



Section I

Introduction and Technical Notes



CANCER IN NORTH AMERICA, 2000-2004

INTRODUCTION

The North American Association of Central Cancer Registries, Inc. (NAACCR) is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population based registries; aggregates and publishes data from central cancer registries; 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 in North America. NAACCR annually produces this statistical monograph on cancer in North America to provide cancer incidence and mortality statistics for the United States and Canada.

This year marks the 17th release of the annual publication of Cancer in North America (CINA). The 2007 monograph includes data from 65 central population-based registries: 52 from the United States (45 states, 5 metropolitan areas, the District of Columbia, and Puerto Rico) and 13 from Canada (10 provinces and 3 territories). This represents all but five states in the United States (Kansas, Maryland, Minnesota, North Carolina, and Vermont). The submitted data reflect 100% population coverage of Canada and 92% of the United States. Combined statistics are created from registries with high quality incidence data for all years, 2000-2004; more than 61% of the Canadian population and 82% of the U.S. population are covered in the combined statistics.

This monograph would not be possible without the commitment by population-based, cancer registries throughout the United States and Canada to collect timely, complete, and accurate data. The NAACCR standing committee, Data Use and Research (DURC), is charged with the annual call for data from member registries to create the CINA monograph and other useful CINA products for data analysis and cancer incidence information (e.g., CINA+ Online, CINA Deluxe). An Editorial Board of member volunteers, with support from the NAACCR Statistical Analytic Unit and staff, has the responsibility to oversee the call for data, evaluation of submissions, and all editorial decisions and activities in production of the monograph. Our efforts are to provide timely and useful information on cancer incidence and mortality for all geographic areas and race/ethnic groups. In recent years, this has been expanded to include data from U.S. territories and U.S. Hispanic/Latino populations. In the future, we are working to enhance the statistics available for the Asian/Pacific Islander and American Indian/Alaska Native populations.

CONTENTS OF THE CINA MONOGRAPH

The CINA monograph is comprised of four volumes as described below. Rates are presented as average-annual, age-adjusted rates using three different standard million populations: the 2000 U.S., the 1996 Canadian, and the World standard populations. We believe that by presenting cancer rates adjusted to all three standards enhances the meaning and utility of the rates for users in the United States, Canada, and international settings.

Volume One, Cancer Incidence presents cancer incidence data for NAACCR-member, population-based central cancer registries in Canada and the United States who have agreed to participate in the CINA monograph. For most cancer registries, five-year averages of data are presented for the years 2000 to 2004. If all five years of data were not available, an average of all available years is presented. Each set of data tables includes demographic and data quality information and registry descriptions to help interpret the statistics reported.

Volume Two, Mortality presents cancer mortality data for all geographic areas of Canada and the United States, including each nation as a whole. Since Quebec mortality is neither released to Statistics Canada nor submitted directly to NAACCR, these data were not available for inclusion.

Volume Three, NAACCR Combined Incidence for the United States, Canada, and North America presents cancer incidence data that have been combined to create five-year, average-annual statistics for the three geographies for cancers occurring in all persons and for children, aged 0 to 14 and 0 to 19 years. Registries submitting data must meet the NAACCR silver or gold criteria for high quality incidence data at the time of data submission. The criteria for the standard are described in detail below in the Data Quality Indicator section. In the United States, cancer counts and incidence rates are presented for all races combined and for black and white populations. In addition, the five most common types of cancer by race and ethnicity are provided for other racial groups, based on the combined United States data. Canadian and North American rates are for all races combined only.

Volume Four, U.S. Hispanic/Latino Cancer Incidence presents registry specific cancer incidence data for the Hispanic/Latino populations. Inclusion criteria for Volume Four are the same as for comparable tables included in both Volumes One and Three.

SOURCES OF DATA

Cancer Incidence. A cancer registry must be population-based and a NAACCR member to be included in NAACCR data publications. All cancer registries in the United States and Canada are NAACCR members, including three territories in Canada and three territories in the U.S. An annual request is sent to all members to submit voluntarily a data file for use in CINA, CINA research and data information products, the U.S. *Annual Report to the Nation*, and the American Cancer Society's *Facts and Figures* annual publication.

All NAACCR member registries receive support from the state, province or territory. In the U.S., they also participate in the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) Program or the Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR) or both. In Canada, all registries submit data to the Canadian Cancer Registry maintained by Statistics Canada.

Mortality Data. Mortality data for 2000 to 2004 for the United States and Puerto Rico were obtained from the National Center for Health Statistics (NCHS) of CDC, as provided to NCI. The Canadian registry mortality data for 2000 to 2004 were obtained from Statistics Canada's Canadian Mortality Data Base (CMDB), which as noted above excludes data from Quebec.

Population Estimates. To assist the reader, all population estimates by age, sex, and race/ethnicity (where relevant) used in the calculation of rates in the monograph are presented for each central registry and for the combined areas of the United States, Canada, and North America.

For the **United States**, individual states, and all SEER areas for 2000 through 2004, population estimates were obtained from the SEER program, based on United States Bureau of Census population estimates for these years. These population estimates represent a modification of the annual time series of population estimates produced by the Population Estimates Program of the Bureau of the Census with support from the NCI.

The population estimates incorporate bridged, single race estimates that are derived from the original multiple race categories in the 2000 Census. These bridged estimates are consistent with the four race groups enumerated in the 1990 Census and were produced under a collaborative arrangement between the National Center for Health Statistics (NCHS) and the Census Bureau. The methodology implemented by the Census Bureau to develop these county estimates is comparable to that used to produce national and state 1990-2000 intercensal estimates and is described on the Census Bureau's website (National Center for Health Statistics 2003).

NCI modifies the Census data for the population estimates for the State of Hawaii. The Epidemiology Program of the Hawaii Cancer Research Center has developed its own set of population estimates, based on sample survey data collected by the Hawaii Department of Health. This effort grew out of a concern that the native Hawaiian

population had been vastly undercounted in previous censuses. The “Hawaii adjustment” to the Bureau of the Census estimates has the net result of reducing the estimated white population and increasing the Asian and Pacific Islander population for the state. The Bureau of the Census estimates for the total population, black population, and American Indian and Alaska Native populations in Hawaii are unaffected. Refer to the SEER Cancer Statistics Review, 1975-2003 and its methodologies for specific documentation regarding modifications made by the NCI to the Census Bureau estimates (Ries 2006).

Puerto Rico provided population estimates for this U.S. territory. Neither race nor ethnicity identifiers are available, thus the data for Puerto Rico is for the entire population, regardless of race or ethnicity. Even though Puerto Rico is generally considered Hispanic, without the population counts by race and ethnicity, it was not possible to calculate specific rates for the Hispanic population living in Puerto Rico. Thus the cancer incidence counts and rates for Puerto Rico are included in Volumes One and Two for the whole population, but not in Volume Four, where race-ethnic specific rates are presented.

For **Canada**, Statistics Canada provided the estimates of the Canadian population for all Canadian provinces and territories, adjusted for census under coverage and non-permanent residents. Race information is not collected in Canada, and thus are not presented here.

CANCER SITE CODING, 2000-2004

Incidence Data. All cancer registries use the International Classification of Diseases for Oncology, third edition (ICD-O-3) to code the anatomic site and morphology. For the cases diagnosed prior to 2001, registries converted the International Classification of Diseases for Oncology, second edition (ICD-O-2) morphology (histology and behavior) codes to ICD-O-3 codes. Cancer incidence statistics include invasive cancers only, with the exception of *in situ* cancer of the bladder. Although tables include incidence statistics for breast cancer *in situ*, these cases are not included in any counts or rates of total cancer incidence.

The SEER program site recode groups were used for classifying types of cancer, using anatomic site and morphology. All categories used to present pediatric cancer rates in Volumes Three and Four are based on the International Classification of Childhood Cancer, third edition (ICCC-3) (Steliarova-Foucher 2005).

Summary tables of all codes and site groups for incidence were not printed, but can be found on the NAACCR website (<http://www.naacccr.org/cancerinnorthamerica>). The following list summarizes the Appendices for the four-volume monograph.

Appendix A: SEER Site Groups for Primary Site based on ICD-O-3

Appendix B: SEER Site Groups for Mortality Data Based on ICD-9 and ICD-10

Appendix C: SEER Site/Histology Recode Based on ICC3 Third Edition and ICD-O-3

Appendix D: Data Quality Indicators by Year and Registry

Appendix E: Race/Ethnic Case and Population Information for U.S. Registries

Appendix F: Comparison of NAACCR Data Item 190 (Spanish/Hispanic Origin) and NHIA Results by Registry

Mortality Data. Underlying cause of death was coded using the International Classification of Diseases (ICD). In the United States, ICD-10 was used for all deaths from 2000 and later. In Canada, ICD-9 was used until 2000, and ICD-10 was used for 2001 and later. Cancer deaths were defined as those coded 140.0 through 208.9 in ICD-9 and C00 through C97 in ICD-10.

The SEER mortality recode scheme was used to classify cancer deaths into the groupings used in the volume (see Appendix B on the NAACCR website, (<http://www.naacccr.org/cancerinnorthamerica>)).

CANCER CODING CHANGES DURING 2000-2004

Cancer Incidence. Several definitional changes occurred in some histologies and behaviors in ICD-O-3 that affected the inclusion and exclusion of reportable cancers diagnosed beginning in 2001. These changes may affect the comparability of data reported here with previous CINA monographs. The changes predominately affected leukemias, lymphomas, and cancer of the ovary. One category of change between ICD-O-2 and ICD-O-3 is the manner in which leukemias and lymphomas are classified and coded. Although conversion of histology codes from ICD-O-2 to ICD-O-3 for cases diagnosed prior to 2001 will help to minimize these differences, some minor differences may still exist, particularly with respect to some relatively rare lymphocytic cancers that can be coded to either leukemia or lymphoma.

Starting with ICD-O-3, several myelodysplastic diseases and syndromes are considered malignant, and therefore are now reportable for cases diagnosed in 2001 and later. Because these cancers were not reportable for the entire time period covered by this monograph, they have been excluded from the tables. Leukemias that represent a disease progression from one of the myelodysplastic diseases or syndromes diagnosed in 2001 and forward are no longer reportable. It is unlikely that this change will have a large impact on the counts or rates for leukemia in the years immediately following this change, but the affect may be larger in subsequent years.

For pediatric cancers, differences in incidence rates may be due to changes between the second and third edition of the International Classification of Childhood Cancers (ICCC). For example, incidence rates of non-Hodgkin lymphoma cancers presented in this monograph are much higher than those presented based the previous version of ICCC. Two changes in the ICCC-3 classification are main contributors to this change. 1) Burkitt lymphoma and unspecified lymphoma, which were separated from non-Hodgkin lymphoma prior to use of ICCC-3, are combined with non-Hodgkin lymphoma in this monograph; 2) Some lymphomas, which were grouped in the miscellaneous lymphoreticular neoplasms in previous monographs, are included in the non-Hodgkin lymphoma category of this monograph.

Borderline serous, mucinous and papillary cystadenomas, which had been reportable as invasive malignancies using ICD-O-2, are no longer reportable because they are not considered invasive or *in situ* malignancies in ICD-O-3. Most tumors with these histologies occur in the ovaries, and this change affects a relatively large proportion of ovarian tumors. Based on previous analysis of NAACCR combined data, this is about 13% of all ovarian cases, but the proportion may vary by registry (Goodman, et al., 2003). For comparability over time, the borderline tumors were removed from analysis. This change went into effect for the 2004 monograph. The ovarian cancer rates provided since this change are only comparable to the rates in the 2004 to 2006 monographs.

Pilocytic astrocytoma is considered to have uncertain behavior in the published version of ICD-O-3, but is reportable as a malignant cancer in North America. Including the childhood astrocytomas in the category of malignant brain tumors may introduce differences between childhood brain cancer rates in North America compared to other areas of the world that may not include these tumors as malignant.

In addition, mesothelioma and Kaposi sarcoma cases were reported as separate categories (see Appendix A on the NAACCR website, (<http://www.naacr.org/cancerinnorthamerica>)). This change has little or no impact on most rates for specific cancers.

Cancer Mortality. Among the many changes in ICD-10 were increases in classification detail, the shift to an alphanumeric classification system, and a number of changes in the coding rules by which a single cause of death is selected from among the multiple causes reported by physicians as causing or contributing to the death. The change from ICD-9 to ICD-10 caused discontinuities in trends for many causes of death, including cancer. The extent of these discontinuities has been measured by comparability studies in which death records are double coded using both the Ninth and Tenth Revisions, and the results compared. Overall, approximately 0.7% more deaths are assigned to cancer when ICD-10 is used than when ICD-9 is used (Anderson et al, 2001). For some

cancers, the differences are larger. Accordingly, the death rate for all cancers combined is higher when ICD-10 is used than when ICD-9 is used. This general rule does not hold for specific cancer sites, whose rates may be higher or lower using ICD-10. However, as discontinuities are small, changes in death rates across the years of the (ICD-9/ICD-10) boundary are still interpretable, especially for major cancer sites.

Cancer deaths among non-residents and deaths of unknown sex or age were omitted from all calculations.

Hispanic/Latino Ethnicity Identification. The ethnicity available in medical records and reported to cancer registries is enhanced by the use of the NAACCR Hispanic Identification Algorithm, version 2 (NHIAv2). NHIAv2 uses a combination of NAACCR variables including directly identified ethnicity from the Spanish/Hispanic Origin variable (NAACCR data element 190 values 1-6), and information indirectly derived based on an evaluation of the strength of the birthplace, race, and surname (including maiden name when available) associations with Hispanic ethnicity status. After applying NHIAv2, cases not ultimately classified as Hispanic are classified as non-Hispanic, with no cases having an unknown Hispanic status. A comparison of the direct and indirect categorization of ethnicity is provided in Appendix F available from the NAACCR website (<http://www.naacccr.org/cancerinnorthamerica>).

The NHIAv2 method is described in detail elsewhere (Howe et al, 2003; NAACCR Expert Panel in Hispanic Identification, 2003; NAACCR Latino Research Work Group, 2005).

DATA QUALITY INDICATORS

NAACCR assesses the quality of cancer incidence data from individual registries for a number of data quality indicators, which are described in detail below. Results for these indicators can be found in Volume One and are summarized in Appendix D (<http://www.naacccr.org/cancerinnorthamerica>). A dash in the tables indicates that data were not submitted for the year or were not able to be calculated.

In order to be included in the NAACCR Combined rates presented in Volumes Three and Four, the data had to meet the criteria for high quality incidence data. These criteria were applied to each year of data individually, except for the estimate of duplicate reports, which was calculated for the years 2000 to 2004 as a whole.

- Data for 2000 through 2004 had to be submitted to NAACCR by December 1, 2006.
- The NAACCR method to estimate completeness of case ascertainment yielded an estimate of 90% or higher.
- The estimate of duplicate case reports had to be less than 2 duplicate reports per 1000 cases.
- The percent of all cases derived from death certificates only (DCOs) was less than 5%.
- Fewer than 3% of cases had missing information for sex, county of residence at diagnosis, and age at diagnosis, and fewer than 5% of the cases had an unknown race.
- At least 97% of the cases had to pass the Call for Data EDITS metafile.

Timeliness of Data. The NAACCR standard defines timely data as data that are available for use in incidence statistics within 23 months of the close of a diagnostic year (i.e., December 1, 2006 for all cases diagnosed in 2004).

Completeness of Case Ascertainment. In order to evaluate registry specific case completeness, the NAACCR Method to Estimate Completeness is used. The method is described in detail elsewhere (Wu, et al., 2002; Howe, 2007). A data analysis tool is available on the NAACCR website that documents and calculates sex-, race-, and site specific estimates based on observed incidence counts and rates, observed local cancer death rates, and a standard rate ratio of incidence to mortality. In addition, adjustments are made to the calculations to account for some variation in sex-, race- and site-specific variation in case fatality.

Duplicate Case Records. Most central cancer registries rely on multiple reporting sources for cancer case reports. At the central cancer registry, multiple reports for the same patient must then be matched and the information from all records consolidated. In addition to determining whether multiple reports refer to the same individual, central cancer registry staff must also determine whether the tumor represents a new primary tumor or a duplicate report for a tumor already recorded. Failure to eliminate duplicate cases and duplicate tumors will result in over-counting cancer cases. As a part of routine cancer registry operations, a variety of tools are used to ensure accurate case linkage and case consolidation. As part of the preparation of the data submission to NAACCR, each registry uses the NAACCR protocol to determine the adequacy of case linkage and consolidation operations in identifying duplicate records.

The NAACCR protocol for assessing duplicate cases can be found on the NAACCR website, www.naacr.org.

Death Certificate Only Cases. The proportion of cases identified by death certificate only (DCO) is an indicator of data quality and completeness. Central cancer registries use death certificates to identify potentially missed cases and to conduct follow back on cases that have cancer on the death certificate but who are not incident cases in the registry. Cases without follow back information are considered to be DCO cases and may have incomplete or missing information, including date and stage of diagnosis. For DCO cases, the date of death is used as the date of diagnosis. Registries that did not use death certificates as a source of case ascertainment have “na” listed in the death certificate only row on the registry description page.

Missing Case Information. NAACCR has developed standards for completeness of data on key data items that are needed to produce meaningful cancer incidence statistics. These key data items include race, sex, county of residence at diagnosis, and age at diagnosis.

Cases with unknown sex or age are omitted from all calculations. Cases with unknown race and county of residence were included in the cancer counts and rates for all races and/or all counties combined.

Data Reliability and Accuracy. All data submitted to NAACCR are evaluated for reliability and accuracy using the EDITS program and a specific set of edits incorporated into a Call for Data Edits Metafile. An edit reviews the internal consistency between and among data elements, such as anatomic site and morphology. Cases that are identified as having errors are reviewed by registry staff and resolved prior to their NAACCR submission. The NAACCR Call for Data EDITS metafile is available on the NAACCR website. [URL: http://www.naacr.org/index.asp?Col_SectionKey=11&Col_ContentID=447, Last accessed March 9, 2007]

Although not used as a criterion in defining high quality incidence data for this monograph, an inter-record assessment program developed by the Centers for Disease Control and Prevention is used to identify errors among all reports related to one person. For example, an inter-record edit will identify whether a person’s birthplace is the same on all records related to this individual.

Site-Specific Microscopic Confirmation. This criterion is not used by NAACCR to determine high quality for the purposes of this publication; however, it is a useful indicator of quality of data collection. A proportion of microscopically confirmed cases that is higher or lower may suggest problems in case ascertainment or abstracting. However, this proportion varies by cancer site. For sites that are more likely to rely on a clinical or radiological diagnosis, e.g., cancers of the pancreas and brain, confirmation rates that are too high may suggest that some clinically diagnosed cases are missing. Also, registries that do not use death certificates for case finding have an artificially high proportion of microscopically confirmed cases, because DCO cases by definition do not have information on whether the tumor was microscopically confirmed. While no NAACCR standard has been determined for microscopic confirmation, the guideline we use is that the proportion should fall between 92 and 96 percent of all cancer cases, based on the experience of the SEER program.

CALCULATION OF STATISTICS

Rates. Rates are per 100,000 population and are age-adjusted by five-year age groups to the 2000 U.S. standard population based on single years of age (Ries, et al. 2006), the 1996 Canadian population standard (Statistics Canada, 2003), and to the World population standard (Parkin, et al., 2002). Rates for childhood and adolescents in Volume Three are expressed per million population. The incidence and death rates in this monograph are annual averages for the period 2000 through 2004. (Note: Not all registries submitted incidence data for all five years; their rates are annual averages for the years submitted.) The age distributions of the three population standards are presented below:

AGE GROUP	2000 U.S.	1996 CDN.	WORLD
00 years	3,794,901	12,342	24,000
01-04 years	15,191,619	53,893	96,000
05-09 years	19,919,840	67,985	100,000
10-14 years	20,056,779	67,716	90,000
15-19 years	19,819,518	67,841	90,000
20-24 years	18,257,225	67,761	80,000
25-29 years	17,722,067	72,914	80,000
30-34 years	19,511,370	87,030	60,000
35-39 years	22,179,956	88,510	60,000
40-44 years	22,479,229	80,055	60,000
45-49 years	19,805,793	71,847	60,000
50-54 years	17,224,359	55,812	50,000
55-59 years	13,307,234	44,869	40,000
60-64 years	10,654,272	40,705	40,000
65-69 years	9,409,940	37,858	30,000
70-74 years	8,725,574	32,589	20,000
75-79 years	7,414,559	23,232	10,000
80-84 years	4,900,234	15,424	5,000
85+ years	4,259,173	11,617	5,000
Total	274,633,642	1,000,000	1,000,000

Standard Errors. Standard errors (S.E.) of the rates were calculated using the formula:

$$S.E. = \sqrt{\sum \frac{w_j^2 n_j}{p_j^2}}$$

where w_j = the fraction of the standard population in age group j , n_j = number of cases or deaths in that age group, and p_j = person years denominator (Breslow and Day, 1987). For many registries, the standard error of the rates is small, as the population covered is large. However, for registries that cover a small population, the standard error may be substantial.

Confidence Intervals. Volume Four, Section V, presents bar charts of the age-adjusted rates by registries with 95 percent confidence intervals for each rate (Tiwari, et al., 2006). Users can determine whether the cancer rate for a specific registry is statistically different from the cancer rate for another registry, the United States, Canada, or North America by determining whether the confidence intervals overlap between the two areas. When they overlap, a statistical test should be done to determine whether the rates are actually statistically similar or not.

Comparison of Rates. In addition to true regional variation in cancer risk, differences in cancer incidence or mortality rates between areas may be due to either differences in the demographic make up of the population or differences in data quality. In making valid comparisons of cancer incidence rates among registries, it is important to review the data quality indicators for each registry before attributing rate differences to regional variation. In addition to data quality, it is important to consider differences in the racial composition of the populations being compared before conclusions are drawn about variations in regional rates. Interpretation without consideration of these factors may contribute to misleading or inaccurate conclusions. (See Appendix E, (<http://www.naaccr.org/cancerinnorthamerica>).

The standard error of adjusted rates can be used to evaluate the statistical significance of rate differences among comparable populations. For example, if the adjusted rates in two populations are R_1 and R_2 and their standard errors are $S.E._1$ and $S.E._2$, an approximate confidence interval for the rate ratio can be calculated using the following formula:

$$(R_1/R_2)^{1+z/x}$$

where $x = (R_1 - R_2) / \sqrt{(S.E._1^2 + S.E._2^2)}$ and $z = 1.96$ for 95% limits (Parkin, et al., 1992). If this interval does not include one, the two rates are statistically significantly different at a p value of 0.05. This test can be inaccurate for rates based on fewer than 16 cases or deaths, and it should not be used for rates based on fewer than six cases or deaths. It should be emphasized that this kind of comparison of adjusted rates must be undertaken with caution as misleading conclusions may be drawn if the ratios of the age specific rates in the two populations are not constant in all age groups. In these circumstances, the ratios of the adjusted rates will vary according to the standard populations used (Esteve, et al., 1994).

Cell Suppression. Counts and rates were suppressed (indicated by “-”) in the tables if the race, gender, and site specific number of case or deaths was less than six. These counts are included in the calculation of all sites combined. A dash is also used to indicate not applicable, as in the gender specific cancers. If the rate was less than 0.05 per 100,000 then the rate is listed as 0.0.

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