cases and more than three-fourths of cancer deaths occurred in whites while almost 20 percent occurred in blacks (Chart 5). The median age and the percentage the top four cancer sites comprise among all cancers for both incidence and mortality are displayed for all racial ethnic groups (Chart 6). Hispanics had the youngest median age of incidence as well as mortality. Approximately 60 percent of cancer diagnosed in non-Hispanic blacks were from the top four sites.

For non-Hispanic whites, besides the top four cancers, melanoma was the next most frequently diagnosed cancer. Pancreatic cancer was the fifth leading cause of death in this group. The number of lung and bronchus cancer deaths was about 1.7 times as large as the number of deaths due to female breast, colon and rectum, and prostate cancers combined (Table 14).

Among non-Hispanic blacks, prostate cancer comprised approximately 18 percent of all diagnosed cancers. Uterine cancer was also among the top five frequently diagnosed cancers for this group. Pancreatic cancer was the next leading cause of death after the top four cancers. The number of lung and bronchus cancer deaths was almost the same as the number of deaths due to female breast, colon and rectum, and prostate cancers combined (Table 14).

Chart 5: 2011 Percentages of N.C. Population, Cancer Incidence and Mortality by Race



For non-Hispanic other races, besides the top four cancers, bladder cancer was another commonly diagnosed cancer. Liver was the fifth leading cause of death due to cancer in this group (Table 14).

For Hispanics, outside of the top four cancers, uterine cancer was the most frequently diagnosed. Lung and bronchus cancer constituted 16 percent of cancer deaths. For other racial and ethnic groups, lung and bronchus cancers made up over 30 percent of cancer deaths. In Hispanics, pancreatic cancer was the fifth leading cause of death due to cancer (Table 14).

Chart 6: 2011 Median Age and Percentage of Top Four Sites for Cancer Incidence and Mortality by Race and Ethnicity

	Incidence		Mortality	
	Median Age	Top 4 Sites	Median Age	Top 4 Sites
Non-Hispanic Whites	66	53.0%	72	49.8%
Non-Hispanic Blacks	62	59.8%	67	52.8%
Non-Hispanic Other Races	62	55.3%	68	48.9%
Hispanics	54	40.7%	63	39.5%

Conclusion

This descriptive report is intended to serve as a reference on cancer incidence and mortality for healthcare planners, researchers and the general public. This publication should not be regarded as a definitive description of the cancer incidence in North Carolina. Although there are important limitations in the use of these data, the observed number of cases and the calculated rates within a county, a gender group, a racial and ethnic group, or an age group have many uses. These uses include planning and evaluating health services at the county and state level and identifying cancer disparities between specific groups. The data provided by the CCR can be used by the Comprehensive Cancer Program in the Division of Public Health and other research organizations for prevention, detection and treatment of cancer.

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