INTRODUCTION TO VOLUME THREE

CANCER IN NORTH AMERICA, 1996-2000

VOLUME THREE: COMBINED CANCER INCIDENCE

PURPOSE

The Data Evaluation and Publication Committee, a standing committee of the North American Association of Central Cancer Registries (NAACCR), produced this monograph. The NAACCR bylaws charge the Data Evaluation and Publication Committee to gather data from member registries, review, evaluate, and compile the information for publication. The year 2003 marks the 13th release of the annual publication of Cancer in North America (CINA) series and the 7th monograph to include cancer mortality data. This monograph reflects the much appreciated participation of NAACCR member registries, with cancer incidence coverage of 12 Canadian provinces and territories, 45 U.S. states, the District of Columbia, and five metropolitan areas in the United States (U.S.). We hope this effort continues to improve the completeness, the timeliness and the quality of data collected by member registries; to promote the use of their cancer registry data; and to provide cancer statistics that are inclusive of all racial/ethnic groups and geographic coverage of North America.

MONOGRAPH FORMAT

The Cancer in North America (CINA), 1996-2000 monograph includes three volumes: Volume One contains cancer incidence data for individual member registries, Volume Two contains cancer mortality data and Volume Three is comprised of NAACCR Combined Incidence Data. The data in Volume Three of this monograph include cancer incidence data for the years 1996 through 2000 from registries that meet the criteria for inclusion in the combined rates. Volume Three has four major sections as described below.

This year Canadian combined statistics are not included in this monograph due to concerns about the appropriateness of NAACCR inclusion criteria for Canadian registries.

VOLUME THREE, SECTION I: Introduction and Technical Notes

This section states the purpose of the monograph, describes the monograph format, details the various data sources and the NAACCR criteria for the combined cancer statistics for the United States, Canada, and North America, and provides data interpretation. Background information about NAACCR is also provided.

VOLUME THREE, SECTION II: NAACCR Combined Incidence Rates

The inclusion of registry data in the combined rates is reserved for those registries of highest quality, as demonstrated by meeting all criteria of completeness and standards of high quality data for each single year of all 1996-2000. The standards for such selection are described below under Technical Notes. All cases from qualified registries were included in the calculation of combined rates. However, in states where a SEER program is located within their boundaries, when both the SEER area and the state (e.g., Detroit, Metropolitan area and Michigan) were qualified for inclusion, only the state (e.g., Michigan) data were included in the combined rates.

In this section, combined cancer statistics and population estimates are presented for the United States. A general description regarding the population covered and several data quality indicators (both general and cancer site-specific) are provided for this geographic area with a map showing the registries meeting inclusion criteria for the combined rates. Combined rates for the major and minor cancer sites by the SEER groups are presented, using the same table format as those in Sections II and III of Volume One for individual registries. For the United States, combined rates are provided for all races (age-adjusted to four standard populations: 2000 U.S., 1970U.S., 1996 Canadian, and World), and for whites and blacks (age-adjusted to two standard populations: 2000 U.S. and 1970 U.S.).
In addition, summary tables of sex-specific counts and incidence rates for selected major cancer sites are presented for all races, whites, and blacks for individual registries included in the combined rates. However, the counts and rates are suppressed when fewer than six cases were reported for the specified sites, although the counts are included in the total and in the combined incidence statistics. Rates are age-adjusted to the 2000 U.S. and the 1970 U.S. population standards for U.S. registries. These summary tables facilitate comparisons among high quality registries. Before comparing rates among these registries, however, it is important to consider whether the populations are comparable by race (i.e., percent other races or percent unknown race on the registry description page in Section II of Volume One). It is also important to evaluate the quality of case ascertainment, as differences in rates may be attributable to case completeness and data quality, as well as to actual regional differences in cancer incidence.

Two tables presenting the five most common cancer types for eight race groups and for persons of Hispanic origin among males and females separately are also included in the combined section for the United States, as an initial step toward providing cancer incidence statistics that are inclusive of all racial/ethnic groups in North America. Several NAACCR committees have begun to assess the reliability of identifiers for race groups other than white and black in the United States. Our intent is that this effort will enable us to expand the presentation of cancer incidence rates in future monographs for more race and ethnic groups. With the availability of national, annual population estimates for American Indians/Alaskan Natives, Asian/Pacific Islanders, and Hispanic persons, evaluation of these population identifiers will be a primary focus during the coming years.

**VOLUME THREE, SECTION III: NAACCR Combined Incidence for Pediatric Cancers**

This section presents combined statistics for cancer among children and adolescents in the United States. These tables present age-adjusted rates for 0-14 year olds and 0-19 year olds as well as 5-year, age-specific rates for selected pediatric cancer types by race and sex. This year, sex-specific, age-adjusted, and age-specific rates were added for the age groups mentioned above. The age-adjusted rates were adjusted to the 2000 U.S., 1970 U.S., 1996 Canadian, and World standard populations. The cases were grouped into pediatric cancer groupings using the International Classification of Childhood Cancer (“ICCC” - see Appendix B) published by the International Agency for Research on Cancer (IARC) in 1996. ICCC has been updated in accordance with the new codes for lymphomas and leukemias which have been added to the ICD-O-2 standard for classifying newly diagnosed cases of cancer.

**VOLUME THREE, SECTION IV: Use of Override Flags in the 1995-1999 CINA File Submission**

This section contains a paper authored by Holly L. Howe and Joellyn Hotes as a data quality assessment. Concern has been expressed that override flags could be set without conducting proper review and follow-back. This would produce an EDITS output that shows no errors, a criterion required for gold certification and inclusion in CINA combined rates. It is of particular concern since the frequency of override flags is not included in the high data quality criteria, and no standard or guideline has been established for a reasonable frequency for setting these flags.

Among the certification categories, the median rate of override flag usage varied widely for some edits, but not others. The gold certified registries did not always have a median rate lower than the median rate of override flags for silver certified registries. The percent passing edits was higher for gold certified registries than silver certified registries on edits for age/site/morphology, site/type, surgery/diagnostic confirmation, histology, and report source. Median rates of override flags usage also differed between registries in the SEER program compared

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1-2 INTRODUCTION TO VOLUME THREE
with the NPCR program except for the sequence number/diagnostic confirmation edit where both had the same median. The median rate of override flags was greater in the SEER program than the NPCR program for the following edits: site/laterality/sequence number, surgery diagnostic confirmation, and site/type.

The results summarized above and other findings are described in greater detail and discussed by the authors, including interpretation for the number of override flags and recommendations for future studies.

TECHNICAL NOTES

Data Sources

Incidence. Each member registry provided its own incidence data for 1996 to 2000. Cancer incidence data for registries in the SEER program were obtained from the SEER public use data file (November 2002 submission) produced by the National Cancer Institute (NCI).

Population Estimates. Estimates of the population for the U.S., individual U.S. states, and all SEER areas for 1996 through 2000 were obtained from the SEER program, based on U.S. 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. Please refer to the SEER Cancer Statistics Review, 1975-2000 and its methodologies for specific documentation regarding modifications made by the NCI to the Census Bureau estimates. The following summarizes these modifications.

The initial modification affects only 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 has 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.

The population estimates now 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 and the Census Bureau.

A revised set 1990 through 2000 population estimates was recently obtained by NCI from the Census Bureau. This file contains populations by year, county, race, Hispanic origin, sex, and age. 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. Thus, statistics published here may differ from those published in previous editions of CINA.

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 1996-2000 populations for Northwest Territories reflects current geographic boundaries.

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Definitions

**Primary Cancer Sites.** SEER rules were used to define cancer sites (see Appendix A)\(^5\) for all ages combined. Numbers and rates include invasive cancers only, with the exception of cancer of the bladder, for which invasive and *in situ* cases were included in the counts and calculation of rates. Numbers and rates for carcinoma *in situ* of the breast were listed separately, when supplied by the registry. *In situ* cases of the breast were not included in the “All Sites” category. Squamous and basal cell carcinomas of the skin were excluded, except those of the lip and genital organs (see Appendix A). Cancers among non-residents of the area and cases with unknown sex or age were omitted from all calculations, but cases with unknown race were included in the computation of “all races” cancer counts and rates.

**Pediatric Cancer Types.** ICCC rules, predominantly based on morphology, were used to define cancer types (see Appendix B) for 0-19 year olds in Section III. Some ICCC groupings are not shown in the tables for pediatric and adolescent cancers because too few cases were found in the five-year data set to calculate stable rates. Numbers and rates were provided for invasive cancers only, with the exception of cancer of the bladder.

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Incidence Rates. Rates were calculated per 100,000 population for all ages combined and per million for children and adolescents and age-adjusted by the direct method to the 2000 U.S., the 1970 U.S., the 1996 Canadian (Cdn.) and the World standards. The incidence rates are annual averages for the period 1996 through 2000.

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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 \(j\) group (5-year age interval), \(n_j\) = number of cases in that age group, and \(p_j\) = person-years denominator. 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. 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:

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\[(R_1/R_2)^{\frac{1}{z/\mu}}\]

where \(x = (R_1 - R_2) / \sqrt{(S.E._1^2 + S.E._2^2)}\) and \(z = 1.96\) for 95\% confidence limits.\(^8\) 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, and it should not be used for rates based on fewer than six cases.

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.\(^9\)

While it is possible to compare incidence rates among populations in various individual registries, it is important to consider whether the groups are comparable by race (i.e., percent other races or percent unknown race from Section II of Volume One). One should also consider the registries’ quality and completeness as differences can be related to both true underlying differences and differences in reporting completeness and data quality. Interpretation without consideration of these factors may contribute to misleading or inaccurate conclusions.

**Combined Rates for the United States, Canada, and North America.** To be included in combined rates, a registry’s data had to meet or exceed six quality criteria for each single year, 1996, 1997, 1998, 1999, and 2000. This standard, equivalent to meeting NAACCR’s silver registry certification criteria for five consecutive years, is stricter than those used in the past. The six quality criteria are:

1. Data were submitted for each of the five years, 1996 through 2000.
3. 97\% of cases pass all internal consistency checks defined by NAACCR’s EDITS metafile, Version 9.1.\(^10\)
4. The code for “unknown” was used to describe:
   - sex in less than 3\% of the cases;
   - age in less than 3\% of the cases;
   - county of residence in less than 3\% of the cases;
   - race in less than 5\% of the cases;
5. Cases registered with information abstracted from death certificates only (DCOs) comprise less than 5\% of all cases for each of the five years’ data submitted.
6. Case ascertainment was estimated to be 90\% or higher for each of the five years’ data submitted.

NAACCR uses the incidence-to-mortality rate ratio method to measure completeness of case ascertainment. The method assumes that cancer death data are complete, and that the ratio of age-adjusted cancer death rates to age-adjusted cancer death rates by sex, race, and site vary little by geographical area in the United States and Canada. Over time, the interpretation of the incidence-to-mortality rate ratio has been refined. The following adjustments were made, either to the method itself or to the interpretation of the rate-ratios:

- It was assumed that 20 percent of any difference observed between analogous race-sex-site-specific, age-adjusted incidence-to-mortality rate ratios from two geographic areas could be attributed to differential case fatality, while 80\% of the difference could be attributed to under-ascertainment of cases in one of the jurisdictions. Previously, it was assumed that 100\% of the difference could be attributed to under-ascertainment.


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• Breast cancer cases were included in the model. Previously, breast cancer cases were excluded from the calculations because geographically diverse increases in mammography utilization had destabilized breast cancer incidence-to-mortality rate ratios. Recent data suggest that mammography use, breast cancer incidence, and breast cancer incidence-to-mortality rate ratios have become more uniform in the United States.

• All 11 SEER (14% of the U.S. population) areas have been used to construct SEER-incidence-to-U.S. mortality rate ratios. SEER has added areas to its geographic base over the years to increase its representativeness of the United States population. Previously, NAACCR had used data from the nine “original” SEER areas (10% of the U.S. population), because much was known about the nature of these data, their stability, and their relation to NAACCR data. As more became known about data from the additional two SEER areas, it became desirable to use data from all 11 areas in the construction of SEER-incidence-to-U.S.-mortality rate ratios, to enhance the representativeness of the ratios for the United States population as a whole.

• For similar reasons, data for both whites and blacks (weighted in proportion to their share of the population) were used to construct incidence-to-mortality rate ratios. Previously, data for whites were used exclusively for this purpose. Whites-only ratios were used with 1996-2000 data from Canada and Hawaii, as race is not used to differentiate population groups in either of these jurisdictions.

Race-specific completeness of case ascertainment in jurisdiction $s$ ($C_{sk}$) was computed by dividing the observed race-specific (white; black) age-adjusted (2000 U.S.) incidence rate for both sexes and all cancer sites combined ($\text{Observed } T$) by the expected race-specific (white; black) age-adjusted (2000 U.S.) incidence rate for both sexes and all cancer sites combined ($\text{Expected } T$):

$$C_{sk} = \frac{\text{Observed } T_{sk}}{\text{Expected } T_{sk}}$$


$$\text{Expected } I_{skij} = (M_{skij}) \left( \frac{I_{SEERkij}}{M_U.S. kij} \right)$$

$$\text{Expected } T_{sk} = \sum_{i=1}^{2} \sum_{j=1}^{N} \text{Expected } I_{skij}$$

where:

$I = \text{Age-adjusted (2000 U.S.) incidence rate for race } k, \text{ sex } i, \text{ site } j, \text{ 1996 to 2000}$

$M = \text{Age-adjusted (2000 U.S.) mortality rate for race } k, \text{ sex } i, \text{ site } j, \text{ 1996 to 2000}$

$s = \text{State, SEER area, province, or territory}$

$SEER = \text{Combined eleven SEER areas}^{11}$

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11 Includes Atlanta, Connecticut, Detroit, Greater Bay Area (San Francisco/Oakland and San Jose/Monterey), Hawaii, Iowa, Los Angeles, New Mexico, Seattle/Puget Sound, and Utah.
The cancer sites included in this calculation were buccal cavity and pharynx, esophagus, stomach, colorectum, liver, pancreas, lung and bronchus, melanoma of the skin (white only), female breast (excl. in situ), cervix uteri, corpus uteri and uterus, NOS, ovary, urinary bladder (incl. in situ), kidney and renal pelvis, brain and other nervous system, Hodgkin’s disease, non-Hodgkin’s lymphoma, multiple myeloma, and leukemia. Cancer of the prostate was not included because differential screening across regions has caused instability in prostate cancer incidence-to-mortality rate ratios.

Overall completeness of case ascertainment in jurisdiction $s$ ($C_s$) was calculated by adding weighted estimates of race-specific completeness of case ascertainment in jurisdiction $s$ ($C_{sk}$), using the proportion of the population in each of the race groups ($P_{sk}$) as weights:

$$C_s = \sum_{k=1}^{2} C_{sk} \times P_{sk}$$

This method of estimating completeness assumes that race-sex-site-specific incidence-to-mortality rate ratios are relatively stable (within 20% limits). The incidence-to-mortality rate ratio standard to which all registries were adjusted, using SEER incidence rates and U.S. death rates, is the current NAACCR standard for this purpose.

The same methods were applied to Hawaii and all Canadian registries, except that jurisdiction-specific data were not race specific, and SEER-incidence-to-U.S.-mortality rate ratios were computed for whites only.

$C_s$ was adjusted for the presence of duplicate records in the data of jurisdiction $s$ ($CA_s$) thus:

$$CA_s = C_s \times U_s$$

where:

- $CA = \text{Adjusted overall completeness of ascertainment}$
- $C = \text{Unadjusted overall completeness of ascertainment}$
- $s = \text{State, SEER area, province, or territory}$
- $U = \text{Proportion of unduplicated records, based on NAACCR’s Protocol for Assessing Duplicate Cases.}$


Every registry included in this volume had an adjusted completeness estimate of at least 90 percent for each year of the five years’ data submitted.

In the United States, 34 registries met all the criteria for inclusion in the combined rates. These were Alaska, Arizona, California, Greater Bay Area, Los Angeles, Colorado, Connecticut, Florida, Atlanta, Hawaii, Idaho, Illinois, Iowa, Kentucky, Louisiana, Michigan, Detroit, Minnesota, Montana, Nebraska, New Jersey, New Mexico, New York, North Carolina, Ohio, Oregon, Pennsylvania, Rhode Island, Utah, Washington, Seattle, West Virginia, Wisconsin, and Wyoming.

Impact of the Modified Population Estimates on the NAACCR Completeness Estimates. Recently the United States Bureau of the Census revised the U.S. population estimates that include errors of closure (using 2000 census data to adjust for the post-1990 census population projections). The revised population estimates have an effect on both the incidence and death rates differentially across cancer site and region. The completeness estimates for all cancer registries have also been affected. Despite this revision, the number of registries meeting the NAACCR combined inclusion criteria has increased compared to last year’s monograph, CINA 1995-1999.

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12 The cancer sites included in this calculation were buccal cavity and pharynx, esophagus, stomach, colorectum, liver, pancreas, lung and bronchus, melanoma of the skin (white only), female breast (excl. in situ), cervix uteri, corpus uteri and uterus, NOS, ovary, urinary bladder (incl. in situ), kidney and renal pelvis, brain and other nervous system, Hodgkin’s disease, non-Hodgkin’s lymphoma, multiple myeloma, and leukemia. Cancer of the prostate was not included because differential screening across regions has caused instability in prostate cancer incidence-to-mortality rate ratios.
Volume III. The population represented by these registries has also increased this year from 55 percent to 68 percent of the United States population.

Data Interpretation

Race-specific Rates. Race-specific (either white or black) incidence rates are presented for an aggregate only when more than five cases are included in that aggregate. (For aggregates with fewer than 6 cases, both counts and rates were suppressed.) Cases of unknown race are included in the “all races” category. Canadian data are presented for all races only. To facilitate comparisons among registries of similar race distribution, the proportion of unknown race and races other than black or white is reported in the Registry Description at the beginning of each registry’s section.

Percent DCOs. The proportion of cases identified by Death Certificate Only (DCO) has been used as a rough guide to assess completeness of case ascertainment. Only invasive cancer cases are included in the denominator of this proportion. The percent of DCO cases in a registry’s data set may be reduced by intensive “follow-back” to identify other sources of information on DCO cases.

Percent of Microscopic Confirmation. The proportion of total cases with microscopic confirmation can also be used as an indicator of the quality of data collection. From 92 to 96 percent of all SEER cases 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 rely mostly on a clinical 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.

Site-specific incidence-to-mortality rate ratios. These ratios can be used comparatively to determine completeness of registry data. A registry with a low incidence to mortality ratio may have incomplete ascertainment of cases. Other factors can also influence the site-specific incidence to mortality ratios, such as distribution of stage of disease at diagnosis or differences in coding of death certificates. Because the mortality rates reflect cases that may have been diagnosed prior to the years included in the incidence rates, the site-specific incidence-to-mortality rate ratios are not intended to be used as an indicator for survival. These ratios may be interpreted in the same way that overall incidence-to-mortality rate ratios are interpreted, adjusting for the larger relative standard errors associated with the incidence and death rates underlying the ratios. These ratios may be interpreted in the same way that overall incidence-to-mortality rate ratios are interpreted, adjusting for the larger relative standard errors associated with the incidence and death rates underlying the ratios.

Cell Suppression, Values of Zero (“0”) and “-” in the Tables. Although all cases from qualified registries were included in the computation of combined rates, counts and incidence rates were suppressed in the summary tables of selected major cancer sites if they had fewer than six cases. Suppression rules were also applied to the tables of pediatric cancer.

When the incidence rate or count for a specific group is presented as 0.0 or 0, this indicates either 1) that the rate is less than 0.05 per 100,000, or 2) that no cases were reported for the group. “-” is used when the count and rate were suppressed because fewer than six cases were found for the group in question. “-” is also used when data were not available for analysis or to signify “not applicable”, as in the case of female cancer of the prostate, an impossibility.

Comparisons Among Registries. All registries responding to the 2003 Call for Data are included in Sections II and III of Volume One. In making valid comparisons among registries, it is important to review the data quality indicators for each registry before attributing rate differences to regional variation. Data quality can be an important contributor to observed differences in rates. Selected site-specific rates from the registries of highest quality are included in the tables in Section II of Volume Three. 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.\textsuperscript{13}

**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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For a copy of this monograph, please contact NAACCR at the above address. The monograph can also be downloaded or viewed from the NAACCR web site (http://www.naaccr.org).

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