

# Cancer Registration in Vermont



**Vermont Department of Health**  
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# Cancer Registration in Vermont • Contents

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In fond memory of Joanne Rathgeb, Vermont breast cancer patient and advocate. She prompted the Vermont Congressional delegation to introduce the National Cancer Registry Act in 1991. We remember her touching words:

*“So, the only kind of ‘radiation’ I’d like to be involved in is to:  
Radiate Health, Radiate Happiness, Radiate Hope”*

(From the monologue, *A Funny Thing Happened on the Way to Radiation...* by Joanne Rathgeb in *Voices of Courage: A Collection of Short Stories and Poems that Cancer Couldn’t Beat*. September 23, 1991.)

# Introduction

## **Purpose of *Cancer Registration in Vermont***

The main purpose of *Cancer Registration in Vermont* is to describe the elements of cancer registration that remain relatively constant every year, such as registry operations, confidentiality, regulations, and data methods. This publication contains technical appendices including State and Federal cancer registry legislation and site group definitions. Cancer rates for Vermont residents may be found in the publication, *Cancer in Vermont*.

The concept of cancer registration is introduced in this publication, including data collection methods, cancer registry functions, and the history of the Vermont Cancer Registry. This document elaborates on reporting sources for incidence and mortality data, as well as some of the possible limitations of the data. The quality assurance measures used to produce incidence statistics are covered in detail.

## **Purpose of the Vermont Cancer Registry**

The main responsibilities of the Vermont Cancer Registry are to collect, edit, analyze, and report cancer data. Operated by the Vermont Department of Health, the registry monitors cancer incidence and mortality among Vermont residents. The Department of Health and other researchers use registry data to study cancer trends, research cancer causes, and improve cancer education and prevention efforts. The registry does not collect information directly from patients, and patient information in the registry is kept strictly confidential. Patient confidentiality is discussed in greater detail later in this section.

## **Cancer Surveillance**

Cancer surveillance is the monitoring of cancer rates and trends in a population. The goal of cancer surveillance is to reduce illness and death from cancer. Data on the diagnosis, extent of disease, and treatment are collected and analyzed at the local, state and national level. Cancer surveillance data can assist public health officials in directing effective cancer prevention and control programs focused on preventing risk behaviors for cancer, such as tobacco use and poor diet. This information can help identify where cancer screening efforts should be enhanced.

According to the report of the Centers for Disease Control and Prevention (CDC), *Cancer Registries: The Foundation for Comprehensive Cancer Control At-A-Glance 1999*, cancer surveillance, conducted through state-based registries, is designed to:

- Determine cancer patterns among various populations.
- Monitor cancer trends over time.
- Guide planning and evaluation of cancer control programs (e.g., determine whether screening and other prevention measures are making a difference).

- Help prioritize health resource allocations.
- Advance clinical, epidemiologic, and health services research.
- Serve as the basis for an aggregated and centralized database of cancer incidence in the U.S.

### History of the National Program of Cancer Registries

In 1991, two Vermont breast cancer survivors, Joanne Rathgeb and Virginia Soffa, delivered nearly 14,000 letters in a campaign called “Do the Write Thing” to start a national cancer registry. As a result of their efforts, U.S. Representative Bernie Sanders, together with U.S. Senator Patrick Leahy, authored and introduced federal legislation to establish the National Program for Cancer Registries on October 24, 1992 (see Appendix A). The National Program for Cancer Registries provided states without registries, such as Vermont, funding opportunities to establish new registries, and it funded improvements for states with existing registries.

The purposes of the National Program for Cancer Registries include: to improve existing cancer registries; to plan and implement registries where they do not exist; to meet standards for data completeness, timeliness, and quality; and to establish a computerized reporting and data-processing system. The Centers for Disease Control and Prevention support cancer registries in 45 states, three territories, and the District of Columbia. (The remaining five states are federally funded through the National Cancer Institute.) Vermont is one of the 13 states that has implemented a new state cancer registry with the federal funding.

### History of the Vermont Cancer Registry

The Vermont Coalition on Cancer Prevention and Control was formed in June 1988 to address cancer in the State of Vermont as a public health concern. Led by the Vermont Department of Health, the coalition consisted of representatives from public, private, and voluntary organizations involved in cancer control activities throughout the state. After reviewing extensive information, the coalition set goals and made recommendations that formed the basis of the *Vermont Plan for Cancer Prevention and Control, 1990-1995*.

One of the goals in the plan was “to monitor and evaluate the cancer incidence, prevalence of risk factors, and effectiveness of intervention programs.” The establishment of a “statewide, population-based cancer incidence registry for Vermont” was the first recommendation for meeting that goal.

In 1992, with financial support from the Vermont Department of Health Breast and Cervical Cancer program and potential funding from the new federal initiative, the Vermont Cancer Coalition established a working group to plan a state cancer registry.

On June 16, 1993, Governor Dean signed into law the Vermont Cancer Registry Act. This Act established a population-based, statewide cancer registry within the Vermont Department of Health.

### Vermont Cancer Legislation

All health care facilities and providers diagnosing or treating cancer in the State of Vermont are required to report cancer cases to the Vermont Cancer Registry, according to the Cancer Registry Law, Title 18, Chapter 4 of the Vermont Statutes Annotated (VSA). A copy of the law is located in Appendix B.

A “health care facility” is any hospital, nursing home, health maintenance organization, home health agency, diagnostic imaging facility, laboratory, radiation therapy facility, or inpatient or ambulatory surgical, diagnostic, or treatment center. “Health care provider” is any person, facility, or institution, licensed, certified or authorized to provide professional health care service.

All cases of cancer diagnosed and/or receiving the first course of treatment in Vermont on or after January 1, 1994 are reportable to the Vermont Cancer Registry, regardless of a patient’s state or country of residence. The legislation requires reporting of any newly diagnosed cancer case to the registry within 120 days of the date of diagnosis or discharge. Failure to report may result in state retrieval of the desired data with the incurred cost being billed to the facility or practice that failed to report the data.

A monetary fine of up to \$500 per day may be charged providers or facilities denying access to the files required for data collection. The Vermont legislation, cited by the North American Association of Central Cancer Registries as a national model, also stipulates confidentiality provisions, provides for freedom from liability and authorizes the release of data for approved research.

Rules supporting the Vermont Cancer Registry Law were effective November 15, 1993 (see Appendix C). The rules define a reference date for the reporting of cancer cases to the state registry; provide a list of non-reportable cancers; specify that cancer data are to be submitted to the registry in approved machine readable format; and require data fields be consistent with data sets defined by the American College of Surgeons and the American Association of Central Cancer Registries, now the North American Association of Central Cancer Registries.

The rules specify the following data categories that must be submitted for each case of cancer: patient identifiers and demographics, provider and facility identifiers, cancer identification, extent of disease at diagnosis, and first course of treatment. The rules refer to the Vermont Cancer Registry Procedure Manual for additional procedures regarding data collection and maintenance of data confidentiality.

## Confidentiality

The law requires that all information collected by the Vermont Cancer Registry be kept “confidential and privileged.” This specifically includes identifying information regarding individual patients, health care providers and health care facilities. Procedures to safeguard and secure the registry database and printed data from the database are included in the Administrative Rules and in the Procedure Manual. The law permits disclosure of confidential data to other cancer registries and federal cancer control agencies to collaborate in a national cancer registry and to health researchers for cancer control and prevention research studies. However, strict requirements, including prior approval of the researcher’s academic committee for the protection of human subjects, must be met.

## Differences Between Hospital and State Registries

Both hospital and state (population-based) cancer registries serve vital functions in cancer research. Hospital registries are primarily concerned with the diagnosis, treatment, and survival of patients in a particular hospital. The research carried out by the hospital cancer registry promotes better patient care and contributes to professional education.

At the time of this publication, the American College of Surgeons approved five Vermont hospital cancer registries. These registries assure active follow-up of patients to evaluate treatment outcomes and survival rates. The registries approved by the American College of Surgeons also carry out several research studies each year. While hospital registries provide useful information and are the core of the state registry, their information alone is not representative of the population as a whole.

Population-based registries, such as the Vermont Cancer Registry, are concerned with the numbers and types of cases occurring within a defined geographical area. The Vermont Cancer Registry follows the Surveillance, Epidemiology and End Results coding rules and North American Association of Central Cancer Registries procedures for information exchange so the data can be compared to other state and national data.

To determine cancer incidence rates for the state, reports must be obtained on every cancer diagnosis in Vermont. To ensure accuracy in calculating incidence rates, cancers occurring among residents who are diagnosed and/or treated outside the state are also included, and all duplicate reports of cases are merged into one record. Cancers in nonresidents of the state are excluded from all calculations. Only invasive cases (meaning the cancer cells have spread to healthy tissue next to the tumor) are included in incidence computation, with the exception of cancer of the bladder.

# Data Collection

## Mortality • Reporting Sources

The mortality data used in this guide are based on death certificates of Vermont residents. By law, all deaths that occur in the state are recorded using a standard death certificate form. The certifying physician completes the cause of death section of the death certificate that includes the conditions, diseases or injuries that resulted in the death (see Appendix D). This information is used to identify deaths caused by cancer or by other underlying causes.

The cancer statistics in this guide are based on the “underlying” cause of death, which is defined as the disease or injury that initiated the sequence of events leading directly to death. When the certifying physician lists more than one cause or condition on the cause of death section of the certificate, the underlying cause is determined by the temporal sequence of the conditions and selection rules used by experienced nosologists (specialists in disease classification).

All death certificates are filed in town clerks’ offices, and copies are sent to the Vermont Department of Health. Copies of death certificates of Vermont residents who die in other states or in Canada are also sent to the Department of Health through a cooperative exchange agreement. Staff at the Department of Health enter the certificates into a computer database, query and edit the data, and share statistical information with the National Center for Health Statistics to become part of a national database. Each year Vermont death statistics are published in the Vital Statistics report, distributed by the Vermont Department of Health (<http://www.state.vt.us/health/>). The National Center for Health Statistics (<http://www.cdc.gov/nchswww/default.htm>) publishes national death statistics in the National Vital Statistics Reports.

## Mortality • Quality Assurance of the Data

Several measures have been adopted at the state and national levels to ensure the completeness and accuracy of the death certificate data. Vital records staff at the Department of Health run computer programs on the data files to identify incomplete, illegible, rare, or otherwise improbable data. They ask certifying physicians to clarify and correct questionable entries.

The National Center for Health Statistics has developed training courses for nosologists, registration staff, and statisticians who work with mortality data. They have developed computer software to standardize and automate the coding of cause of death. This software increases the accuracy and ensures the consistent application of coding rules particularly in identifying the underlying cause of death when several causes are listed. Finally, National Center for Health Statistics handbooks for funeral directors, certifying physicians, and medical examiners provide detailed instructions on how to complete the death certificate. Other brief publications cover how to

complete the all-important cause of death section.

### **National Center for Health Statistics**

U.S. mortality rates are compiled by National Center for Health Statistics, and they include all cancer deaths in the country. The National Center for Health Statistics is a program of the Centers for Disease Control and Prevention, and is the primary federal organization responsible for the collection, analysis, and dissemination of health statistics.

### **Incidence • Reporting Sources**

All health care facilities are required to report new diagnoses of cancer to the Vermont Cancer Registry for the purpose of calculating population-based cancer incidence rates. All reporting sources use standardized, confidential means for data submission. Hospitals report the large majority of cases. Physicians' offices and nursing homes report cases when the patients seen by them do not plan to go to a Vermont hospital for care, but this accounts for less than one percent of all cases. There are no freestanding outpatient surgical facilities, laboratories, or radiation treatment centers in Vermont.

#### **Hospitals**

All fifteen Vermont hospitals report to the Vermont Cancer Registry on a regular basis, following federally established protocols. All facilities, except two, submit data electronically. The hospitals that report using paper forms see fewer than 25 cases per year. Appendix E contains the Vermont Cancer Registry abstract form.

Hospital cancer registrars are charged not only with reporting cases, but also with identifying all of the cases seen in a hospital that meet eligibility requirements. Accurate and timely incidence reporting of cancer in the State of Vermont relies on the ability of cancer registrars to perform exhaustive searches of their institutions' records for reportable cases of cancer. This casefinding process involves routine review of pathology logs, radiology logs, discharge summaries, and multiple other information sources.

#### **Physicians**

Unlike hospitals, which collect complete case information, physician practices must initially complete only a short form, which includes information on the reporting physician, patient, diagnosis and any treatment given in the physician's office. The form is then held on file for a period of time to allow possible collection of additional information later from a Vermont hospital or a report from an adjoining state. If the

physician's report is not matched with a hospital report, state registry personnel contact the physician to complete case entry into the state database.

#### **Other States**

Cases of cancer diagnosed and/or receiving the first course of treatment in Vermont are reportable to the Vermont Cancer Registry, regardless of a patient's state of residence. While the Vermont Cancer Registry only reports on cancers of Vermont residents, the registry does have legal reciprocal agreements with other states. Therefore, the registry is required to provide cancer information on non-Vermont residents to the state where the patients reside. Conversely, other states are required to provide cancer information to the Vermont Cancer Registry regarding Vermont residents when they are diagnosed and/or treated in another state.

#### **Surveillance, Epidemiology and End Results**

The National Cancer Institute funds a network of population-based registries called Surveillance, Epidemiology and End Results, commonly referred to as SEER. The program is composed of thirteen population-based registries, which represented approximately 14 percent of the national population at the time of this publication. With respect to selected demographic and epidemiologic factors, they provide a reasonably representative subset of the United States population. The combined data of the Surveillance, Epidemiology and End Results areas are used as the best estimate of national cancer incidence rates and are the gold standard to which states compare their data.

# Quality Assurance

The Vermont Cancer Registry collaborates with hospitals and other reporting sources to report data of the highest quality in the most efficient manner. The Vermont Cancer Registry has several procedures in place to evaluate the quality of data submitted by reporting institutions. The quality assurance procedures ensure completeness and accuracy of reporting. They include the review of all cases submitted (electronic edit checks and visual review), as well as the administration of re-abstracting and casefinding audits.

## Electronic Edits

Electronic edits are effective in identifying blank and invalid codes, as well as impossible variable combinations, such as date of birth after date of diagnosis. The Vermont Cancer Registry uses two software packages to apply electronic edit checks to incoming cancer data, the central registry software and an independent edit software, GenEDITS, provided by the Centers for Disease Control and Prevention.

There are many reasons for using the GenEDITS program in conjunction with the edits in cancer registry software programs. Nationwide, this program is used at all levels of cancer data collection - hospital, state, and national. This serves to maintain data quality and consistency when pooling and comparing data sets from multiple sources.

Electronic data submissions are run through edits upon receipt, and any failures are resolved at that time. Additionally, edits are run on the entire cancer registry database on a quarterly basis to detect and correct any newly introduced errors.

## Visual Review

Another quality assurance tool utilized by the Vermont Cancer Registry is visual review. One hundred percent of hospital, physician, and death certificate only cases are visually reviewed for completeness and accuracy. Any discrepancies between the reported data and published data collection guidelines are identified and resolved. The reporting source is queried whenever necessary.

## Procedures for New Registrars and Consultants

All new registrars and consultants operating in the state of Vermont must submit cancer cases for visual review by the Vermont Cancer Registry quality control staff. This applies to any new abstractor in the state of Vermont, regardless of experience or certification.

The cases are closely reviewed with comments and suggestions forwarded from the Vermont Cancer Registry quality control staff to the abstractor. Particular attention is given to the use of standard reporting guidelines set forth in the Vermont Cancer

Registry Hospital Procedure Manual, including the coding, documentation, and interpretation of data item definitions. Upon satisfactory review, the registry grants the new abstractor permission to begin submitting cases in the usual fashion.

## **Casefinding**

### **Consults**

When a hospital pathology laboratory detects cancer in a specimen from a patient not treated in the hospital, the hospital is required to report the pathological finding to the Vermont Cancer Registry as a “consult-only” case. A typical example is when a biopsy is performed in a physician’s office, and the tissue sample is sent to a hospital for microscopic analysis. The hospital registrar identifies the case upon routine casefinding but is only required to send a minimal amount of information on the case to the registry. The consult-only case is then matched to the registry database. If the case is not located in the database, then a report is obtained from the physician who performed the biopsy.

### **Death Clearance**

The Vermont Cancer Registry uses death clearance as a final means to identify reportable cancer cases overlooked by other casefinding protocols. All death certificates with any mention of cancer that are not included in the registry are reviewed to determine if the cases should be included. Each death certificate is investigated to determine if the cancer was diagnosed on or after January 1, 1994. After the querying process is completed, all previously unreported cancers that meet eligibility criteria are included in the registry database.

## **Assessment of Duplicate Records and Case Consolidation**

Multiple case reports may be submitted to the Vermont Cancer Registry for the same patient’s cancer. More than one hospital can be involved in the diagnosis and/or treatment of the patient, and each hospital is required to report the case to the registry. To avoid over-reporting of malignancies, all cases of the same patient’s cancer are identified. The most accurate patient and tumor information is compiled and merged into one record.

## **Auditing**

### **Casefinding**

This type of audit measures how well a reporting facility identifies and submits reportable cancers to the Vermont Cancer Registry. Casefinding auditing is the process whereby central registry staff members review listings in the hospital (previously

described in Data Collection) and identify the reportable cases. This list is compared to those cases actually reported by the facility within the same period (generally two consecutive months selected at random for the previous year). Hospitals are required to demonstrate 95 percent completeness. The reporting institution is required to abstract and submit cases for all reportable cases found in the casefinding audit.

#### **Re-abstracting**

This type of audit measures how well a case submitted to the Vermont Cancer Registry reflects the statements made within a patient's medical record. Re-abstracting is the process whereby a central registry staff member abstracts a medical record belonging to the reporting institution. The central registry abstract is compared to the case as it exists in the central registry database at the time of the audit. A standard set of data items, containing a minimum number of twenty, is evaluated for every case audited. State registry staff members re-abstract between 2 and 10 percent of the number of cases submitted by each hospital to the state registry. Hospitals are required to demonstrate 95 percent accuracy overall.

# Data Methods

## Definition of Incidence and Mortality Rates

The incidence rate is calculated as the number of new cancers diagnosed in the state during one year divided by the number of residents in the state during the year. The mortality rate is calculated similarly, using the number of cancer deaths, rather than the number of new cancers diagnosed. These rates are reported in units per 100,000 residents.

Crude rates such as these are simple ratios of number of events per number of people in the population at risk for experiencing an event. Crude rates are useful for making comparisons among populations with similar demographic characteristics.

Rates are often calculated for smaller groups of people within the population having a particular characteristic in common. An example is an age-specific rate, such as the proportion of 70-74 year old males diagnosed with prostate cancer in a year.

Incidence rates are used to identify areas needing further cancer research. Differences in incidence rates might prompt a search for clues as to why the rates are higher in one group than another. Incidence rates are used to suggest specific populations in need of cancer prevention and screening.

Public health officials compare mortality rates in different populations when they study the development of a particular cancer in relation to previous exposures to risk factors. Specific types of cancer with high mortality rates due to poor prognosis can be targeted for research. Mortality data are also used to measure improvements in early diagnosis and treatment. When incidence data are unavailable, mortality rates are used to estimate the rate of cancer in a population. This use of mortality data is reliable only when the disease is usually fatal and the period between diagnosis and death is short. This is a reasonable use of mortality data for cancers with shorter survival rates, such as pancreatic cancer, but it is unreliable in cancers with good prognosis, such as testicular cancer.

## Age Adjustment

Age adjusted rates are calculated by weighting the Vermont age-specific cancer rates with a standard population. (Appendix F contains the 1970 U.S. standard population, which applies to cancer incidence data through the diagnosis year 1998.) The standardized, age adjusted rate represents the hypothetical rate that would be observed if Vermont's population had the same age distribution as the standard population.

Age adjustment means that any observed differences in rates cannot be attributed to age differences in the groups being compared. Geographic areas may have different proportions of older people in their populations. Since most cancers are diagnosed in older people, the areas with more older people would appear to have higher rates than the areas with a younger population. Age adjustment allows the comparison

of rates among populations having different age distributions by standardizing the age-specific rates in each population to one standard population.

Due to the significant change in age groups over time, the rates based on one age adjustment standard are not comparable to other studies that are age adjusted to a different standard.

### Confidence Intervals

A confidence interval is a range of values within which the population's experience is expected to fall. The confidence level states the degree of confidence that the true rate is contained in the confidence interval. All rates in this report are calculated at a 95 percent confidence level. For example, the 1994-1996 age adjusted Vermont male colorectal cancer incidence rate is 52.5 (47.7,57.7) per 100,000 population. There is 95 percent confidence that the true age adjusted Vermont male colorectal cancer incidence rate is between 47.7 and 57.7.

The width of a confidence interval is related to the degree of uncertainty of the true rate. A wide interval indicates greater uncertainty. Population size can influence the width of a confidence interval. Smaller populations generally have wider confidence intervals; conversely, larger populations generally have narrower confidence intervals. A greater number of years of data can reduce the width of confidence intervals.

Confidence intervals can be used to assess statistical significance when comparing rates of two populations. If the confidence intervals of the two groups (such as Vermont and the U.S.) overlap, then any difference between the two rates is mainly due to random variation and is not statistically significant.

### Rate Comparisons

To determine if there is a statistically significant difference between the Vermont cancer incidence rate and the U.S. cancer incidence estimate, the Vermont rate is compared to the SEER rate. If the SEER rate falls within the confidence interval for the state rate, then there is no statistical difference. For example, the 1994-1996 Vermont female breast cancer incidence rate is 108.3 (101.9,115.0) per 100,000 population. The 1994-1996 SEER rate is 114.4 per 100,000 population. Since the SEER rate is found within the confidence interval of the Vermont rate, no statistical difference exists between the two rates.

If the U.S. estimate falls outside the confidence interval for the state rate, then a statistically significant difference exists. For example, the 1994-1996 Vermont male lung cancer incidence rate is 83.7 (77.6,90.2) per 100,000 population. The 1994-1996 SEER rate is 71.7 per 100,000 population. Since the lower confidence interval for the Vermont rate is higher than the SEER rate, the Vermont rate is interpreted as being

statistically higher than the SEER rate.

To determine if there is a statistically significant difference between the cancer incidence rates of a county and the U.S., the county rate is compared to the SEER rate. If the SEER rate falls within the confidence interval for the county rate, then no statistically significant difference exists. For example, the 1994-1996 Addison County female colorectal cancer incidence rate is 45.5 (30.0,67.9) per 100,000 population. The 1994-1996 SEER rate is 36.4 per 100,000 population. Since the SEER rate is found within the confidence interval of the Addison County rate, no statistical difference exists between the two rates.

If the SEER rate falls outside the confidence interval for the county rate, then a statistically significant difference exists. For example, the 1994-1996 Lamoille County female colorectal cancer incidence rate is 81.1 (53.4,121.5) per 100,000 population. The 1994-1996 SEER rate is 36.4 per 100,000 population. Since the lower confidence interval for the Lamoille County rate is higher than the SEER rate, the Lamoille County rate is statistically significantly higher than the SEER rate.

#### **Confidentiality • County- and Race-Specific Rates**

Producing statistics with small numbers increases the risk that individuals can be identified in the data. The limited number of years of data in the registry and the small population of the state (an estimated 590,000 people in 1997) require registry policies and procedures to prevent the unintentional identification of individuals. To protect patients' privacy, county-specific data are published only for the most commonly diagnosed cancer sites. In addition, data on rare cancer sites, race, and other variables that could identify Vermonters are not published. It is expected that more detailed reports will become available when the number of years of data has increased.

#### **Limitations of the Incidence Data • Possible Data Collection Biases**

A small portion (3.6%) of incident cases was registered (1994-1996 data) with a death certificate as the only reporting source. The gold standard for this data quality indicator is less than 3 percent, and the silver standard is less than 5 percent, according to the North American Association of Cancer Registries Registry Certification. The percent of death-certificate-only cases in the Vermont Cancer Registry data set is well within the acceptable limits.

Death-certificate-only cases are included in the data set as a last resort, if follow-back information from the attending or certifying physician is lacking. If cancer is mentioned on the death certificate, and the case cannot be excluded based on the fact that it was diagnosed prior to the registry's reference date (using time of onset

until time of death to determine the time period of diagnosis), then it must be registered in the absence of follow-back information.

Death-certificate-only cases may include prevalent (living with the disease), as well as incident (newly diagnosed), cases. This is more of a problem with new registries that do not have records of cases diagnosed in previous years. Incidence counts could be slightly elevated as a result of including the death-certificate-only cases. Nevertheless, federal standards for data reporting require these cases to be included in the data analysis.

#### Interpretive Biases

Vermont incidence rates are compared to national rates using Surveillance, Epidemiology and End Results (SEER) data. Specifically, SEER comparison rates for whites are used instead of those for all races because the nonwhite population in Vermont, averaged over 1992-1996, was 1.5 percent, compared with the total U.S. nonwhite population of 16.9 percent. The national rates for whites are the closest comparison available for Vermont data.

Nationwide, people of white race have a higher risk compared to other races for female breast, melanoma, and bladder cancer incidence. Whites have a lower risk compared to other races for prostate, colorectal, and cervical cancer incidence. The much smaller populations of Vermont residents of other races may have very different risks of these cancers. Combining these cases over many years will be required to determine cancer rates. Fortunately, the risk experienced by these populations and the public health measures required to protect them can be determined from the scientific literature based on national and regional populations with greater diversity.

#### Underreporting

Cancer registration is a dynamic process, and additions, deletions, and updates are constantly made to the data. The incidence data reported at any time could be modified to some extent in future reports. Previously unreported cases will be added, and diagnosis date will be updated, as more information becomes available.

#### Clinical-Only Cases

Only one percent of the reported incidence cases for 1994-96 data were diagnosed exclusively by clinical findings, such as physical examination, rather than a tissue biopsy or radiographic scan. While clinical-only diagnostic confirmation is also rare for other population-based registries, it is possible that some cases diagnosed solely by clinical means have gone unreported.

#### Death-Certificate-Only Cases

A small portion of incident cases is registered with a death certificate as the only reporting source. Death-certificate-only cases are included in the data set as a last resort, if no information could be obtained when the Vermont Cancer Registry contacted the attending or certifying physician. These cases are incomplete because more data items are contained within a cancer report than are found on a death certificate.

#### Hospital Casefinding

The Vermont Cancer Registry relies heavily on hospital casefinding for a majority of its cancer reports. Any insufficiencies in hospital registrars' identification of reportable tumors could affect incidence rates. Vermont hospital registrars undergo semianual training in casefinding and abstracting procedures, and past casefinding audits of hospitals have revealed 95 percent completeness rates. Nevertheless, it is possible that some cases of cancer have been missed by routine casefinding procedures.

#### Non-Hospital Reporting Sources

Although policies and procedures are in place for physician's offices, nursing homes and other non-hospital settings to report cancers directly to the Vermont Cancer Registry when the patients will not be referred to a Vermont hospital, these cases sometimes goes unreported. The Vermont Cancer Registry does not currently provide formal training for non-hospital reporting sources. Therefore, the reportability criteria for some cases, such as rare skin cancers, may be unclear, and these cases could have gone unreported.

#### Out-of-State Cases

At the time of this publication, Vermont had legal interstate exchange agreements with Arkansas, Florida, Massachusetts, Mississippi, New Hampshire, New York, Texas, and Wyoming. It is possible that Vermont residents were diagnosed in states without agreements; these cases would not be reported to the Vermont Cancer Registry.

#### Veterans Administration Medical Center

Although federal programs are not required by law to report cancer incidence cases to the Vermont Cancer Registry, historically, the Veterans Administration Medical Center has generously provided the case information to the Vermont Cancer Registry. Due to recent staffing limitations, however, the number of cases reported has declined in recent years, and the data set is known to be incomplete. The number of missing cases reported from 1994 until the time of this publication is small, but state rates could be affected, especially if the types of unreported tumors are rare.

# Appendix A

## The Cancer Registries Amendment Act

42 USC §§ 280e-280e-4 US Code as of: 01/26/1998

### Sec. 280e. National program of cancer registries

#### (a) In general

The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States, or may make grants or enter into contracts with academic or nonprofit organizations designated by the State to operate the State's cancer registry in lieu of making a grant directly to the State, to support the operation of population-based, statewide cancer registries in order to collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), data concerning-

- (1) demographic information about each case of cancer;
- (2) information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;
- (3) administrative information, including date of diagnosis and source of information;
- (4) pathological data characterizing the cancer, including the cancer site, stage of disease (pursuant to Staging Guide), incidence, and type of treatment; and
- (5) other elements determined appropriate by the Secretary.

#### (b) Matching funds

(1) In general The Secretary may make a grant under subsection (a) of this section only if the State, or the academic or nonprofit private organization designated by the State to operate the cancer registry of the State, involved agrees, with respect to the costs of the program, to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs or \$1 for every \$3 of Federal funds provided in the grant.

(2) Determination of amount of non-Federal contribution; maintenance of effort

(A) Non-Federal contributions required in paragraph (1) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

(B) With respect to a State in which the purpose described in subsection (a) of this section is to be carried out, the Secretary, in making a determination of the amount of non-Federal contributions provided under paragraph (1), may include only such contributions as are in excess of the amount of such contributions made by the State

toward the collection of data on cancer for the fiscal year preceding the first year for which a grant under subsection (a) of this section is made with respect to the State. The Secretary may decrease the amount of non-Federal contributions that otherwise would have been required by this subsection in those cases in which the State can demonstrate that decreasing such amount is appropriate because of financial hardship.

(c) Eligibility for grants

(1) In general

No grant shall be made by the Secretary under subsection (a) of this section unless an application has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such a manner, and be accompanied by such information, as the Secretary may specify. No such application may be approved unless it contains assurances that the applicant will use the funds provided only for the purposes specified in the approved application and in accordance with the requirements of this section, that the application will establish such fiscal control and fund accounting procedures as may be necessary to assure proper disbursement and accounting of Federal funds paid to the applicant under subsection (a) of this section, and that the applicant will comply with the peer review requirements under sections 289 and 289a of this title.

(2) Assurances

Each applicant, prior to receiving Federal funds under subsection (a) of this section, shall provide assurances satisfactory to the Secretary that the applicant will -

(A) provide for the establishment of a registry in accordance with subsection (a) of this section;

(B) comply with appropriate standards of completeness, timeliness, and quality of population-based cancer registry data;

(C) provide for the annual publication of reports of cancer data under subsection (a) of this section; and

(D) provide for the authorization under State law of the statewide cancer registry, including promulgation of regulations providing -

(i) a means to assure complete reporting of cancer cases (as described in subsection (a) of this section) to the statewide cancer registry by hospitals or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer;

(ii) a means to assure the complete reporting of cancer cases (as defined in subsection (a) of this section) to the statewide cancer registry by physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or

other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;

(iii) a means for the statewide cancer registry to access all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes, and all other facilities, individuals, or agencies providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified patient;

(iv) for the reporting of cancer case data to the statewide cancer registry in such a format, with such data elements, and in accordance with such standards of quality timeliness and completeness, as may be established by the Secretary;

(v) for the protection of the confidentiality of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers;

(vi) for a means by which confidential case data may in accordance with State law be disclosed to cancer researchers for the purposes of cancer prevention, control and research;

(vii) for the authorization or the conduct, by the statewide cancer registry or other persons and organizations, of studies utilizing statewide cancer registry data, including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and

(viii) for protection for individuals complying with the law, including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.

(d) Relationship to certain programs

(1) In general This section may not be construed to act as a replacement for or diminishment of the program carried out by the Director of the National Cancer Institute and designated by such Director as the Surveillance, Epidemiology, and End Results Program (SEER).

(2) Supplanting of activities In areas where both such programs exist, the Secretary shall ensure that SEER support is not supplanted and that any additional activities are consistent with the guidelines provided for in subsection (c) (2) (C) and (D) of this section and are appropriately coordinated with the existing SEER program.

(3) Transfer of responsibility The Secretary may not transfer administration responsi-

bility for such SEER program from such Director.

(4) Coordination To encourage the greatest possible efficiency and effectiveness of Federally supported efforts with respect to the activities described in this subsection, the Secretary shall take steps to assure the appropriate coordination of programs supported under this part with existing Federally supported cancer registry programs.

(e) Requirement regarding certain study on breast cancer In the case of a grant under subsection (a) of this section to any State specified in section 280e-3(b) of this title, the Secretary may establish such conditions regarding the receipt of the grant as the Secretary determines are necessary to facilitate the collection of data for the study carried out under section 399C.

# Appendix B

The Vermont Cancer Registry Law  
18 VSA §§ 151-157

The Vermont Cancer Registry Law  
Title 18. Health  
Chapter 4. Cancer Registry

## § 151. DEFINITIONS

As used in this chapter:

- (1) “Cancer” means all malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma, Hodgkin’s disease, and leukemia, but excluding basal cell and squamous cell carcinoma of the skin.
- (2) “Health care facility” shall have the meaning given in section 9432 of this title.
- (3) “Health care provider” shall have the meaning given in section 9432 of this title.

## § 152. ESTABLISHMENT OF CANCER REGISTRY

(a) The commissioner shall establish a uniform statewide population-based cancer registry system for the collection of information determining the incidence of cancer and related data. The secretary shall adopt rules necessary to effect the purposes of this chapter, including the data to be reported, and the effective date after which reporting by health care facilities and health care providers shall be required.

(b) All cancers diagnosed or treated in the state shall be reported to the representative of the health department authorized by the commissioner to compile the cancer data, or any individual, agency, or organization designated to cooperate with that representative.

(c) The commissioner shall establish a training program for the personnel of participating health care facilities and a quality control program for cancer data. The commissioner shall collaborate in studies with clinicians and epidemiologists and publish reports on the results of such studies. The commissioner shall cooperate with the National Institutes of Health and the Centers for Disease Control in providing cancer incidence data.

## § 153. PARTICIPATION IN PROGRAM

(a) Any health care facility diagnosing or providing treatment to cancer patients shall report each case of cancer to the commissioner or his or her authorized representative in a format prescribed by the commissioner within 120 days of admission or diagnosis. If the facility fails to report in a format prescribed by the commissioner, the commissioner’s authorized representative may enter the facility, obtain the informa-

tion, and report it in the appropriate format. In these cases, the facility shall reimburse the commissioner or the authorized representative for the cost of obtaining and reporting the information.

(b) Any health care provider diagnosing or providing treatment to cancer patients shall report each cancer case to the commissioner or his or her authorized representative within 120 days of diagnosis. Those cases diagnosed or treated at a Vermont facility or previously admitted to a Vermont facility for diagnosis or treatment of that instance of cancer are exceptions and do not need to be reported by the health care provider.

(c) All health care facilities and health care providers who provide diagnostic or treatment services to patients with cancer shall report to the commissioner any further demographic, diagnostic, or treatment information requested by the commissioner concerning any person now or formerly receiving services, diagnosed as having or having had a malignant tumor. Additionally, the commissioner or his or her authorized representative shall have physical access to all records which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified cancer patient. Willful failure to grant access to such records shall be punishable by a fine of up to \$500.00 for each day access is refused. Any fines collected pursuant to this subsection shall be deposited in the general fund.

#### § 154. CONFIDENTIALITY

(a) All information reported pursuant to this chapter shall be confidential and privileged. The commissioner shall take strict measures to ensure that all identifying information is kept confidential.

(b) All identifying information regarding an individual patient, health care provider, or health care facility contained in records of interviews, written reports and statements procured by the commissioner or by any other person, agency or organization acting jointly with the commissioner in connection with cancer morbidity and mortality studies shall be confidential and privileged and shall be used solely for the purposes of the study. Nothing in this section shall prevent the commissioner from publishing statistical compilations relating to morbidity and mortality studies which do not identify individual cases or sources of information.

#### § 155. DISCLOSURE

(a) The commissioner may enter into agreements to exchange confidential information with other cancer registries in order to obtain complete reports of Vermont residents diagnosed or treated in other states and to provide information to other states regarding their residents diagnosed or treated in Vermont.

(b) The commissioner may furnish confidential information to other states' cancer registries, federal cancer control agencies, or health researchers in order to collaborate in a national cancer registry or to collaborate in cancer control and prevention research studies. However, before releasing confidential information, the commissioner shall first obtain from such state registries, agencies, or researchers agreement in writing to keep the identifying information confidential and privileged. In the case of researchers, the commissioner shall also first obtain evidence of the approval of their academic committee for the protection of human subjects established in accordance with Part 46 of Title 45 of the Code of Federal Regulations.

#### § 156. LIABILITY

(a) No action for damages arising from the disclosure of confidential or privileged information may be maintained against any person, or the employer or employee of any person, who participates in good faith in the reporting of cancer registry data or data for cancer morbidity or mortality studies in accordance with this chapter.

(b) No license of a health care facility or health care provider may be denied, suspended or revoked for the good faith disclosure of confidential or privileged information in the reporting of cancer registry data or data for cancer morbidity or mortality studies in accordance with this chapter.

(c) Nothing in this section shall be construed to apply to the unauthorized disclosure of confidential or privileged information when such disclosure is due to gross negligence or willful misconduct.

#### § 157. VERMONT MAMMOGRAPHY REGISTRY

The confidentiality, disclosure, and liability provisions of sections 154, 155 and 156 of this title shall likewise apply to all mammography and pathology data relating to breast cancer and any associated identifying information acquired by the Vermont mammography registry (VMR). In the case of VMR, the rights and obligations of the health commissioner shall be assumed by the appropriate VMR governing body or official.

# Appendix C

## Vermont Cancer Registry Rules

Weil's CVR No. 13-140-052 (Health Department)  
Secretary of State Rule No. 93-79

### CANCER REGISTRY RULES

#### I Introduction

Title 18, Section 152(a) of the Vermont Statutes Annotated (VSA) requires the Commissioner of Health to establish a uniform statewide population-based cancer registry system for the collection of information determining the incidence of cancer and related data. These Cancer Registry Rules have been adopted to effect the purposes of the Cancer Registry Law, 18 VSA, Chapter 4.

#### II Establishment of Cancer Registry

A Vermont Cancer Registry is hereby established within the Department of Health to collect information regarding statewide cancer incidence and related data.

#### III Effective Date of Reporting

Effective November 1, 1993, any health care facility or health care provider diagnosing or providing treatment to cancer patients must report each case of cancer to the Director of the Vermont Cancer Registry within 120 days of admission or diagnosis as prescribed by these regulations.

The definitions of "health care facility" and "health care provider" appear as Title 18, Section 9432 of the Vermont Statutes Annotated.

#### IV Data to be Reported

##### 1. Reportable Cancers

All cancers with a behavior code of "2" (in situ) or "3" (malignant) in the *International Classification of Diseases for Oncology* (2nd Edition, 1990) (*ICD-0-2*) must be reported.

However, the following skin cancers, as coded in ICD-0-2, are excluded from reporting:

- A. 8000-8004 Neoplasms, malignant, NOS of the skin (C44.0-C44.9)
- B. 8010-8045 Epithelial carcinomas of the skin (C44.0-C44.9)
- C. 8050-8082 Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)
- D. 8090-8110 Basal cell carcinomas of any site except genital sites

NOTE: Skin cancers in the genital sites (vagina, clitoris, labium, vulva, prepuce, penis, and scrotum) ARE reportable since they are more likely to metastasize than the usual carcinomas of the skin. (These cancers are reportable both nationally and internation-

ally.)

## 2. Data Elements

The following data categories are required to be reported in a machine readable format approved by the Director of the Vermont Cancer Registry for each case of cancer:

- A. Patient Identifiers and Demographics
- B. Provider and Facility Identifiers
- C. Cancer Identification
- D. Extent of Disease at Diagnosis
- E. First Course of Treatment
- F. Follow-up

No follow-up data needs to be reported prior to January 1, 1995.

## V Quality Control

1. Each health care facility or health care provider shall permit periodic quality control reviews including casefinding, abstracting, coding, and data submission processing. Unless other arrangements are made with a facility or provider, no fewer than 10 working days notice is established as the minimum notice period applicable whenever the Vermont Cancer Registry wishes to have access to information on site at a facility.
2. The Vermont Cancer Registry will ensure the provision of cancer registry training and consultation.
3. Reporting facilities shall assist the Vermont Cancer Registry in annual reconciliation of cancer mortality and incidence data.

## VI Procedure Manual

In order to facilitate reporting and to protect the data collected, the Vermont Cancer Registry will supplement these regulations with a Vermont Cancer Registry Procedure Manual which will be made available to all data reporters. Any data fields delineated in the Vermont Cancer Registry Procedure Manual will be consistent with data sets defined by the American College of Surgeons and the American Association of Central Cancer Registries.

All identifying information regarding an individual patient, health care provider, or health care facility contained in records of interviews, written reports, and statements procured by the Commissioner of Health or by any other person, agency, or organization acting jointly with the Commissioner in connection with cancer morbidity and mortality studies shall be confidential and privileged and shall be used solely for the purposes of the study. In accordance with the Cancer Registry Law, the Commissioner shall, however, be able to publish statistical compilations, enter into agreements to

exchange information with other cancer registries, and furnish confidential information to other states' cancer registries, federal cancer control agencies, or health researchers.

To ensure the protection and confidentiality of the identifying information collected by the Vermont Cancer Registry, the Vermont Cancer Registry Procedure Manual will contain, among other things:

- Procedures to safeguard and secure the registry database and printed data generated from the database containing identifying information;
- Procedures to destroy (e.g., by shredding) all printed materials containing identifying information when such materials are to be disposed of;
- Procedures to make certain that all persons with access to Vermont Cancer Registry identifying information are aware of the Health Department's Confidentiality Regulation and policy and have signed a written statement acknowledging their responsibility to maintain confidentiality and subjecting them to penalties for violation of confidentiality requirements.

# Appendix D

## Vermont Certificate of Death

**NAME KNOWN TO PHYSICIAN**

DH-PHS-DTH-89C

DEPARTMENT OF HEALTH  
**VERMONT CERTIFICATE OF DEATH**

08252

LOCAL FILE NUMBER

STATE FILE NUMBER

TYPE OR PRINT  
IN BLACK INK

|   |   |  |   |  |   |
|---|---|--|---|--|---|
| 1. DECEDENT'S NAME (First, Middle, Last)  |   | 2. SEX   |   | 3. DATE OF DEATH (Month, Day, Year)  |   |
| 4. SOCIAL SECURITY NUMBER   |   | 5a. AGE (Yrs.)<br>—Last birthday   | 5b. UNDER 1 YEAR<br>Months Days                             | 5c. UNDER 1 DAY<br>Hours Minutes   | 6. DATE OF BIRTH (Mo., Day, Yr.)  |
| 7. BIRTHPLACE (City and State or Foreign Country)   |   | 8. PLACE OF DEATH (Check only one)<br><b>HOSPITAL</b><br><input type="checkbox"/> Inpatient <input type="checkbox"/> ER/Outpatient <input type="checkbox"/> DOA<br><b>OTHER</b><br><input type="checkbox"/> Nursing Home <input type="checkbox"/> Residence <input type="checkbox"/> Other (Specify) _____ |   |  |   |
| 9. FACILITY NAME (If not institution, give street and number)   |   |  | 10. CITY OR TOWN OF DEATH                                   |  | 11. VETERAN? (If so, what war?)   |
| 12. MARITAL STATUS —<br>Married, Never Married,<br>Widowed, Divorced (Specify)  | 13. SURVIVING SPOUSE (If wife, give maiden name)                                    | 14. DECEDENT'S USUAL OCCUPATION (Give kind of work done<br>during most of life. Do not use retired.)   |   | 15. KIND OF BUSINESS / INDUSTRY  |   |
| 16. DECEDENT'S EDUCATION<br>(Specify only highest grade completed)<br>Elementary/Secondary (0-12) College (1-4 or 5+)   |   | 17. WAS DECEDENT OF HISPANIC ORIGIN? (Specify No or Yes — If yes, specify<br>Cuban, Mexican, Puerto Rican, etc.)<br><input type="checkbox"/> No<br><input type="checkbox"/> Yes (Specify) _____  |   | 18. RACE — White, Black, American Indian, etc. (Specify)                     |   |
| 19. RESIDENCE—STATE   |   | 20. CITY, TOWN, OR LOCATION  | 21. MAILING ADDRESS (Street, City or Town, State, Zip Code) |  |   |
| 22. FATHER'S NAME (First, Middle, Last)   |   |  | 23. MOTHER'S NAME (First, Middle, Maiden Surname)           |  |   |
| 24a. INFORMANT'S NAME (Type/Print)  |   | 24b. MAILING ADDRESS (Street, City, or Town, State, Zip Code)  |   |  |   |
| 25. PART 1. Enter the diseases, injuries, or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock, or heart failure. List only one cause on each line.<br><b>IMMEDIATE CAUSE</b> (Final disease or condition resulting in death)<br>a. _____ DUE TO (OR AS A CONSEQUENCE OF) _____<br>b. _____ DUE TO (OR AS A CONSEQUENCE OF) _____<br>c. _____ DUE TO (OR AS A CONSEQUENCE OF) _____<br>d. _____ DUE TO (OR AS A CONSEQUENCE OF) _____<br>Sequentially list conditions, if any, leading to immediate cause. Enter <b>UNDERLYING CAUSE</b> (Disease or injury that initiated events resulting in death) <b>LAST</b> . |   |  |   |  | Approximate Interval Between Onset and Death  |
| 26. PART 2. Other significant conditions contributing to death but not resulting in the underlying cause given in Part 1.   |   |  |   |  | 26a. WAS AN AUTOPSY PERFORMED? (Yes or No)  |
|   |   |  |   |  | 26b. WERE AUTOPSY FINDINGS AVAILABLE PRIOR TO COMPLETION OF CAUSE OF DEATH? (Yes or No) |
| 27a. MANNER OF DEATH<br><input type="checkbox"/> Natural <input type="checkbox"/> Accident <input type="checkbox"/> Suicide<br><input type="checkbox"/> Homicide <input type="checkbox"/> Undet <input type="checkbox"/> Pending  |   | 27b. DATE OF INJURY (Month, Day, Year)   | 27c. HOUR   | 27d. HOW DID INJURY OCCUR? (Enter nature of injury in Part 1 or Part 2)      |   |
| 27e. INJURY AT WORK (Specify Yes or No)   | 27f. PLACE OF INJURY (At Home, Farm, Factory, Street, Office Bldg., etc. (Specify)) |  | 27g. LOCATION (Street, or R.F.D. No., City or Town, State)  |  |   |
| TO THE BEST OF MY KNOWLEDGE, ON THE BASIS OF THE CASE HISTORY, EXAMINATION AND/OR INVESTIGATION, DEATH OCCURRED AT THE TIME, DATE AND PLACE AND DUE TO CAUSE(S) AND MANNER STATED.  |   |  |   |  | 29a. DATE SIGNED (Mo., Day, Yr.)  |
|   |   |  |   |  | 29b. HOUR OF DEATH  |
| 28a. (Signature)  |   |  |   |  | 29c. PRONOUNCED DEAD ON (Date) (Time)   |
| 28b. NAME AND ADDRESS OF CERTIFIER (Type or Print)  |   |  |   |  | 30. NAME OF ATTENDING PHYSICIAN IF OTHER THAN CERTIFIER (Type or Print)                 |
| 31a. METHOD OF DISPOSITION <input type="checkbox"/> Temporary Storage<br><input type="checkbox"/> Burial <input type="checkbox"/> Cremation <input type="checkbox"/> Removal from State<br><input type="checkbox"/> Donation <input type="checkbox"/> Other (Specify) _____   |   | 31b. PLACE OF TEMPORARY STORAGE (Cemetery, City or Town, State)  |   | 31c. PLACE OF FINAL DISPOSITION (Cemetery or Crematory, City or Town, State) |   |
| 32a. SIGNATURE OF FUNERAL DIRECTOR OR AUTHORIZED PERSON   |   | 32b. NAME AND ADDRESS OF FACILITY OR AUTHORIZED PERSON   |   |  | 33. DATE OF DISPOSITION (Month, Day, Year)  |
| 34a. REGISTRAR — Signature  |   |  |   |  | 34b. DATE RECEIVED BY LOCAL REGISTRAR (Month, Day, Year)                                |
| 35a. TRUE COPY Clerk Signature  |   | 35b. TOWN  |   | 35c. DATE (Month, Day, Year)   |   |
| ATTEST.   |   |  |   |  |   |

TO BE SIGNED  
BY REGISTRAR  
ON COPY ONLY



# Appendix F

## 1970 U.S. Standard Population

Sources: U.S. Bureau of the Census, Census of Population 1970.  
SEER Cancer Statistics Review 1973-1996 National Cancer Institute

| Age      | U.S. Standard Million<br>Population, 1970 |
|----------|---|
| All Ages | 1,000,000                                 |
| <5       | 84,416                                    |
| 5-9      | 98,204                                    |
| 10-14    | 102,304                                   |
| 15-19    | 93,845                                    |
| 20-24    | 80,561                                    |
| 25-29    | 66,320                                    |
| 30-34    | 56,249                                    |
| 35-39    | 54,656                                    |
| 40-44    | 58,958                                    |
| 45-49    | 59,622                                    |
| 50-54    | 54,643                                    |
| 55-59    | 49,077                                    |
| 60-64    | 42,403                                    |
| 65-69    | 34,406                                    |
| 70-74    | 26,789                                    |
| 75-79    | 18,871                                    |
| 80-84    | 11,241                                    |
| 85+      | 7,435                                     |

# Appendix G

## Incidence Site Groupings

SEER Recode for Primary Site  
based on *ICD-O-2*

|                        |  |                       |
|------------------------|--|-----------------------|
| Oral Cavity and Throat | C000:C009<br>C019:C029<br>C079:C089<br>C040:C049<br>C030:C039<br>C050:C059<br>C060:C069<br>C110:C119<br>C090:C099<br>C100:C109<br>C129<br>C130:C139<br>C141<br>C140<br>C142:C148 | Excluding M-9590:9989 |
| Esophagus              | C150:C159  | Excluding M-9590:9989 |
| Stomach                | C160:C169  | Excluding M-9590:9989 |
| Colon and Rectum       | C180:C189<br>C260<br>C199<br>C209  | Excluding M-9590:9989 |
| Liver                  | C220<br>C221   | Excluding M-9590:9989 |
| Pancreas               | C250:C259  | Excluding M-9590:9989 |
| Larynx                 | C320:C329  | Excluding M-9590:9989 |
| Lung                   | C340:C349  | Excluding M-9590:9989 |

SEER Recode for Primary Site cont.  
based on *ICD-O-2*

|                          |                                     |                                     |
|--------------------------|-------------------------------------|-------------------------------------|
| Melanoma of the Skin     | C440:C449                           | Only Types:<br>872:879              |
| Breast                   | C500:C509                           | Excluding M-9590:9989               |
| Cervix                   | C530:C539                           | Excluding M-9590:9989               |
| Uterus                   | C540:C549<br>C559                   | Excluding M-9590:9989               |
| Ovary                    | C569                                | Excluding M-9590:9989               |
| Prostate                 | C619                                | Excluding M-9590:9989               |
| Testis                   | C620:C629                           | Excluding M-9590:9989               |
| Bladder                  | C670:C679                           | Excluding M-9590:9989               |
| Kidney                   | C649,C659                           | Excluding M-9590:9989               |
| Brain and Nervous System | C710:C719<br>C700:C709<br>C720:C729 | Excluding M-9590:9989               |
| Thyroid                  | C739                                | Excluding M-9590:9989               |
| Hodgkin's Disease        |                                     | Only Types:<br>9650:9667            |
| Non-Hodgkin's Lymphoma   |                                     | Only Types:<br>9590:9595, 9670:9717 |
| Multiple Myeloma         |                                     | Only Types:<br>9731:9732            |

SEER Recode for Primary Site cont.  
based on *ICD-O-2*

Leukemias

Only Types:

9821, 9828, 9823, 9820, 9822,  
9824, 9825, 9826, 9861, 9867,  
9871-9874, 9863, 9868, 9860,  
9862, 9864, 9866, 9891, 9893,  
9890, 9892, 9894, 9801, 9841,  
9803, 9842, 9800, 9802, 9804,  
9827, 9830, 9840, 9850, 9870,  
9880, 9900, 9910, 9930:9941

All Sites

C000:C809

# Appendix H

## Mortality Site Groupings

SEER Site Groupings for *ICD-9*

NCHS Mortality Data - Underlying Cause of Death *ICD-9* Codes

|                        |                               |
|------------------------|-------------------------------|
| Oral Cavity and Throat | 140.0-149.9                   |
| Esophagus              | 150.0-150.9                   |
| Stomach                | 151.0-151.9                   |
| Colon and Rectum       | 153.0-154.1<br>159.0          |
| Liver                  | 155.0-155.2                   |
| Pancreas               | 157.0-157.9                   |
| Larynx                 | 161.0-161.9                   |
| Lung                   | 162.2-162.9                   |
| Melanoma of the Skin   | 172.0-172.9                   |
| Breast                 | 174.0-174.9<br>175._          |
| Cervix                 | 180.0-180.9                   |
| Uterus                 | 182.0-182.1<br>182.8<br>179._ |
| Ovary                  | 183.0                         |
| Prostate               | 185._                         |

SEER Site Groupings for ICD-9 cont.  
 NCHS Mortality Data - Underlying Cause of Death ICD-9 Codes

|                          |   |
|--------------------------|---|
| Testis                   | 186.0-186.9                               |
| Bladder                  | 188.0-188.9                               |
| Kidney                   | 189.0,189.1                               |
| Brain and Nervous System | 191.0-191.9<br>192.0-192.3<br>192.8-192.9 |
| Thyroid                  | 193._                                     |
| Hodgkin's Disease        | 201.0-201.9                               |
| Non-Hodgkin's Lymphoma   | 200.0-200.8<br>202.0-202.2<br>202.8-202.9 |
| Multiple Myeloma         | 203.0<br>203.2-203.8                      |
| Leukemias                | 202.4, 203.1<br>204.0-208.9               |
| All Sites                | 140.0-208.9                               |

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### For More Information:

The data on which the cancer incidence rates in this report are based are available for research purposes in a public use file. All personal identifiers and other data fields that might lead to the identification of individuals have been deleted.

- To request the Vermont Cancer Registry public use data set or copies of this or other registry reports:

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website: [www.state.vt.us/health](http://www.state.vt.us/health)

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This report can be made available in other accessible formats.

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