

TECHNICAL NOTES

To understand the data provided in *Cancer in Oregon*, it is important to understand the sources of data, collection methods, data quality, and the significance of reported measures. The following provides background for understanding and interpreting the data contained in this report.

DATA SOURCES

Oregon Incidence Data

All cancer incidence data were obtained directly from the Oregon State Cancer Registry (OSCaR). Reportable diagnoses include all malignant neoplasms diagnosed beginning January 1, 1996, that are *in situ* or invasive with the following exceptions: basal and squamous cell carcinoma of the skin (except of genitalia), and carcinoma *in situ* of the cervix. In addition, beginning with cases diagnosed January 1, 2004, benign brain and central nervous system tumors also became reportable, though they are not included in total incidence counts. (See Appendix A – Reportable Incidence Cases.)

By law, all reportable cancers and benign brain and CNS tumors diagnosed or treated in Oregon must be reported to OSCaR by the patient's physician. In practice, most of the cases included in this report were reported by hospital cancer registrars, who are trained to collect and report cases according to national standards. Since cancer reporting started in 1996, 89 percent of new cancer diagnoses have come from hospitals, 9 percent from physician offices, and 1 percent were identified from review of death certificates. The remaining cases were identified by review of pathology reports from laboratories or by autopsy. Many of the physician office cases were initially identified through follow-up on laboratory reports and death certificates.

The majority of cancer diagnoses reported to OSCaR are the first primary cancer diagnosed for the patient. However, nearly 20% of the cancer diagnoses occur in individuals with a previous cancer. Incidence rates are calculated using the total number of new invasive primary cancers (and *in situ* bladder cancers) diagnosed in a specific time period as the numerator and the population as the denominator.

Cancer data presented in this report follow nationally accepted standards for groupings of site categories for analysis. Cancer groupings for analysis are classified using the National Cancer Institute's SEER Program SEER Site Recodes. (Please see Appendix D, SEER Site Recode ICD-O-3 from NCI SEER program.) The majority of neoplasms are grouped by the site in which they originate. Neoplasms of the lymphatic, hematopoietic, and reticuloendothelial systems, however, are grouped by their histologies (leukemias, lymphomas, etc.) and not by the primary site where they occurred. Melanoma of the skin is a combination of both anatomic site and histological type.

Oregon Mortality Data

All cancer mortality data were obtained from the Center for Health Statistics (CHS) death certificate database. CHS is the state's repository for all vital records and is a major information source for vital statistics and health survey data about Oregonians. Because of different age groups used in age-adjusting, mortality rates in this report are not comparable to rates published by CHS.

Beginning with deaths occurring in 1999, cause of death has been classified using the tenth revision of the International Classification of Disease (ICD-10). The ICD-10 system is closely

compatible with the ICD-Oncology (ICD-O) system used for reporting cancer cases, based on site of origin, whereas the ICD-9 system was not. (See Appendix B, Cancer Causes of Death for SEERSite recodes used in this report and a comparison of ICD-9 and ICD-10.)

For mortality years 1996-1998, the ICD-9 codes did not directly match ICD-O codes. Therefore, discrepancies exist for those years between Oregon's Center for Health Statistics (CHS) counts and the mortality counts reported in this publication. Beginning in 1999, with the change to ICD-10 coding, mortality coding matches exactly for most sites. However, since 2001, the Registry includes newly reportable cancers which are excluded from the CHS cancer counts: polycythaemia vera, refractory anemia and other myelodysplastic syndromes, chronic myeloproliferative disease, and essential thrombocythaemia. (See Appendix B Mortality Recodes for Cancers Newly Reportable in 2001 for a complete list of these causes of death; for further information see Comparability of Cause of Death Between ICD-9 and ICD-10: Preliminary Estimates in *National Vital Statistics Report*, Vol. 49, No. 2, May 18, 2001, Anderson, Minino, Hoyert, Rosenberg.)

Population Data

Population denominators used to calculate Oregon incidence and mortality rates are from the Population Estimates Branch of the US Census Bureau. Denominator data for 1996-1999 are based on the State and County Characteristics Population Estimates from the US Census. Denominator data for 2001-2005 were based on the National Center for Health Statistics (NCHS) estimates of the July 1, 2001-July 1, 2005, United States resident population from the Bridged-race Vintage 2005 postcensal population estimate by year, county, single-year of age, bridged-race,

Hispanic origin, and sex prepared under a collaborative arrangement with the US Census Bureau 2006. Available on the Internet at: <http://www.cdc.gov/nchs/about/major/dvs/popbridge/popbridge.htm>.

Beginning with the 2000 US Census, respondents have had the option of self-ascribing more than one race. Because cancer registry data continue to be reported with ascription to a single race, it is essential to have comparable numerator data (cancer counts) and denominator data (population counts) to calculate rates. Therefore, population data for the year 2000 and forward are from the 2000 US Census bridged data set, which uses allocation probabilities developed by NCHS to assign the Census's multiple race variables and 31 race categories to a single-race variable with four race categories. For specific information about the bridging methodology, see the NCHS website: <http://www.cdc.gov/nchs/about/major/dvs/popbridge/popbridge.htm>.

Screening Data

Cancer screening data were obtained from the Behavioral Risk Factor Surveillance System (BRFSS) maintained by Oregon's Center for Health Statistics. BRFSS is an ongoing random-digit-dialed telephone survey of adults concerning health-related behaviors. Information is used to guide health promotion and disease prevention programs. BRFSS includes questions on health behavior risk factors such as seat belt use, diet, weight control, tobacco and alcohol use, physical exercise, preventive health screening, and use of preventive and other health care services. See the Oregon BRFSS website: <http://www.dhs.state.or.us/dhs/ph/chs/brfs/brfss.shtml>.

National Data

National incidence data are from the *State Cancer Profiles* by National Cancer Institute's National Program of Cancer Registries (<http://www.statecancerprofiles.cancer.gov>).

National mortality data were calculated using the Surveillance, Epidemiology, and End Results (SEER) Program's SEER*Stat Database: Mortality - All Cause of Death, Public-Use With State, Total U.S. (1969-2004), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2007. Underlying mortality data were provided by NCHS. [www.cdc.gov/nchs].

National incidence rankings were obtained from the U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 2004 Incidence and Mortality*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2006, available at: <http://apps.nccd.cdc.gov/uscs/>. Mortality rankings were obtained from profiles generated by the National Cancer Institute's State Cancer Profiles available at the following website: <http://statecancerprofiles.cancer.gov/>.

DATA QUALITY AND CASE COMPLETENESS

Internal Data Review

When OSCaR receives reports, they are closely reviewed and edited for quality control. The accuracy and usability of OSCaR data has increased through efforts on several different levels. Registry operations and linkage projects including monthly linkage with vital statistics death information help ensure that Registry data are reviewed and corrected on many levels.

Audits. OSCaR conducts random audits of reporting hospitals and facilities across the state to assess quality and completeness of data maintained in the central registry. Hospitals are divided into groups for random selection based on hospital size. In addition, the Registry audits case-reporting completeness from hospitals anytime there is a reduction in case reporting.

Case Completeness. Identifying missed cases through review of pathology reports and death certificates is part of normal Registry procedure. In addition, through data sharing agreements, neighboring states supply records for Oregon residents diagnosed out of state.

Death Clearance. Death clearance is a death certificate review process used to identify additional cases by comparing cancer cases identified from the death certificate file with cases in the Registry file. Deaths due to cancers that have not been reported to the Registry are investigated by contacting the physician who certified the death. After physician inquiry is completed, cases found through the death certificate that still have no physician report are classified as death certificate only (DCO) cases. Cases for which a response and full report are received are classified as physician office reports. Deaths due to cancer diagnosed prior to the Registry's starting date, January 1, 1996, are not added to the Registry.

Full death clearance procedures were not necessary during the first few years of Registry operation since most cancer deaths were due to cancers diagnosed prior to 1996. Initially, death clearance was performed only for selected cancer sites that have low short-term survival: esophagus, liver, lung, pancreas, stomach, multiple myeloma, and unknown cancers. In 1999, death certificate review procedures were expanded to include all

cancer sites. Typically, cancer cases identified by death certificate are those with a poor prognosis, often diagnosed at distant stage or that are not staged due to the patient's poor health.

Due to increased review, more death-certificate only cases were identified from 1999 to present. DCO cases differ from other cases due to increased severity of disease but are categorized as "unknown stage" due to lack of staging information.

Linkages. One notable data quality effort involves assessing and correcting race misclassification for American Indian/Alaska Native patients. Through a cooperative effort between the Oregon State Cancer Registry and the Northwest Portland Area Indian Health Board (NPAIHB), a linkage is done annually with local tribal clinic registry data to determine if AI/ANs have been misclassified as another race. One-fourth of the AI/AN cases currently in the OSCaR database were identified through data linkages.

External Data Review

Federal funding requires that OSCaR be audited by an outside agency every five years to assess the quality and completeness of registry data. In July 2003, Macro International Inc. conducted an audit of OSCaR data. The audit estimated OSCaR's overall case completeness rate at 98.9%, and the overall data accuracy rate for 13 essential data elements at 96.0%. OSCaR was commended for exceeding national standards for both outcomes.

The North American Association of Central Cancer Registries (NAACCR) annually reviews cancer registries for their ability to produce complete, accurate, and timely data. The NAACCR certification program recognizes registries that meet the highest standards with a Gold or Silver Certification. OSCaR data for

diagnosis year 2004 received Gold Certification. OSCaR has received certification for every year of complete data. Additional information about NAACCR certification is available on the web: http://www.naacr.org/index.asp?Col_SectionKey=11&Col_ContentID=54.

EPIDEMIOLOGICAL MEASURES

Cancer Counts

All malignant and non-malignant brain and CNS tumors diagnosed among Oregon residents are reported to OSCaR. Cases are categorized based on the International Classification of Diseases for Oncology (ICD-O) and are presented using the Surveillance, Epidemiology, and End Results (SEER) Program SEERSite recodes.

Cancer counts represent the number of primary cancers reported to OSCaR, not the number of persons with cancer. People diagnosed with more than one primary tumor count as more than one "case". About 20% of the cases reported to OSCaR occur in a person who has already been diagnosed with another cancer.

The number of cancers is reported in two ways - total cancers and invasive cancers. With the exception of *in situ* bladder cancers, the invasive cancer category excludes *in situ* cancers. The total cancer category includes all cancers, regardless of stage at diagnosis, with the exception of *in situ* cervical cancer and basal and squamous cell carcinoma of the non-genital skin since they are not reported to the Registry.

Total count may exceed sum of male and female counts due to the inclusion in the total of persons identified in case reports as hermaphrodites and transsexuals.

Cancer Rates

In analyzing Oregon's cancer data, we looked at various measures commonly used in epidemiologic studies of cancer. One measure is a rate. Rates help compare the burden of disease across populations of various sizes.

Incidence rates provide information on the frequency with which cancers occur in the population. Only invasive cancers (and *in situ* bladder cancers) are included in rate calculations. The mortality rate describes the frequency of deaths due to invasive (and *in situ* bladder) cancer. Unless otherwise noted, all rates in this report are per 100,000 population. Rates based on counts of fewer than 11 cases are considered unstable and are not displayed in tables.

Crude Rates. Crude rates are used when a summary measurement of burden is needed and there is no need to adjust for age. Since cancer risk is very dependent upon age, age-adjusted rates are more useful for comparison among regions, time periods, etc. Crude rates are not included in the tables in the annual report but are still reported for individual sites in the *FastFacts* sections.

The following population denominators were used to calculate crude rates:

Oregon's Population by Year			
Year	Total	Male	Female
1996	3,247,111	1,604,527	1,642,584
1997	3,304,469	1,634,309	1,670,160
1998	3,352,449	1,659,190	1,693,259
1999	3,393,941	1,681,715	1,712,226
2000	3,430,707	1,701,604	1,729,103
2001	3,472,629	1,723,589	1,749,040
2002	3,520,355	1,748,055	1,772,300
2003	3,559,596	1,768,478	1,791,118
2004	3,594,586	1,786,769	1,807,817
2005	3,641,056	1,810,911	1,830,145

Age-Adjusted Rates. Age-adjusted rates are calculated to allow comparisons between two different populations with different age distributions. Age-adjusted rates are expressed as events per 100,000 individuals per year. All age-adjusted rates in this report are calculated using the Year 2000 standard population with 19 age groups (<1, 1-4, 5-9, 10-14, 15-19, 20-24...85+).

Cancer Trends

All trend data should be interpreted with caution. Over the years, changes in coding and collection standards have occurred, which affect the comparability of the data. In 1999, the national change from ICD-9 classification to ICD-10 changed how cause of death is recorded and how cancer mortality data correlate with cancer incidence data. In 2001, major changes affecting coding for staging and cancer reporting came into effect for cases collected by cancer registries nationwide.

Trends were calculated using two-year averages of the age-adjusted rates as endpoints. The trends are used to compare general Oregon trends with national trends based on direction (increase or decrease) and slope (rapid or slow change). This trend analysis is intended to describe broad, temporal changes of cancer rates in Oregon.

Trends are affected by a number of factors including the following:

- improved reporting from hospitals,
- recent increases in treatment at outpatient facilities,
- changes in reporting requirements,
- changes in coding instructions,
- changes in demographic characteristics of underlying populations,
- random variation, and
- true changes in the cancer burden.

All trends are based on rates per 100,000 population that are age-adjusted to the 19-age-group Year 2000 Standard Population (Census P25-1130, <http://seer.cancer.gov/stdpopulations/19ages.proportions.html>).

Geographic Comparisons

County Comparisons. This report compares incidence and mortality rates by county.

These analyses may help target screening and educational efforts. Because some counties with small populations only have a few cases reported, rates for those counties are unstable and must be interpreted with caution.

Regional Comparisons. It is important to recognize that multiple factors influence geographic variation in cancer rates. Despite the multitude of factors influencing cancer variation by region, these maps may be used to suggest regions to target screening and prevention programs or to expand treatment facilities.

In counties where the number of cases was too small to come up with reliable incidence rates and trends, those counties have been grouped with neighboring counties in order to provide more reliable rates and trends

In addition to random variation, the following are also responsible for geographic variation of cancer rates:

Population Demographics. Some cancers have different rates among different racial or ethnic groups. For example, breast cancer rates are generally higher in white women and prostate cancer rates are generally higher in black men. Therefore, racial makeup of an area should be considered when evaluating regional differences.

Screening. In areas with higher cancer screening rates, more cancers will be diagnosed. For several cancers, notably cervical, breast, and colorectal, a higher percentage of early stage diagnoses associated with higher screening rates can result in more favorable prognosis for these cancers. Comparing both incidence and mortality rates is important to gain a more complete picture of regional cancer differences.

Reporting. Although OSCaR has a total case completeness rate of over 95%, cancer reporting may differ by region in terms of completeness and type of report source (hospital vs. physician office).

Software

All incidence and mortality counts were generated using SEER*Stat [Surveillance Research Program, National Cancer Institute SEER*Stat software (<http://www.seer.cancer.gov/seerstat>) Version 6.3.6, March 16, 2007]. Data were formatted for SEER*Stat using SEER Prep [Surveillance Research Program, National Cancer Institute SEER*Prep software (<http://www.seer.cancer.gov/seerprep/>) Version 2.3.6, May 2006]. Trends were calculated using age-adjusted rates and reported as an annual percent change (APC). The APC is calculated by fitting a weighted, least-squares regression line to the natural logarithm of the rates using year as a regression variable.

GLOSSARY

Age. The age of the patient is in completed years at the time of diagnosis or death.

Age-Adjusted Rate. The age-adjusted rate is “the rate that would occur if the observed age-specific rates were present in a population with an age distribution equal to that of a standard population” (Anderson RN, Rosenberg HM. Age standardization of death rates: Implementation of the Year 2000 Standard. National Vital Statistics Reports; vol. 47 no. 3. Hyattsville, Maryland: National Center for Health Statistics, 1998).

Since cancer rates vary with age and populations vary with respect to their age distribution, cancer incidence and mortality rates are age-adjusted to allow comparison of rates. In this report, age-adjusted rates are calculated by the direct method, multiplying age-specific rates by the age distribution of the 2000 United States Standard Population with 19 age groups.

Age-Specific Rate. The age-specific rate is the average annual rate per 100,000 population for a specific age group.

Annual Percent Change. The Annual Percent Change (APC), or trend, is the average percent change in the annual rate among years for the time period analyzed. This is calculated using SEER methodology.

Benign. A benign tumor has abnormal growth without cancerous behavior. It is non-malignant. A benign tumor can be life threatening because of rapid growth or its location.

Childhood Cancer. This report includes all cancers occurring in individuals under the age of 20 in the section on childhood cancer. Children’s

cancer rates are usually expressed per 1,000,000 population. The International Classification of Childhood Cancer (ICCC), which emphasizes tumor morphology, is used for defining tumors occurring in children.

Confidence Interval. Confidence intervals show range of random variation. When two confidence intervals do not overlap, the two rates are considered statistically significantly different and the difference between the two rates is more than that expected by random chance. However, with a 95% confidence interval, we expect that five times out of 100, the differences will occur by chance. With 36 counties and 20 cancer sites, we might see as many as 36 instances where the rate for a county is statistically significantly different from the state rate just by chance. Confidence intervals were calculated using SEER methodology.

Crude Rate. The crude rate is the number of events in the population, without regard to the age distribution of the population.

Ethnicity. Hispanic or Latino ethnicity is calculated separately from race and includes Mexican, Puerto Rican, Cuban, South or Central American (other than Brazil), and other specified Hispanic, Latino, or Spanish.

ICD-9. The Ninth Revision of the International Classification of Diseases. Mortality data for years 1996-1998 are recorded using ICD-9. This classification system is not directly compatible with the ICD-O classification system used for cancer reporting.

ICD-10. The 10th Revision of the International Classification of Diseases. Mortality data recording converted to ICD-10 beginning with death year 1999. This classification system

mirrors the ICD-O system used for cancer reporting.

ICD-O-3. ICD-O-3 is the Third Edition of the International Classification of Diseases for Oncology, a variation of the ICD system specifically designed for cancer coding. Cancer incidence is reported to the Registry using the ICD-O system. The ICD-10 cancer site classifications closely follow this system.

Incidence. Cancer incidence is the annual or average annual count of new invasive cancers and *in situ* bladder cancers. Cancer incidence is the number of new diagnoses and not the same as the number of Oregonians living with cancer.

Malignant. A tumor made up of cancer cells of a type that can spread to other parts of the body is considered malignant.

Metastatic/Distant. The most advanced stage of a cancer in which cells from the original tumor break away, travel to other parts of the body, and continue to grow. Although the cancer has spread to an additional site or sites, it is still named after the original site of the tumor. These cancers are classified as late-stage cancers.

Mortality. Cancer mortality is the annual or average annual number of deaths due to cancer.

M/I Ratio. The M/I (mortality-to-incidence) ratio provides a measure of disease severity. The M/I ratio is the number of deaths divided by the number of invasive incidence cases for a specified cancer during a specific time period. The higher the value, the poorer the prognosis for that cancer. It is possible to have an M/I Ratio exceed 1.0 if the number of deaths for a population is greater than the number of new diagnoses during the specific time period.

NAACCR (North American Association of Central Cancer Registries). 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.

NPCR (National Program of Cancer Registries). NPCR was established at the Centers for Disease Control and Prevention by the passage of Public Law 102-515. NPCR collects information on cancer cases from registries covering 96% of the nation's population.

Prevalence. Cancer prevalence is the rate or number of people in a specific population living with cancer.

Primary Site. The primary site is the human organ or system in which the malignancy originates.

Race. In this report, race consists of one variable with four race categories: African American, American Indian/Alaskan Native, Asian/Pacific Islander, and white.

SEER (Surveillance, Epidemiology, and End Results). The National Cancer Institute provides information on cancer incidence and survival in the United States through the SEER program.

Stage at Diagnosis. Stage at diagnosis describes how far a tumor has spread from its site of origin at the time of diagnosis. The cancer stages, in order of severity and spread, are *in situ*, localized, regional, and distant. Local, regional and distant

stages are considered invasive. A number of cancers are also reported as unstaged (unknown stage at diagnosis). Except for *in situ* bladder cancer, *in situ* cancers are not included in the calculation of incidence rates. All reported cancers are included in the calculation of stage at diagnosis.

<i>In Situ</i>	A tumor that fulfills all microscopic criteria for malignancy, but does not invade or penetrate surrounding tissue.
Localized	A tumor that is invasive but remains restricted to the organ of origin.
Regional	A tumor that has spread by direct extension to immediately adjacent organs or tissues and/or metastasized (spread through the blood stream) to regional lymph nodes, but appears to have spread no further.
Distant	A tumor that has spread by direct extension beyond the immediately adjacent organs or tissues, and/or metastasized to distant lymph nodes or other distant tissues.
Unstaged	Insufficient information available to determine the stage of disease at diagnosis.

YPLL. The years of potential life lost (YPLL) index measures years before a specific age that a person dying prematurely would otherwise have contributed to society. In this report, years of potential life is indexed to age 65. For example, a person dying of cancer at age 35 would have a YPLL at age 65 of 30 years.