

Introduction

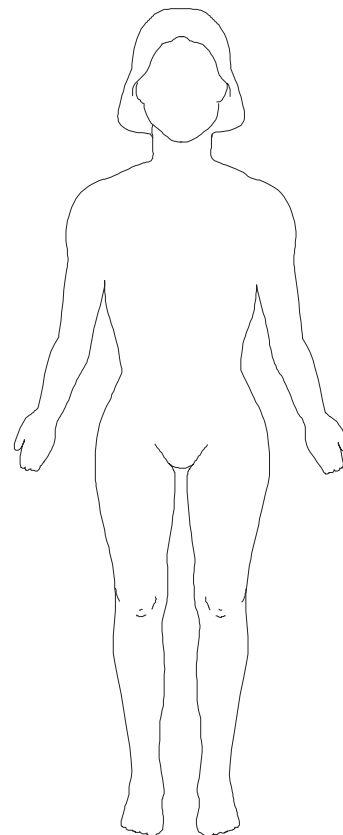
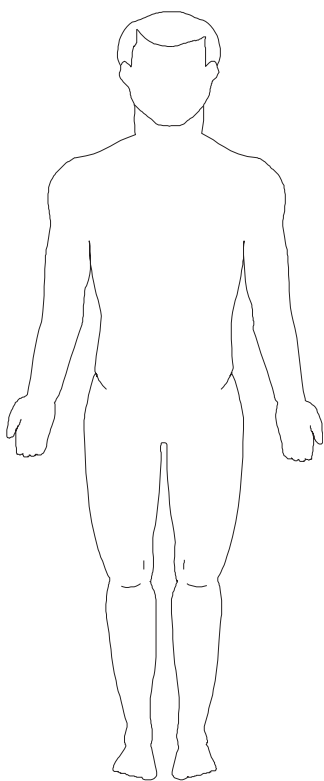
Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells (American Cancer Society, 2004). It can strike at any age and can spread to any part of the body. It is the second leading cause of death in the United States, accounting for one of four deaths (ACS, 2003a; ACS, 2004; U. S. Department of Health and Human Services, 2002). Among children between the ages of one and 19 years, cancer causes more deaths than any other disease (ACS, 2003a; Ries et al., 1999). Nationwide, it is expected that 563,700 persons will die of cancer in 2004 (ACS, 2004). In West Virginia, cancer is also the second leading cause of death (West Virginia Department of Health and Human Resources, 2002) and the greatest cause of years of potential life lost (i.e. premature deaths).

Research has demonstrated that many cancers can be prevented or, if detected and treated at early stages, cured (ACS, 2003a; National Cancer

Institute, 2002). All cancers caused by cigarette smoking and heavy use of alcohol could be prevented completely (ACS, 2003a). About one-third of cancer deaths are related to nutrition, physical inactivity, obesity, and other lifestyle factors (ACS, 2003a). Some cancers are related to infectious exposures such as the hepatitis B virus, human papillomavirus, human immunodeficiency virus, and *Helicobacter pylori* (ACS, 2003b, 2004). Behavioral changes, vaccines, and antibiotics may help prevent such cancers (ACS, 2003b, 2004). Many skin cancers could be prevented by protection from the sun's rays (ACS, 2003a, 2004; National Council on Skin Cancer Prevention, 2004).

Regular screening by health care professionals can detect cancers of the breast, colon, rectum, cervix, prostate, testis, mouth, tongue, and skin at earlier stages. Self-examinations for breast and skin cancer may also result in earlier detection. When cancer is detected at earlier stages, treatment is more likely to be successful. If all of these cancers were detected at earlier stages and properly treated, 95% of patients with these cancers would survive at least five years.

Information from the West Virginia Cancer Registry (WVCR) is used to examine the incidence and mortality rates of cancer in West Virginia. It helps identify high-risk populations who can then be targeted for prevention and early detection services. WVCR data are also being used in epidemiologic studies of oral/pharyngeal cancers, colon cancers, and lung cancers. These studies will, in turn, aid in prevention, detection, and treatment of cancer in West Virginia and the nation.



West Virginia Cancer Registry

The West Virginia Department of Health and Human Resources, Bureau for Public Health, implemented a statewide, population-based Breast and Cervical Cancer Incidence Registry (BCCIR) in 1991 to monitor patterns of breast and cervical cancer among West Virginia women. In 1992 the Legislature amended the West Virginia Code to establish a statewide cancer registry. The BCCIR was expanded to include cancer diagnoses of all anatomical sites in 1993 and renamed the West Virginia Cancer Registry (WVCR).

Methods of Data Collection

The WVCR collects data on all cancer cases, with the exception of basal cell and squamous cell carcinomas of the skin and carcinoma in situ of the cervix, diagnosed in West Virginia residents on or after January 1, 1993. Reporting sources include hospital-based cancer registries, hospitals without cancer registries, freestanding pathology laboratories, freestanding radiation treatment centers, clinics, nursing homes, physicians, and death certificates. Appendix A lists all participating hospitals, pathology laboratories, and freestanding cancer treatment centers as of January 2004.

To identify cases of cancer in residents who traveled outside West Virginia for diagnosis and/or treatment, the WVCR has established reciprocal agreements for data exchange with the central cancer registries in Alaska, Arkansas, the District of Columbia, Florida, Kentucky, Maryland, Mississippi, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Texas, Virginia, Washington, Wisconsin, and Wyoming.

To identify cases not found by routine casefinding activities, deaths among West Virginia residents with cancer listed as an underlying cause of death are matched against the WVCR data. Those cases which are verified to be reportable based on year of diagnosis are added to the WVCR database.

The Breast and Cervical Cancer Screening Program, Office of Maternal, Child, and Family Health, at least annually provides the WVCR a listing of cancer cases diagnosed as a result of that screening initiative. Those cases are matched with the WVCR database to insure that all reportable cases are included.

Finally, physicians and other medical providers are required to report all newly diagnosed cases of cancer not admitted to a hospital in West Virginia. This assists in identifying melanomas of the skin and other cancers diagnosed and treated on an outpatient basis or referred out-of-state (thus, not identifiable through routine casefinding activities).

The following data items have been collected on all residents diagnosed with cancer from January 1, 1993, forward:

- | | |
|--|---|
| * Name | * Number of primary lesions if more than one |
| * Date of birth, sex, and race | * Cancer site and type |
| * Social Security Number | * Stage at diagnosis |
| * Address at diagnosis, including county | * Reporting facility or physician |
| * Telephone number | * Physician(s) providing diagnosis, treatment, and/or follow-up |
| * Date of diagnosis | |

Treatment information was added to the required data items in 1995, and occupation and industry information was added in 1996.

Cancer Reporting

The WVCR reporting system is depicted in Figure I.1. Reports on individual cases of cancer are submitted electronically to the WVCR by hospital-based cancer registries and central registries in other states. Facilities without cancer registries provide access to medical records of cancer cases for the WVCR cancer data specialists to abstract their cases. The WVCR collects and analyzes the data and disseminates summaries of statistical findings.

Methodology

Incidence Data

In this report, all incidence rates for West Virginia are based on cancer data collected by the WVCR. Annual incidence rates are included for West Virginia from 1993 through 2001. United States incidence rates are included from 1993 through 2000. Due to a one-year lag in national cancer incidence data, 2001 national rates were not available for this publication.

Five years of combined data, 1997 - 2001, were used to present rates by age, stage at diagnosis, and county of residence. The incidence rates based on five years of data should be interpreted as the average annual rates that occurred from 1997 through 2001.

Mortality Data

Mortality data were provided by the state's Health Statistics Center. Based on information recorded on death certificates, underlying causes of death were used to determine rates of cancer mortality in West Virginia. Deaths occurring from 1993 through 1998 due to primary sites of cancer were identified from appropriate rubrics in the International Classification of Diseases, Ninth Revision (ICD-9). These rubrics corresponded to the ICD-9 rubrics utilized by the National Cancer Institute in reporting cancer mortality data (Ries et al., 2003). West Virginia resident deaths occurring from 1999 through 2001 were identified from appropriate rubrics in the International Classification of Diseases, Tenth Revision (ICD-10).

This report includes annual mortality rates for West Virginia from 1993 through 2001. United States mortality rates are included from 1993 through 2000. The national cancer mortality rates for 2001 were not available for this publication.

Age-Adjustment to the Year 2000 Standard Population

Age-adjustment is the process used to compare incidence and mortality rates over time, or among geographic areas or other populations that have different age distributions. For example, without adjusting for age, it would be inaccurate and misleading to compare the cancer rates of West Virginia, which has a relatively large percentage of elderly residents, to those of Alaska, which has a younger population. This is especially important when examining cancer rates, since cancer is more frequently diagnosed in older people. Age-adjustment eliminates the confounding effect of age when comparing rates in different populations.

Cancer Reporting in West Virginia

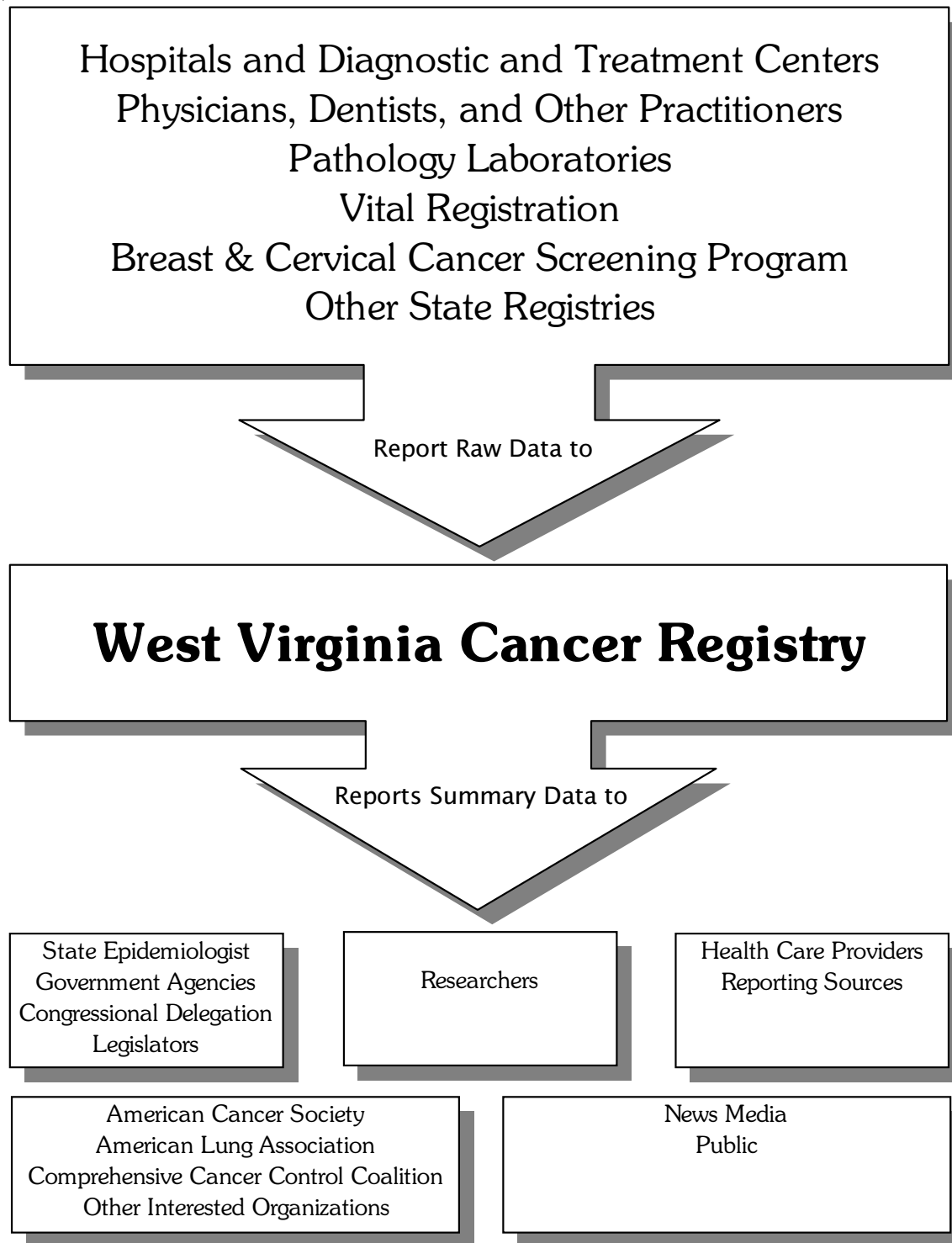


Figure I.1

Federal agencies adopted the year 2000 projected U.S. population distribution as the new standard for adjusting incidence and mortality from 1999 on. In previous years, at least three different population standards were used, resulting in difficulties comparing data prepared by national and federal agencies and causing confusion among data users and the general public. Use of the Year 2000 Standard was recommended to promote uniformity of data among agencies.

The Year 2000 Standard applies to data from calendar year 1999 and forward. Because this report includes incidence and mortality rates from 1999 forward, the WVCR has conformed to the recommendation of adjusting to the Year 2000 Population Standard. This change required recalculation of the age-adjusted rates for the years 1993 to 1998 to allow valid comparisons between current and past years.

Comparisons of Rates for West Virginia and the U.S.

Comparisons of cancer incidence and mortality rates for West Virginia and the U.S. are complicated by a one-year lag in reporting national rates. For example, current national cancer data only cover up to 2000, while data for West Virginia cover 1993 through 2001.

Average Rates

Age-specific incidence and mortality rates are calculated as average annual age-specific rates to provide more accurate estimates. When the total number of cancer cases for an anatomical site is broken down by age, very small numbers often result. Combining five years of data to calculate an average annual age-specific rate provides a more reliable estimate of this measure.

Similarly, average annual age-adjusted incidence and mortality rates are presented in this report. Since rates can fluctuate year to year due to small numbers, average rates calculated from five years of data can provide better estimates of these measures than individual year rates.

Population Denominators

West Virginia population estimates by gender and age for 1993 through 2001 were obtained from the U.S. Bureau of the Census (Appendix D). These estimates were used as denominators in the calculation of 1993 - 2001 incidence and mortality rates for West Virginia. County population estimates (Appendix E) were obtained from the same source.

Confidentiality of Cancer Data

Chapter 16-5A-2a of the West Virginia Code adopted by the West Virginia Legislature in 1992 specifically states:

All information reported pursuant to this section is confidential and shall be used for the purpose of determining the sources of malignant neoplasms and evaluating measures designed to eliminate, alleviate or ameliorate their effect. A report provided to the cancer registry disclosing the identity of an individual who was reported as having cancer shall only be released to reporting sources and persons demonstrating a need which is essential to health related research, except that the release shall be conditioned upon the reporting source and personal identities remaining confidential.

Documents which identify individual cancer patients, individual hospitals, or individual physicians are regarded as confidential and are subject to specific regulations for maintenance of confidentiality. WVCR staff are fully aware of their responsibility to protect the confidentiality of patients' files and sign a confidentiality agreement upon employment with the registry.

Information which identifies a specific patient is only released to the reporting source, to a central cancer registry with whom a reciprocal agreement has been made, or to cancer researchers meeting all requirements established by the WVCR. Confidentiality guidelines are specifically addressed in any release of identifying cancer data.

Data about the cancer experience of an identified hospital or physician, regardless of whether the patient-identifying information is contained within, are available only with prior written permission from the hospital or physician involved.

Access to WVCR records is limited to WVCR personnel.

Definitions of Terms

Cancer - a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death.

Cancer Clusters - the occurrence of an unusually high number of cases and/or deaths from cancer of a specific body site among a defined population during a specific time. Possible "clusters" are usually reported when someone has a family member, friend, or neighbor diagnosed with cancer. This close contact with cancer often brings an awareness of others who have cancer and may lead to the perception that there is an unusually large number of cancer cases in a certain area. Determining that a true "cluster" exists requires multiple years of incidence and mortality data and statistical tests to establish if the number of cases is significantly higher than expected.

Cancer Registry - the office within the Bureau for Public Health where information is maintained on persons diagnosed with cancer. The WVCR maintains information on West Virginia residents diagnosed with cancer on or after January 1, 1993. The registry collects and stores information on cancer patients and prepares reports on the data collected.

Case - an incidence of a reportable primary site of cancer. (Note: A cancer patient may be diagnosed with more than one primary site of cancer. The number of cases in this report refers to the number of primary sites reported, not the number of cancer patients.)

Confidence Interval - an established range within which an estimated rate is expected to fall. The confidence interval specifies the probability that the estimated rate actually falls within that range. A 95% confidence interval means that one can be 95% certain that the true rate falls within the computed interval.

Histology - the study of the structure of tissues to determine the exact type of cancer, the behavior of the cancer, and the differentiation of tumor cells (grade).

Microscopic Confirmation - the microscopic examination of tissues or cells removed from the suspected cancer site for the purpose of verifying a malignancy.

Primary Site - the organ or tissue that has been determined to be the place of origin of the malignancy.

Stage of Disease - a classification system to describe the extent of the spread of disease from the site of origin at the time of diagnosis. The staging classification used for this report is the *Summary Staging Guide for Cancer: Surveillance Epidemiology and End Results Reporting*. The summary stages are defined as follows:

In situ - a tumor that fulfills all the microscopic criteria for malignancy except invasion

Local - a malignant tumor that appears to be confined entirely to the organ of origin with no evidence of metastasis elsewhere in the body

Regional - a malignant tumor that has extended beyond the limits of the organ of origin into adjacent organs or tissues by direct extension, regional lymph nodes by metastasis, or both and appears to have spread no farther

Distant - a malignant tumor that has spread by direct extension beyond adjacent organs or tissues or by metastasis to distant sites or distant lymph nodes

Stage unknown - insufficient information in patient's medical record to determine stage of disease

Statistical Significance - a measure of the strength of association between variables. Two measurements are considered significantly different when their confidence intervals do not overlap. In this document, measurements of statistical significance are calculated at the 95% confidence level.

Definitions of Rates

Rate - the number of events occurring in a specific population during a given period of time. Rates in this report are expressed per 100,000 population.

Crude Rate - the total number of events per 100,000 total population.

Age-Adjusted Rate - the incidence and mortality per 100,000 population expected for West Virginia if the age distribution were the same as the standard population. For incidence and mortality in this report, the standard population used was the 2000 projected U.S. population. Age-adjusted rates allow meaningful comparisons of the incidence of events in different population groups by controlling the effects of age differences between populations.

Average Annual Age-Specific Rate - the average number of events in a specified age group population in a one-year time period. In this report, age-specific rates are based on five-year age groupings. Age groupings of less than 15 years, 15 through 24 years, 25 through 44 years, 45 through 64 years, and 65 years and older are also used. Average annual age-specific rates were calculated by combining the number of cases in a specified age group for multiple years and dividing by the combined age-specific populations for those years.

Average Annual Age-Adjusted Rate - the average yearly incidence and mortality per 100,000 population expected for West Virginia if the age distribution were the same as the standard population. Average

annual age-adjusted rates are determined by applying average annual age-specific rates calculated for five-year age intervals to the age distribution of the standard population using the direct method of adjustment. As noted above, the standard population used in this report is the 2000 projected U.S. population.

Incidence Rate - the number of new cancers of a specific site/type occurring in a specified population during a year, expressed as the number of cancers per 100,000 population. It should be noted that the numerator of the rate can include multiple primary cancers occurring in one individual and, with the exception of cancer of the urinary bladder, excludes carcinoma in situ. Except for age-specific rates, all incidence rates are age-adjusted to the 2000 U.S. standard population.

Mortality Rate - the number of deaths with cancer given as the underlying cause of death occurring in a specified population during a year, expressed as the number of deaths due to cancer per 100,000 population. Except for age-specific rates, all mortality rates are age-adjusted to the 2000 U.S. standard population.

Reliability of Rates

Rates based on small numbers of events over a given time period or for sparsely populated geographic areas can vary widely year to year. This limits their usefulness in comparisons and estimation of further occurrences. Great caution should be used in assigning significance to rate changes from one year to the next for the majority of cancer sites in West Virginia and for geographic regions within the state. Multiple-year summary rates and trends over time provide better measurements and add credence to statements regarding rates.

Crude rates are not reliable for the purpose of comparing two different populations since they do not take into account demographic factors which influence the rate, such as age, sex, and race. Age-, sex-, and race-adjusted rates will provide a more reliable measurement to compare experiences over geographic areas or time periods.

Caution should always be used in attributing differences in rates to any particular factor or set of factors. Many variables may influence rates; valid interpretation of the reason for rate difference requires extensive research.

Although county rates of cancer incidence are based on population-based registries rather than estimates, caution should still be exercised in interpreting differences between jurisdictions. Given small numbers of cases and small populations, average annual age-adjusted rates for counties can vary widely year to year. In an effort to better assess the significant differences between county and state or U.S. rates, 95% confidence intervals were calculated for average annual age-adjusted county rates based on the following formula:

$$p \pm 1.96 \times \sqrt{\frac{p(1-p)}{n}}$$

In this formula, p represents the rate, and n represents the population. Differences in rates were interpreted to be statistically significant if the West Virginia rate or the U.S. rate fell outside the 95% confidence interval for the county rate.

Incidence and mortality rates for individual years from 1993 through 2000 found in this report are slightly higher than those found in last year's report, *Cancer in West Virginia, Incidence and Mortality, 1993 - 2000*. Following publication of annual reports, additional data for prior years are still received from various sources (central cancer registries in other states, previously unidentified cases from hospitals, etc.). These data are added to the WVCR database to increase its accuracy and completeness. As additional cases from a prior year are identified, these are included in calculations of incidence or mortality rates for that year of diagnosis, causing these rates to increase slightly over time.

Finally, cancer registries, like most projects, grow and develop over time. With increasing years of experience, improved data collection systems within West Virginia, and increasing data exchange with other state central cancer registries, it is likely that more complete, accurate, and geographically representational information will be obtained. This may be reflected in slight increases in rates due to improved case acquisition and registry development.

Limitations of 1993 Through 2001 Data Collection

There are potential weaknesses in the 1993 - 2001 data collection. The first is the dependence on data exchange with central cancer registries in other states to identify West Virginia residents who were diagnosed and treated elsewhere. The WVCR currently has data exchange agreements with central registries in 17 states including the five bordering states. These central registries may experience delays in reporting in their states, which affect the timeliness of reporting to the WVCR.

Another potential weakness is the reporting of cases of cancer which were identified in out-of-state pathology laboratories and treated outside the hospital setting. The WVCR is dependent on physicians to report these cases that would not be identified by routine casefinding activities.

Each year the WVCR estimates the expected number of invasive cancer cases by computing SEER incidence to West Virginia mortality rate ratios that were standardized for age, sex, race, and primary tumor. At the time this report was prepared, the WVCR had accessioned 93% of the 1993 expected number of cases, 94% of the 1994 estimate, 98% of the 1995 estimate, 99% of the 1996 estimate, 103% of the 1997 estimate, 100% of the 1998 estimate, 101% of the 1999 estimate, 101% of the 2000 estimate, and 100% of the 2001 estimate. Delays in reporting by some sources impact the completeness of registry data.