

# CANCER IN NORTH AMERICA, 1995-1999

## VOLUME ONE: 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 them for publication. The year 2002 marks the 12<sup>th</sup> release of the annual publication of *Cancer in North America (CINA)* series and the 6<sup>th</sup> monograph to include cancer mortality data. This monograph reflects the enthusiastic participation of NAACCR member registries, with cancer incidence coverage in all Canadian provinces and territories, 43 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)*, 1995-1999 monograph includes three volumes: Volume One contains cancer incidence data, Volume Two contains cancer mortality data, and Volume Three is comprised of NAACCR Combined Incidence Rates. The data in Volume One of this monograph include cancer incidence data for the years 1995 through 1999, unless indicated otherwise, for all participating registries. Volume One has three major sections as described below.

#### **VOLUME ONE, 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 rates for the United States, Canada, and North America, and data interpretation. It also provides some background information on NAACCR and lists member rosters of the Data Evaluation and Publication Committee and its subcommittees.

#### **VOLUME ONE, SECTION II: Registry-specific Cancer Incidence by Sex and Race, Age-adjusted to the 2000 U.S. and the 1970 U.S. Population Standards**

Incidence data are presented in this monograph for 61 central population-based registries: 49 from the United States (43 states, 5 metropolitan areas and the District of Columbia) and 12 (10 provinces and 2 territories) from Canada. This represents total coverage in Canada and all but 7 states (Arizona, Florida, Kansas, Mississippi, Oklahoma, South Dakota, and Vermont) in the U.S. None of the U.S. territories submitted their data this year.

The first page for each participating registry provides descriptive information about the registry, identifies the contact person(s), and summarizes several data quality and completeness indicators. This descriptive information about each registry is useful in evaluating the general data quality of the registry and the comparability of incidence rates and interpreting differences in incidence rates among the registries. These indicators are the percentages of death certificate only (DCO) cases, duplicate records (from the NAACCR protocol), and the NAACCR estimated completeness of case ascertainment adjusted for duplicates. The NAACCR adjusted estimates of completeness were not provided for registries that did not submit their results for the *Protocol for Assessing Duplicate Cases* (3 Registries). Although the data quality indicators presented on this page are for all covered years combined, data qualities have been evaluated for each of the single years of data. To assist in data comparisons across registries, the percentages of total cases that are of races other than white or black and of unknown race are also listed. The sources for case finding are included, with the diagnosis year that each was implemented (e.g., hospitals, death certificates, pathology laboratories, radiation therapy sites, interstate data

exchanges, physician's offices, ambulatory surgical centers, and nursing homes or hospices). The "Year case finding began" specifies the first diagnosis year of cases reported to a registry, not the year of operation in which a registry initiated case finding.

In addition to these general quality indicators, several cancer site-specific data quality indicators are presented. These cancer sites are selected based on both their frequent occurrence and their importance in cancer control and prevention activities. For each cancer, four data quality indicators are listed: the percent of DCO cases for that cancer site; the percent of microscopically confirmed cases; and the site-specific incidence-to-mortality rate ratios for whites and for blacks (except for Hawaii and Canadian Registries, for which ratios are calculated for all races combined). The same time periods for incidence rates, adjusted to the 2000 U.S. population standard, (numerator) and mortality rates (denominator) are used in computing the rate ratios. Incidence-to-mortality rate ratios are suppressed when fewer than 6 cases in either numerator or denominator were reported. For cancer types occurring in only one gender, e.g., prostate and ovary, the ratios are calculated based on the rates for the specific gender.

Following the registry description, annual age- and sex-specific population estimates for all races, whites, and blacks are reproduced for each registry in the United States. For Canadian registries, population estimates are presented for all races combined.

The cancer incidence tables show the total five-year (unless indicated otherwise) incidence counts and the average annual incidence rates age-adjusted to the 2000 U.S. and the 1970 U.S. population standards, by the SEER recode groupings for primary site based on the *International Classification of Diseases for Oncology, Second Edition (ICD-O-2)* and sex for all races, whites, and blacks for each registry in the U.S. except for Hawaii (all races only). Canadian registries use ICD-9 for their incidence data from 1995-1999. For Canadian registries, rates are presented only for all races combined because race identifiers are not collected by Canadian cancer registries.

### **VOLUME ONE, SECTION III: Registry-specific Cancer Incidence by Sex, Age-adjusted to the 1996 Canadian and World Population Standards**

Age-adjusted incidence rates for all races combined were also calculated for males and females separately using the 1996 Canadian and World population standards for all U.S. and Canadian participating registries.

#### **TECHNICAL NOTES**

##### **Data Sources**

**Incidence.** Each member registry provided its own incidence data for 1995 to 1999; if all five years were not available, data were provided for as many of the five years as possible. Cancer incidence data for registries in the SEER program were obtained from the SEER public use data tape (November 2001 submission) produced by the National Cancer Institute (NCI). Statistics Canada provided data for all Canadian registries; except Alberta and Ontario that submitted their own data.

**Mortality.** Mortality data for 1995 to 1999 for U.S. registry areas were obtained from the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC), as provided to NCI. For Canadian registries, the mortality data were obtained from Statistics Canada.

**Population Estimates.** Estimates of the population for the U.S., individual U.S. states, the District of Columbia, and all SEER metropolitan areas for 1995 through 1999 were obtained from the SEER program, based on U.S. Bureau of Census population estimates for these years. Statistics Canada provided the estimates of the Canadian population for all Canadian provinces and territories, adjusted for census under-coverage and non-permanent residents.

## Definitions

**Primary Cancer Sites.** SEER rules were used to define cancer sites (see Appendix)<sup>1</sup> for all ages combined data. Numbers and rates were calculated for invasive cancers only, with the exception of cancer of the bladder, for which invasive and *in situ* cases were included in the calculation of numbers and 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). Cancers in non-residents of the area and cases of unknown sex or age were omitted from all calculations, but cases of unknown race were included in the computation of “all races” cancer rates.

**Incidence Rates.** Rates were calculated per 100,000 population and age-adjusted by the direct method to the 2000 U.S., the 1970 U.S., the 1996 Canadian (Cdn.) and the World standards.<sup>2</sup> The incidence rates are annual averages for the period 1995 through 1999. (Note: Not all registries submitted five years’ data; their rates are annual averages for the years submitted.) The age distributions of the four population standards are presented below:

AGE GROUP	2000 U.S.	1970 U.S.	1996 CDN.	WORLD
0-4	6,913.5	8,441.6	6,623.5	12,000
5-9	7,253.3	9,820.4	6,798.5	10,000
10-14	7,303.2	10,230.4	6,771.5	9,000
15-19	7,216.9	9,384.5	6,784.1	9,000
20-24	6,647.8	8,056.1	6,776.1	8,000
25-29	6,452.9	6,632.0	7,291.4	8,000
30-34	7,104.4	5,624.9	8,703.0	6,000
35-39	8,076.2	5,465.6	8,851.0	6,000
40-44	8,185.1	5,895.8	8,005.5	6,000
45-49	7,211.8	5,962.2	7,184.7	6,000
50-54	6,271.6	5,464.3	5,581.2	5,000
55-59	4,845.4	4,907.7	4,486.8	4,000
60-64	3,879.3	4,240.3	4,070.5	4,000
65-69	3,426.4	3,440.6	3,785.8	3,000
70-74	3,177.3	2,678.9	3,258.9	2,000
75-79	2,699.9	1,887.1	2,323.1	1,000
80-84	1,784.2	1,124.1	1,542.4	500
85+	1,550.8	743.5	1,161.7	500
Total	100,000.0	100,000.0	100,000.0	100,000

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

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

<sup>1</sup>Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Edwards BK (eds). *SEER Cancer Statistics Review, 1973-1998*, National Cancer Institute. Bethesda, MD, [http://seer.cancer.gov/Publications/CSR1973\\_1998/](http://seer.cancer.gov/Publications/CSR1973_1998/), 2001.

<sup>2</sup>Waterhouse J, Muir C, Correa P, Powell J (eds). *Cancer Incidence in Five Continents, Volume III*. Lyon, France: International Agency for Research on Cancer, IARC Scientific Publications No. 15, 1976.

where  $w_j$  = the fraction of the standard population in age<sub>*j*</sub> group,  $n_j$  = number of cases in that age group, and  $p_j$  = person-years denominator.<sup>3</sup> For many registries, the S.E. of the rates are small, as the population covered is large. However, for registries that cover a small population, the S.E. may be substantial.

**Comparison of Rates.** The S.E. 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  $S.E._1$  and  $S.E._2$ , an approximate confidence interval for the rate ratio can be calculated using the following formula:

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

where  $x = (R_1 - R_2) / \sqrt{(S.E._1^2 + S.E._2^2)}$  and  $z = 1.96$  for 95% confidence limits.<sup>4</sup> 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 10 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.<sup>5</sup>

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, 1995, 1996, 1997, 1998, and 1999. 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, 1995 through 1999.
2. Duplicate cases did not exceed 0.2 percent, using NAACCR's *Protocol for Assessing Duplicate Cases*.
3. All cases pass all internal consistency checks defined by NAACCR's EDITS metafile, Version 9.
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.

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<sup>3</sup>Breslow NE and Day NE. *Statistical Methods in Cancer Research, Volume II*, Lyon, France: International Agency for Research on Cancer, IARC Scientific Publications No. 32, 1987, p. 59.

<sup>4</sup>Parkin DM, Muir CS, Whelan SL (eds). *Cancer Incidence in Five Continents, Volume VI*. Lyon, France: International Agency for Research on Cancer, IARC Scientific Publications No. 120, 1992, p.869.

<sup>5</sup>Esteve J, Benhamou E, *Raymond L. Statistical Methods in Cancer Research, Volume V*. Lyon, France: International Agency for Research on Cancer, IARC Scientific Publications No. 128, 1994.

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 incidence 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 become more refined. This year, 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 sex-race-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
- Breast cancer cases were included in the model. Previously, breast cancer cases were excluded from the calculations because geographically diverse increases in mammography 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. Melanoma cases were excluded for blacks in the calculation of completeness estimates.
- 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 data) 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 1995-1999 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  $\underline{s}$  ( $C_{sk}$ ) 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<sup>6</sup> (“Observed T”) by the *expected* race-specific (white; black) age-adjusted (2000 U.S.) incidence rate for both sexes and all cancer sites combined<sup>6</sup> (“Expected T”):

$$C_{sk} = \frac{ObservedT_{sk}}{ExpectedT_{sk}}$$

The *expected* incidence rate for jurisdiction  $\underline{s}$  was computed from jurisdiction-race-sex-site-specific age-adjusted (2000 U.S.) death rates and incidence-to-mortality rate ratios computed from SEER race-sex-site-specific age-adjusted (2000 U.S.) incidence rates and U.S. race-sex-site-specific age-adjusted (2000 U.S.) death rates, thus:

$$ExpectedI_{skij} = (M_{skij}) \left( \frac{I_{SEERkij}}{M_{U.S.kij}} \right)$$

$$ExpectedT_{sk} = \sum_{i=1}^2 \sum_{j=1}^N ExpectedI_{skij}$$

where:

- $I$  = Age-adjusted (2000 U.S.) incidence rate for gender  $i$ , site  $j$ , race  $k$ , 1995 to 1999
- $M$  = Age-adjusted (2000 U.S.) mortality rate for gender  $i$ , site  $j$ , race  $k$ , 1995 to 1999
- $s$  = State, District of Columbia, SEER area, province, or territory
- $SEER$  = Combined eleven SEER areas<sup>7</sup>
- $U.S.$  = United States
- $T$  = Age-adjusted (2000 U.S.) incidence rate for total sites<sup>6</sup>

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:

- $CA$  = Adjusted overall completeness of ascertainment
- $C$  = Unadjusted overall completeness of ascertainment
- $s$  = State, District of Columbia, SEER area, province, or territory
- $U$  = Proportion of unduplicated records, based on NAACCR's *Protocol for Assessing Duplicate Cases*.

For more information on the revised completeness estimate method, consult the following reference: Holly L. Howe. Conclusions of the Work Group for High Quality Criteria for Data Use. NAACCR Narrative [serial online] 2001; Winter:8 Available from URL: <http://www.naacr.org/News/index.html> [accessed January 7, 2002]

Every registry included in the combined rates had an adjusted completeness estimate of at least 90 percent for each year of the five years' data submitted.

In the United States, 28 registries (23 states and 5 metropolitan areas in the SEER program) met all the criteria for inclusion in the U.S. combined rates. These were California, the Greater Bay Area (California), Los Angeles (California), Colorado, Connecticut, Delaware, Metropolitan Atlanta (Georgia), Hawaii, Idaho, Illinois, Iowa,

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<sup>6</sup>The cancer sites included in this calculation were oral cavity, esophagus, stomach, colorectum, liver, pancreas, lung, melanoma, female breast, cervix, uterus, ovary, bladder, kidney, nervous system, Hodgkin's Disease, non-Hodgkin's lymphoma, 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.

<sup>7</sup>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.

Kentucky, Louisiana, Michigan, Metropolitan Detroit (Michigan), Minnesota, Nebraska, New Jersey, New Mexico, New York, North Carolina, Pennsylvania, Rhode Island, Utah, Seattle/Puget Sound (Washington), West Virginia, Wisconsin and Wyoming. Since both California and its SEER areas of Los Angeles and Greater Bay Area were qualified for inclusion, only the state (California) data were included in the calculation of combined rates. Also, since Michigan and its SEER area of Detroit were qualified, only state (Michigan) data were included in the calculation of combined rates.

In Canada, 7 registries met all the criteria for inclusion in the Canadian combined rates. These were Alberta, British Columbia, Manitoba, New Brunswick, Northwest Territories, Prince Edward Island and Saskatchewan.

Although all cases from qualified registries were included in 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.

## 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, as are the data for Hawaii. 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, Volume One.

**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.

Many new registries postpone the collection of DCO cases until the registry has at least five years' data, because deaths which occur prior to the five-year mark are very likely to have been diagnosed before the registry's date of establishment. Were these deaths to be collected and registered as DCO cases, they would 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 for case ascertainment in the period 1995 to 1999 are indicated in the Registry Description at the beginning of each registry's section.

**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. Between 92 and 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. 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 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.

**Values of Zero (“0”) and “-” in the Tables.** 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 rate and count 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 2002 *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.<sup>8</sup>

## **NAACCR MISSION**

The North American Association of Central Cancer Registries, Inc. (NAACCR), the Association, 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 from cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America.

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<sup>8</sup>Chen, VW. Should we or shouldn't we compare cancer incidence rates among registries? in Howe HL (ed.) *Cancer Incidence in North America, 1988-1991*. Sacramento, CA: North American Association of Central Cancer Registries, April 1995, p. V-1.

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