



Section I

Introduction and Technical Notes



CANCER IN NORTH AMERICA, 1999 - 2003

VOLUME THREE: NAACCR COMBINED INCIDENCE

INTRODUCTION

The North American Association of Central Cancer Registries, Inc. (NAACCR) annually produces a statistical monograph on cancer in North America to provide cancer incidence and mortality statistics for the United States and Canada.

The year 2006 marks the 16th release of the annual publication of Cancer in North America (CINA) series, the 10th monograph to include cancer mortality data, and the second to include cancer incidence data for Latino populations. Volume three of this monograph includes data from 43 central registries in the United States that met the NAACCR criteria for high quality of cancer incidence data. The registries are Alabama, Alaska, California, Greater Bay, Los Angeles, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Atlanta, Hawaii, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Detroit, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New York, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Texas, Utah, Washington, Seattle, West Virginia, and Wisconsin. These registries cover about 82% of the total United States population. The Canadian registries that met the high quality data criteria are also included in this volume. The registries included are Alberta, Manitoba, New Brunswick, Prince Edward Island, and Saskatchewan. A combined Canadian rate is not presented due to the large proportion of Canadians residing in provinces and territories that did not meet all of the inclusion criteria. The NAACCR Data Evaluation and Certification Committee (DECC) continues to review and discuss its application in Canada.

This monograph would not be possible without substantial effort by individual registries to collect timely, complete, and accurate data. NAACCR bylaws charges its standing committee, the Data Use and Research Committee (DURC), to gather data from member registries and review, evaluate, and compile the information for publication. It is the collective goal of NAACCR and its members to provide cancer statistics that are inclusive of all racial/ethnic groups in the United States and of all geographic areas in the United States and Canada.

MONOGRAPH FORMAT

The *Cancer in North America (CINA) 1999-2003* monograph includes four volumes:

- Volume One presents population-based cancer incidence data for individual central cancer registries within Canada and the United States who have agreed to participate in the CINA monograph.
- Volume Two presents cancer mortality data for all geographic areas of Canada and the United States. The Canada combined and United States combined mortality data are presented as well.
- Volume Three contains cancer incidence data combined from registries that met NAACCR criteria for high quality cancer incidence data (NAACCR Combined Incidence Data).
- Volume Four presents cancer incidence data for the Hispanic/Latino populations covered by central cancer registries in the United States who have agreed to participate in the CINA monograph. Combined incidence data for registries that met NAACCR criteria for high quality of cancer incidence data are also presented.

CONTENTS OF VOLUME THREE

Volume Three presents cancer incidence data that have been combined to create information for the United States, based on data from registries that meet at least the NAACCR Silver level criteria for high quality data at the time of data submission. In the United States, this includes cancer counts and incidence rates for populations of all races combined and for black and white populations separately. Registry data for Latino populations that meet the criteria are presented in Volume Four. Race-specific tables that include registry-specific data are also provided to facilitate comparisons among them. 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. Counts and rates for pediatric cancers are provided as well. The contents are as follows:

- Section I: Introduction and Technical Notes
- Section II: Average-annual Age-adjusted Cancer Incidence Rates for the NAACCR (United States) Combined by Sex and Race; Average-annual Age-adjusted Cancer Incidence Rates by Sex for Select Canadian Registries
- Section III: Average-annual Age-adjusted Pediatric Cancer Incidence Rates for the NAACCR (United States) Combined by Sex, Age, and Race
- Appendix A: The Recoding Classification Schema of Primary Site into SEER Site Groups, Based on ICD-O-2 (1/27/2003)
- Appendix B: The Recoding Classification Schema of Primary Site into SEER Site Groups, Based on ICD-O-3 (1/27/2003)
- Appendix C: SEER Site Histology Recode Based on International Classification of Childhood Cancer, Third Edition (ICCC-3) based on ICD-O-3 (5/3/2006)
- Appendix D: Data Quality Indicators by Year and Registry
- Appendix E: Percent Distribution of Incidence Cases and Population by Registry and Race, United States, 1999-2003

DATA QUALITY INDICATORS

NAACCR assesses the quality of cancer incidence data from individual registries for the following data quality indicators:

- The rate of duplicate case records on the data file
- Completeness of case ascertainment
- The proportion of cases with unknown or missing race, sex, county, or age information
- The proportion of death certificate only cases
- The proportion of error free records based on standard computerized edits and inter-record edits programs
- Timeliness of data

The method to measure each indicator is described in the following sections. If a registry did not submit data for all the years covered in this report, a dash is shown on the registry description page for the data quality indicators for the years not submitted.

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 consolidated. In addition to determining whether a subsequent report is for the same individual, the central cancer registry must also determine whether the tumor represents a new primary tumor, or a subsequent report for a tumor already recorded. Failure to eliminate duplicate cases and duplicate tumors will result in over-counting cancers. 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 assess duplicate records on a sample of cases to determine if duplicates still exist on the data file.

The NAACCR protocol for assessing duplicate cases can be found on the NAACCR website, www.naacr.org. The NAACCR standard for unresolved duplicates is fewer than 1 per 1,000 cases for the highest quality standard, Gold, and fewer than 2 per 1,000 cases for Silver. If the registry did not report the results of the NAACCR duplicate protocol, “na” is listed as the duplicate prevalence on the registry information page at the beginning of each registry’s portion of Section II.

Completeness of Case Ascertainment. In order to evaluate registry-specific case completeness, NAACCR developed a completeness measure based on cancer site, race, and sex-specific incidence-to-mortality rate ratios. The NAACCR standards for completeness based on this metric are 95% completeness for Gold and 90% for Silver.

Briefly, the method uses the age-adjusted incidence rates observed in the SEER program and the age-adjusted mortality rates for the entire United States to determine a standard incidence-to-mortality rate ratio. This standard is then applied to the registry-specific age-adjusted mortality rates to estimate an expected age-adjusted incidence rate. The expected incidence rate is then compared to the observed age-adjusted incidence rate to estimate completeness. This method provides a completeness measure that is relative to the completeness of the SEER program. It also includes an adjustment of the estimate based on the observed regional variation of the case-fatality rate ratio, due to regional variation in the decreasing trend of cancer mortality. The incidence-to-mortality rate ratio method is described in detail in *Cancer in North America, 1996-2000*.¹

For registries within the United States (other than Hawaii), the method is applied separately for black and white populations. For Hawaii and Canadian registries, the SEER incidence-to-mortality rate ratio for the white population is used as the standard for all races combined.

Missing Race, Sex, County, Age. NAACCR has developed standards for completeness of data on key data items that cancer registries need to produce meaningful cancer incidence statistics for their geographic area. These key data items include race, sex, county of residence at diagnosis, and age at diagnosis. To achieve the Gold standard, not more than 2% of cases can be missing information on sex, county, and age; and not more than 3% of cases from the United States registries can be missing race information. For the Silver standard, not more than 3% of cases can be missing sex, county, and age; and not more than 5% of cases from the United States can be missing race. The percent of cases missing these data items can be found on the registry information page at the beginning of each registry's portion of Section II of Volume One.

Cases with unknown sex or age were omitted from all calculations. Cases with unknown race were included in the computation of "all races" cancer counts and rates. Cases with unknown county of residence were included in the calculations, but cases that were not residents in the registry's jurisdiction were excluded.

Death Certificate Only Cases. The proportion of cases identified by death certificate only (DCO) is a measure 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. The proportion of cases that are DCO for each year is listed in the registry information page at the beginning of each registry's portion of Section II. Only invasive cancer cases are included in the denominator of the proportion. The NAACCR standard for percent of cases ascertained by death certificate only is not more than 3% for the Gold standard and not more than 5% for Silver.

Many new registries postpone the use of death certificates for case finding until the registry has data for at least five years, because deaths occurring in the early years of registration are likely to have been diagnosed before the registry's date of establishment. Were these deaths to be collected and registered as DCO cases, they might inflate cancer incidence during the first several years of registry operations because they are registered in the year of death. 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.

Passing EDITS. All data submitted to NAACCR is checked for quality using a standard set of quality control criteria termed EDITS (NAACCR EDITS metafile, Versions 10.2). EDITS contain checks of internal consistency between data elements, such as anatomic site and morphology, or between morphology and age. Cancer case reports that do not meet these criteria are either flagged by the central registry as having been confirmed as correctly coded, or the case generates an error when the EDITS software is applied. For example, EDITS will cause an error if a cancer case is reported to have carcinoma in the brain. Carcinomas do not arise in the brain because the brain does not contain epithelial tissue. Registries use EDITS to identify cases that have potential data errors so that they can be resolved prior to submission to NAACCR. The NAACCR Gold level standard is for all cases (100%) to pass EDITS. The Silver level standard is for 97% of cases to pass EDITS. The NAACCR EDITS metafiles are available on the NAACCR website.

Inter-record edits are used to find errors between records related to one patient rather than data fields within one record. For example, the IR01edit checks to see that the patient's birthplace is the same code on all records for the same patient. NAACCR requires that all participating registries run the Centers for Disease Control and Prevention (CDC) Inter-record Edits program and resolve all errors. The NAACCR standard is that 100% of the records pass inter-record edits. The CDC Inter-record Edits program link is available on the NAACCR website.

Timeliness of Data. The NAACCR standard for timeliness of data specifies that a registry must complete the accessioning and processing of the incident cases within 23 months of the case diagnosis year.

Site-Specific Microscopic Confirmation. Data users may also be interested in the proportion of total cases with microscopic confirmation. Although this criterion is not used by NAACCR to determine high quality for the purposes of this publication, it can also be a useful indicator of quality of data collection. Between 92 and 96 percent of all cancer cases registered in the SEER program are confirmed microscopically. 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 have unknown microscopic confirmation. There is no NAACCR standard for the proportion of records with microscopic confirmation.

Criteria for Combined Rates. In order to be included in the NAACCR Combined rates in this volume, the data from participating cancer registries had to meet the criteria for high quality data listed below. These criteria were applied to each year of data individually, except for the prevalence of duplicate reports, which were applied to the years 1999 to 2003 as a whole.

- Data for 1999 through 2003 had to be submitted to NAACCR by December 2, 2005.
- The prevalence of duplicate case reports had to be less than 2 per 1000.
- 97% of cases had to pass EDITS.
- Fewer than 3% of cases had unknown gender, county of residence at diagnosis or age at diagnosis, and fewer than 5% had unknown race.
- Percent of cases from death certificates only (DCOs) was less than 5%.
- Completeness of case ascertainment estimate was 90% or higher.

TECHNICAL NOTES

Data Sources

Incidence. Incidence data for the United States are from cancer registries that participate in the SEER (Surveillance Epidemiology and End Results) and NPCR (National Program of Cancer Registries) programs and are submitted to NAACCR. Each member registry provided its own incidence data for 1999 to 2003; all five years were required for inclusion in the combined rates. Cancer incidence data for registries in the United States SEER program were obtained from the SEER public use data file for seven registries, Connecticut, Hawaii, Iowa, Detroit, New Mexico, Utah, and Seattle (November 2005 submission) produced by the National Cancer Institute (NCI). In some instances, a SEER metropolitan program area such as Detroit may be located within the boundaries of statewide population based registry (e.g. Michigan). If the statewide registry does not meet the criteria for inclusion in this volume but the SEER metropolitan registry does, the SEER registry was included. If both meet the criteria, then the state registry data are included. Statistics Canada provided data for seven Canadian registries, while Alberta, Manitoba, Nova Scotia, and Ontario registries submitted their own data file. The cancer registry of British Columbia, submitted data on behalf of the Nunavut Cancer Registry.

Cancer registries reported invasive cancers only, with the exception of *in situ* cancers of the bladder and breast. Squamous and basal cell carcinomas of the skin were not reportable, except those of the lip and genital organs (see Appendices A and B).

Population Estimates - United States. Estimates of the population for the United States, individual United States states, and all SEER areas for 1999 through 2003 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.²

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, 1975-2002³ and its methodologies for specific documentation regarding modifications made by the NCI to the Census Bureau estimates.

With the increasing availability of single year of age population data, single-age standardizing populations were needed in order to be able to age-adjust by single ages as well as by any arbitrary age groups (e.g. <18, 18+). Since single years of age standards have not been previously published, SEER obtained the original single-age population projections from the Bureau of the Census that were used by NCHS in developing the 2000 United States standard million populations. The single-age standard millions were created from the single-age populations following NCHS's methodology. As expected, the sum of the single ages in the 19 age groups do not match the NCHS published standards. Rather than adjusting the new single-age standards to match previously published numbers, the raw NCHS population numbers were used for the standards. The new standards sum to 274,633,642 rather than 1,000,000.⁴

To maximize the flexibility and use of the cancer statistics presented in this monograph, incidence data are age-adjusted to not only the 2000 United States population standard, but also the 1996 Canadian population standard and the World population standard.

The registry information page in Section II of Volume One provided for each participating registry includes the estimated population of each registry by race and year, as well as the percent of the population in each race group for the 1999-2003 time period. Appendix E, Volume One also summarizes the percent of the population in each race group.

Population Estimates - 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.

The registry information page in Section II of Volume One provided for each participating registry includes the estimated population of each registry by year. Appendix E also summarizes this information for all registries. Canadian data are not stratified by race.

Definitions

Primary Cancer Sites for Incidence Data. All cancer registries participating in the monograph used the International Classification of Diseases for Oncology, third edition (ICD-O-3) to report the anatomic site of cancer and morphology to NAACCR. 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. This volume uses the SEER program's site recode groups for classifying types of cancer, using anatomic site and morphology (see Appendices A and B). The SEER Program's Site/Histology Recode based on the International Classification of Childhood Cancer, third edition (ICCC-03)⁵ based on ICD-O-3, was used to group cancers among 0-19 year olds.

There were several changes in the coding of histology and behavior effective with cases diagnosed from 2001 and forward with the adoption of ICD-O-3 that may affect the comparability of the data provided in this monograph compared to previous versions of CINA. These predominately affect 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 much impact on the counts or rates for leukemia in this monograph, but the affect may be larger in subsequent years.

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 *insitu* 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.⁶ For comparability over time, the borderline tumors were removed from analysis. This change went into effect for the 1997-2001 version of this monograph, and the ovarian cancer rates provided since this change are not comparable to the rates in the previous editions of this monograph.

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 Appendices A and B). This change has little or no impact on most rates for specific cancers.

Rates. Rates were calculated per 100,000 population and age-adjusted by the direct method to the 2000 United States, the 1996 Canadian (Cdn.) and the World population standards.⁷ Rates for childhood and adolescents in Volume Three were expressed per million. The incidence and mortality rates in this monograph are annual averages for the period 1999 through 2003. 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.⁸ For many registries, the standard error of the rates are small, as the population covered is large. However, for registries that cover a small population, the standard error may be substantial.

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.^{3,9}

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.¹⁰ 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.¹¹

For the first time this year, the SEER Program's Site/Histology Recode based on the International Classification of Childhood Cancer, third edition (ICCC-03)⁵ based on ICD-O-3, was used to group cancers among 0-19 year olds. Differences in incidence rates in this monograph compared with rates published in previous monographs may be due, in part, to the different classification systems used to group these cancer sites. For example, incidence rates on non-Hodgkin lymphoma cancers, presented in this monograph, are much higher than in previous monographs. 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 in previous monographs, 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.

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.

NAACCR MISSION

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.

Please address all comments and suggestions about the monograph to:

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The monograph is available for download or viewing from the NAACCR website (<http://www.naaccr.org>).

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