

# **Chapter I: Introduction**

## Chapter I: Introduction

This report contains information on the incidence and mortality of cancer in Minnesota from 1988-2004. Cancer incidence and mortality provide two important measures of the impact of cancer. Incidence measures how many new cases of the disease are diagnosed, while mortality measures how many people die of the disease. The Minnesota Department of Health (MDH) collects and analyzes data on both the incidence and mortality of cancer. Incidence data are collected by the Minnesota Cancer Surveillance System (MCSS), and mortality data are collected by the Minnesota Center for Health Statistics (MCHS). MCSS prepared the analyses included in this report.

MCSS is an ongoing program within the Chronic Disease and Environmental Epidemiology Section of the MDH. The primary objectives of MCSS are to: (1) monitor the occurrence of cancer in Minnesota and describe the risks of developing cancer, (2) inform health professionals and educate citizens regarding specific cancer risks, (3) answer the public's questions and concerns about cancer, (4) promote cancer research, and (5) guide decisions about how to target cancer control resources.

The need for accurate information about the occurrence of cancer was recognized by the Minnesota legislature in 1981, when legislation was introduced to establish a statewide cancer surveillance system. In 1987, following a 6-year process which included consensus building, development of methods, and a feasibility study, legislation (Minnesota Statutes 144.671-144.69) was passed to establish MCSS. MCSS began operations on January 1, 1988.

MCSS receives part of its funding from the National Program of Cancer Registries (NPCR), which is administered by the U.S. Centers for Disease Control and Prevention (CDC). NPCR funding began in October 1994 and is scheduled to continue at least through June 2012. The support of the NPCR enables MCSS to collect additional information on each case of cancer, perform death clearance, perform quality control studies, provide specialized training to

Minnesota professionals who collect and code cancer data, and increase the analysis and utilization of the collected data.

An attempt has been made to minimize the use of technical jargon in this report. However, because of the nature of the material and the diverse audience that this report must serve, some technical terms remain. The Glossary (Appendix D) and Appendices A, B, and E will assist those desiring more basic definitions, as well as those requiring additional detail.

To minimize repetition of discussion and materials presented in previous reports, liberal cross-referencing is employed. The eight previous reports are: *The Occurrence of Cancer in Minnesota 1988*; *The Occurrence of Cancer in Minnesota 1988-1990: Incidence, Mortality, and Trends*; *The Occurrence of Cancer in Minnesota 1988-1992: Incidence, Mortality, and Trends*; *The Occurrence of Cancer in Minnesota 1988-1994: Incidence, Mortality, and Trends*; *The Occurrence of Cancer in Minnesota 1988-1996: Incidence, Mortality, and Trends*; *The Occurrence of Cancer in Minnesota 1992-1997: Cancer in Minnesota 1988-1999*; and *Cancer in Minnesota 1988-2002*. These reports will be referenced as MCSS 1991, MCSS 1993, MCSS 1995, MCSS 1997, MCSS 1999, MCSS 2001, MCSS 2003, and MCSS 2005, respectively; they are available from MCSS. MCSS 1999, 2001, 2003, and 2005 are available on the MCSS web site.\*

### Data Sources

#### Incidence Data

MCSS collects information on microscopically confirmed malignant and in situ tumors, as well as benign tumors occurring in the head and spinal cord. MCSS does not collect information on the most common forms of skin cancer (basal and squamous cell carcinomas).

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\* [www.health.state.mn.us/divs/hpcd/cdee/mcss](http://www.health.state.mn.us/divs/hpcd/cdee/mcss)

## Introduction

Enough information is collected so that MCSS can classify each new diagnosis by type of tumor (primary site, histologic cell type), tumor stage (how advanced the cancer is), and demographic characteristics of the patient (age, sex, race, and residence) as of the date of diagnosis of the cancer, as well as a summary of the first course of cancer-directed treatment. Information about the patient, cancer, stage, and treatment that the pathology laboratory cannot provide is obtained from hospital-based cancer registries or from the patient's hospital or clinic record.

Hospitals and pathology laboratories provide data to MCSS in two main ways. Hospitals that have computerized cancer registries containing summaries for each cancer patient treated at the hospital submit computerized case reports. The remaining cancer diagnoses are reported through pathology laboratories. Pathology laboratories submit photocopies or electronic files of the pathology report, which contains information about the cancer, and the medical record face sheet or an equivalent form, which contains the patient's demographic data. More than 795,000 reports of cancer representing approximately 467,000 different cancers were registered with MCSS as of October 2007. For the period covered by this report, January 1, 1988 to December 31, 2004, 355,149 newly diagnosed, invasive cancers were registered. *In situ* cancers of the urinary bladder are included with invasive cancers so that Minnesota data are consistent with national standards.

The data upon which this report is based are dynamic. That is, they are always being updated and improved. For example, in MCSS' first legislative report (MCSS 1991), filed 16 years ago, 17,728 cancers were included in the analyses of 1988 data. The current database for 1988 contains information on 18,010 cancers (some of the increase is because the data reported for 1988 did not include *in situ* cancers of the bladder). MCSS staff are constantly updating data for all years when new information becomes available. In this regard, all data are subject to change when appropriate. For purposes of analyses, the data are "frozen" (closed) in order that numbers and rates be

consistent throughout the report. The date of closure for 1988-2004 data included in this report was October 23, 2007.

## Mortality Data

Mortality data are obtained from death certificates. Death certificates are collected, coded, and computerized by the MCHS. Although the MCHS codes contributing causes of death as well as the underlying cause of death, only the underlying cause of death was used in calculating cancer mortality rates.

## Population Data

Minnesota population estimates were obtained from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program web site.\* These represent intercensal estimates for the years 1988 and 1999. For the years 2000 through 2004, the population estimates incorporate bridged single-race estimates, which are derived from the original multiple race categories in the 2000 Census. Because of a directive from the federal Office of Management and Budget, the 2000 Census collected race information in a new way – people could select more than one race, instead of being forced to select only one. Bridged estimates attempt to re-categorize those selecting more than one race to a single race (what they would have chosen if only given one choice), based on data from other surveys. A description of the methodology used to develop the bridged single-race estimates is available on the National Center for Health Statistics web site.†

## Data Presentation and Interpretation

### Incidence Data

Cancers diagnosed prior to 1992 were originally coded according to the 1987 Field Trial Edition of the International Classification of Diseases for Oncology (ICD-O-FT), cancers diagnosed between 1992 and 2000 were originally coded according to the 2nd edition (ICD-O-2), and

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\* [www.seer.cancer.gov/popdata](http://www.seer.cancer.gov/popdata)

† [www.cdc.gov/nchs/about/major/dvs/popbridge/popbridge.htm](http://www.cdc.gov/nchs/about/major/dvs/popbridge/popbridge.htm)

cancers diagnosed from 2001 forward were coded according to the 3rd edition (ICD-O-3). All the diagnoses have been translated, using a computer algorithm either alone or in combination with review, into the ICD-O-3 standard. Cancers are presented according to grouping definitions developed by the SEER program. Following SEER reporting practices in *SEER Cancer Statistics Review, 1975-2004*, cases with histology defined as “borderline malignancy” under ICD-O-2 coding rules and “invasive” under ICD-O-3 coding rules are not included in this report. These histologies (9950, 9960-9962, 9980-9984, and 9989) include chronic myeloproliferative disorders and myelodysplastic syndromes); they were not collected prior to 2001 and account for a total of 1,856 diagnoses over the four-year period 2001-2004. In addition, histologies coded as “invasive” under ICD-O-2 but as having “uncertain behavior” under ICD-O-FT and ICD-O-3 (histology codes 8442, 8451, 8462, 8472, and 8473) are not included in the current rates. Most of them are borderline ovarian tumors and account for approximately 700 diagnoses that were included in MCSS 2003 but not subsequent ones. Data are available upon request.

Most tables included in this chapter present incidence data for invasive cancers only, with the exception of *in situ* bladder cancers. Following SEER reporting practices, *in situ* bladder cancers are included in data on invasive bladder cancers and in data on all cancer sites combined because the distinction between *in situ* and invasive bladder cancer is often unclear, and some *in situ* bladder cancers may be life threatening. *In situ* cancers for other sites are only included in tables showing stage distribution for that specific site.

### **Mortality data**

The information presented in this report includes all deaths with cancer specified as the underlying cause of death during the specified time period, regardless of the year of diagnosis. The underlying cause of death for reports from 1988 - 1998 were coded to International Classification of Diseases, Ninth Revision; for reports occurring in 1999-2002, the International

Classification of Diseases, Tenth Revision was used. Cancers were grouped according to SEER’s algorithm, using the ICD version that was in use at the time the death occurred.

### **Age-adjustment**

Age-adjustment is a statistical method that minimizes differences in rates that would occur solely because the populations being compared do not have the same age distributions. Because cancer occurs more frequently with increasing age, a population with a larger proportion of elderly individuals will have more cancers occur than a younger population of the same size, even if cancer rates at any given age are exactly the same in the two groups. Age-adjustment produces a hypothetical summary rate, the rate that would occur if the group had the age distribution of a “standard” population. If cancer rates among groups being compared are age-adjusted to the same standard population, rates will not be biased by differences in age, and a determination of whether one group has a greater risk of developing or dying from cancer will be more meaningful.

All rates presented in this report were directly age-adjusted to the 2000 U.S. standard population, provided in Appendix E. A number of different population standards have been utilized in the past. Using the 2000 U.S. standard increases the absolute value of the rate, and therefore, rates in this report cannot be compared to those in MCSS reports using other standards.

### **Comparisons to SEER**

The SEER program has collected population-based cancer incidence data from nine selected geographic areas in the U.S. since 1973 and from an additional four areas since 1992. Because a cancer registry covering the entire U.S. does not exist, SEER data on cancer occurrence are widely cited as national data. The SEER incidence rates presented in tables in Chapter III for comparison to Minnesota are for the 17 SEER areas covering about 17% of the U.S. population, as presented in race-specific tables in their recent report, *SEER Cancer*

## Introduction

*Statistics Review, 1975-2004.* Consistent with SEER reporting practices, national cancer mortality rates are for the entire U.S.

For brevity, SEER/U.S. rates (except those for all cancer sites combined) are only presented for all races combined and for non-Hispanic whites. Caution should be used in comparing Minnesota and SEER/U.S. cancer rates for all races combined. Because cancer rates vary markedly by race and ethnicity, the overall risk of developing cancer in a geographic area depends in part on the relative proportion of race and ethnic groups in the population. The race and ethnic distributions of Minnesota and the 17 SEER areas are very different. In particular, Hispanics, who tend to have considerably lower cancer rates than non-Hispanic whites, comprised slightly over three percent of the Minnesota population during 2000-2004 and approximately 20 percent of the overall population in the 17 SEER areas. This means that for many sites, Minnesota rates for all races combined will be higher than that reported by the 17 SEER areas. Comparison of rates among non-Hispanic whites better reflects the difference in risk of developing cancer in the two areas.

When comparing Minnesota and SEER, it is also important to recognize that rates reported by the SEER program include cases that were diagnosed based on clinical observations, while the MCSS does not currently collect information on those cases. During 2000-2004, 3.7 percent of invasive cancers in the 17 SEER registries were coded as clinical diagnoses. If all other factors were the same, one would therefore expect the overall cancer rate in Minnesota to be 3.7 percent lower than SEER simply because of the exclusion of these cases, and not because Minnesotans have a lower risk of cancer. However, there are several factors that indicate that excluding clinically diagnosed cancers from the SEER database may not make SEER and MCSS rates more comparable. First, the quality of health care in Minnesota is high, and the proportion of clinically diagnosed cancers that are sent to a laboratory for confirmation appears to be higher than in other geographical areas. Second, some cases that are originally reported

to SEER based on clinical observations may eventually be confirmed microscopically, but the information is not updated in the registry. And third, audits of MCSS operations have indicated that case ascertainment is extremely high.

Nonetheless, certain types of cancer typically have a substantial proportion of clinical diagnoses, and Minnesota incidence rates may be artificially low for these sites. These include cancers of the eye and orbit (30% of cases reported as clinically diagnosed in SEER), liver (22%), pancreas (18%), brain (11%), Kaposi sarcoma (11%), kidney (8%), and lung and bronchus (8%). For these sites, mortality rates should be used to assess how Minnesota compares to national data.

### Completeness and Quality of Data

MCSS Field Service staff first identified 9.5 percent of all the cancer diagnoses reportable to MCSS during their independent review of pathology reports. This review is an important feature of MCSS quality control in that it assures that virtually all eligible cancers are included in the data. For all of the individual cancers diagnosed during 1988-2004, 4.6 percent (nearly 20,000) would have been missed without this review.

MCSS data are very complete and of very high quality. This is documented by several measures of data quality. First, MCSS began performing death clearance in 1995. Death clearance is a quality control process by which cancer-related deaths are linked with the MCSS database to identify cancer cases that have not been reported by routine methods. Potentially missed cancers are then followed back to determine if the cancer indeed should have been included in the MCSS database. Unresolved cancers are included in the database as "Death Certificate Only" (DCO) cases. Death clearance can identify sources where cancer reporting might be improved. Results indicate that MCSS case ascertainment is excellent. Of all the cancers diagnosed between 1995 and 2004 (the years for which death clearance has been performed), 1.4 percent would not have been identified without the death certificate, and 1.3 percent were based solely on

a death certificate (DCO). A high-quality cancer registry should have between 1 percent and 3 percent of its cases as DCO.

Second, in December 2005 MCSS submitted a nonidentified file of its provisional data for 2003 to the Registry Certification Committee of the North American Association of Central Cancer Registries (NAACCR). NAACCR is the organization in North America that develops standards and models for the collection of cancer data in central cancer registries. Table I-1 contains the results of the certification process. MCSS achieved the highest rating, the Gold Standard, for all criteria. Due to major staffing changes in 2006, clean-up of 2004 data was delayed; therefore a file was not submitted to NAACCR for certification of 2004 data. This delay partially accounts for the fact that this report was not completed in 2007.

Third, in July 2002 a contractor of the NPCR performed an external audit of the completeness and quality of MCSS data. Case completeness was estimated at 99.9 percent. Data accuracy was also exceptionally high, with an overall accuracy of 98.7 percent (51 errors identified out of 3,835 data items reviewed). The error rates for all audited data items were at or better than the average among other central registries funded by the NPCR, as well as those funded by the National Cancer Institute through its Surveillance, Epidemiology, and End Results program.

Fourth, MCSS has completed several of its own studies of the accuracy of the data contained in the central registry. These studies indicate that MCSS data are of comparable quality to data of other central cancer registries in the U.S. (MCSS Quality Control Reports 97:2, 99:1, 00:1, 01:1, 04:1, 05:1, 05:2, and 05:3). The last 4 reports are available on-line at the MCSS web site.\* Special attention has been paid to the data fields that were new to MCSS in 1995, stage at diagnosis and the information on the first course of cancer therapy.

### **Data on Race and Ethnicity**

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\* [www.health.state.mn.us/divs/hpcd/cdee/mcss](http://www.health.state.mn.us/divs/hpcd/cdee/mcss)

Race is an important variable for cancer surveillance. The risk of cancer varies by race and ethnicity – the reasons for the variations have yet to be fully delineated, but most likely include cultural, economic, societal, and genetic factors – so it is important to be able to compute race-specific cancer rates. Calculating a cancer rate requires two sets of numbers: numerators, or counts of events; and denominators, or the number of people at risk. In Minnesota, there are race- and/or ethnicity-specific challenges to the accuracy of both the numerators and the denominators. MCSS has done much work to reduce the problems with numerators.

Race is not always included in the reports submitted to MCSS, and prior to the 1995 diagnosis year MCSS did not have the resources to perform active follow-up to find the missing information. This is reflected in the fact that no indication of the patient's race was reported for 7.0 percent of the cancers diagnosed during the period 1988-1994. The percentage can be improved by assuming that individuals of unknown race are white if they live in counties that had more than 95 percent of residents listed as white in the census. After making this assumption, race was "unknown" for only 3.1 percent of the cancers diagnosed during the period 1988-1994. The effect of active follow-up is demonstrated by the fact that the percent with unknown race is much lower for cancers diagnosed in 1995 through 2004 (2.8 percent before and 1.5 percent after making an assumption based on county of residence).

Another challenge with incidence data is the fact that American Indians are often not identified as such in the medical record. Beginning in 2003, NPCR has supported the linkage of state cancer registry data with the roster of American Indians enrolled in the Indian Health Service (IHS). With appropriate data privacy protections in place, MCSS participated in this linkage project, and cancers newly diagnosed through 2004 have been linked with the IHS roster. The number of cancers in American Indians in the MCSS database increased by 44 percent as a result of the linkage. Minnesota death certificates were also linked with the IHS roster, increasing the number of cancer deaths among American

## Introduction

Indians by 9 percent. Waiting for the IHS death certificate linkage to occur accounts for much of the fact that this report was not ready in February 2007.

Ethnicity (Hispanic origin) for cancer incidence is still more difficult to collect accurately in Minnesota. Even when medical records are reviewed, usually no mention is found of whether or not a person is of Hispanic origin. In preparation for *MCSS 2005*, MCSS investigated how to apply Hispanic surname matching to improve the available data on cancer in the Minnesota Hispanic population. MCSS adapted the NAACCR Hispanic Identification Algorithm (NHIA) to work in Minnesota. Briefly, NHIA, which is described on the NAACCR web site,<sup>\*</sup> was followed except that Hispanic name matching was applied only in counties that had at least 4 percent Hispanics in the 2000 Census. Eleven counties, representing 90 percent of Hispanics in Minnesota, met this criterion. NHIA excludes individuals from Hispanic name matching if their race is Filipino or American Indian, or if they were born in a country with a high prevalence of Spanish surnames but low probability of Hispanic ethnicity. The resulting cancer incidence rates for Hispanics were more consistent both with other states' Hispanic cancer incidence data and with mortality data for Minnesota Hispanics and are therefore now included in Minnesota cancer data. After examining the effects of applying NHIA to Minnesota mortality data, it was decided that reporting of Hispanic ethnicity on the death certificate appeared complete enough without additional manipulation.

Despite recent improvements in the completeness of data on the patient's race, the ability of MCSS to evaluate racial and ethnic differences in cancer risk among Minnesotans remains limited by several factors. First, although the Minnesota population is increasingly diverse, populations of color are still relatively small. Out of a total Minnesota population of 4.9 million, the 2000 census enumerated 168,813 African Americans,

142,797 Asian/Pacific Islanders, 52,009 American Indians, 143,382 Hispanics of any race, and 75,335 persons of mixed or "other" race, together representing 12 percent of the total Minnesota population. Because all but the five most common cancers occur infrequently, only a few cases or deaths will be reported each year for most cancers from populations of color in Minnesota. This means that the random fluctuation of a few cases or deaths can cause rates for these groups to vary considerably from year to year.

Secondly, race and ethnicity as recorded in the medical record may or may not match what the individual would report on the Census form. In order to match the Census definition of race, individuals should be allowed to report their own race(s) and ethnicity. Admissions practices and forms at health care facilities do not always follow this practice; thus the race as recorded in the medical record might be from the patient's self-report, or it might be based on assumptions made by an observer at the facility.

Finally, the population estimates that are available to calculate rates may be inaccurate because they represent (1) undercounts of persons of color during the national census, (2) inaccurate population estimates during the intercensal period, and/or (3) inappropriate recoding of individuals who report more than one race into single-race categories. An example of the second, "intercensal," problem was the discovery, following completion of Census 2000, that the estimates of the Hispanic population in Minnesota for the late 1990's had been nearly 75% too low. Population estimates for the years between the 1990 and 2000 Censuses were subsequently revised, and thus the Minnesota Hispanic cancer mortality rates published since 2005 are different from those published in *MCSS 2003*. A potential example of the third, "recoding to single-race," problem relates to the data on American Indians. Although only 1.2 percent of Minnesotans overall reported more than one race in the 2000 Census, 32 percent of American Indians reported at least one race in addition to American Indian. The MCSS database contains only 38 (0.02 percent) cases with more than one reported race.

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<sup>\*</sup><http://www.naacrr.org/filesystem/pdf/NHIA%20v2%2009-21-05.pdf>

Thus, there is a mismatch between how race is identified in the numerator (MCSS) and how it was identified in the denominator (census), especially for American Indians. As previously stated, the bridged census estimates attempt to re-categorize individuals selecting more than one race to the single race they would have chosen if only given one choice. It is not known how American Indian individuals enrolled in IHS would report their racial identity on a Census form, nor whether IHS-enrolled American Indians are any different in this respect from American Indians not enrolled in the IHS, and thus it is unknown whether the current bridging method is the appropriate one to use when calculating American Indian cancer rates after incorporating an IHS linkage.

All of these factors limit our confidence in race- and ethnic-specific cancer rates in Minnesota, and make it challenging to interpret the differences we find. Despite these limitations, we believe that identifying race and ethnic differences in cancer risks is an important function of MCSS, and is important in developing policies and interventions directed at cancer control. We have, therefore, aggregated data over the 5-year period, 2000-2004, to present cancer data by race and ethnicity. In addition, rates based on fewer than ten cases or deaths are suppressed. Nonetheless, the shortcomings discussed above should be kept in mind when evaluating race and ethnic differences in cancer rates presented in this report.

### Uses of MCSS Data

As previously stated, MCSS has five primary objectives. The following is a brief summary of how MCSS is accomplishing each objective.

*Monitoring the occurrence of cancer in Minnesota and describing the risks of developing cancer.* Using a variety of tools, some developed in-house and some obtained from SEER,<sup>\*</sup> MCSS epidemiologists have analyzed data and produced a series of publications describing cancer occurrence and

risks (Table I-2b). Cancer mortality data have also been analyzed and included in this description of cancer occurrence in Minnesota. Estimates of cancer prevalence (the number of persons living with a diagnosis of cancer) in Minnesota, using methods developed by MCSS epidemiologists, are included as well.

MCSS provides data files without personal identifiers to the National Program of Cancer Registries, the North American Association of Central Cancer Registries, and the Central Brain Tumor Registry of the United States. These organizations combine data from multiple registries to produce publications describing cancer incidence and trends in the United States and/or North America (included in Table I-2c).

*Informing health professionals and educating citizens regarding specific cancers.* In 2005 - 2006, 20 formal presentations were made before local public health, community, academic, and regulatory groups on the occurrence of cancer in Minnesota and related topics. Examples of other activities to inform and educate are the quarterly MCSS newsletter, *MCSS Notes*,<sup>†</sup> the biennial *Minnesota Cancer Facts & Figures*,<sup>‡</sup> authored by an MCSS epidemiologist and published by the American Cancer Society, and an article in the May-June 2005 *Disease Control Newsletter*.<sup>§</sup> A list of publications (2005 - 2006) authored by MCSS staff is found in Table I-2a, b.

*Answering the public's questions and concerns about cancer.* MCSS received approximately 100 requests for information on cancer rates or cancer risks. These inquiries represent all geographic regions of the state. Although most of these inquiries are from individual citizens, inquiries also frequently come from citizens' groups, schools, and workplaces, as well as the public health, scientific, and medical communities. Responses to these inquiries range from providing simple, descriptive statistics to

<sup>\*</sup> [www.seer.cancer.gov/software](http://www.seer.cancer.gov/software)

<sup>†</sup> [www.health.state.mn.us/divs/hpcd/cdee/mcss/MCSSNotes.html](http://www.health.state.mn.us/divs/hpcd/cdee/mcss/MCSSNotes.html)

<sup>‡</sup> [http://www.cancerplanmn.org/sites/528d17b0-2c73-45c9-894d-872fc0beac4e/uploads/MN\\_Facts\\_and\\_Figures\\_2006\\_2.pdf](http://www.cancerplanmn.org/sites/528d17b0-2c73-45c9-894d-872fc0beac4e/uploads/MN_Facts_and_Figures_2006_2.pdf)

<sup>§</sup> <http://www.health.state.mn.us/divs/idepc/newsletters/dcn/2005/>

## Introduction

detailed record-linkage studies of a defined cohort.

*Promoting cancer research.* MCSS has assisted cancer researchers by providing information and data needed for the planning and support of grant applications. MCSS has also received 29 data use applications since 1988, which are described in Table I-3. The involvement of MCSS in the approved studies has varied from providing information about the completeness of case finding to providing rapid identification of cases for case-control studies. In addition, MCSS data have been used to investigate concerns about cancer occurrence in the workplace. Many scientific articles related to cancer etiology and prevention have been published based on these studies (Table I-2c).

*Guiding decisions about how to target cancer control activities.* MCSS epidemiologists continued their involvement in the implementation of CancerPlan Minnesota,\* serving the Minnesota Cancer Alliance. This data-based strategic plan is intended to be a framework for action to effectively reduce the burden of cancer among all Minnesotans. It is a five-year plan, with the majority of its measurable objectives written for 2010. Health care professionals, community and civic leaders, hospital administrators, and public health professionals use MCSS data to identify populations who would benefit from screening programs, write grant proposals to obtain funds for establishing screening programs for particular cancers, aid in deciding where satellite treatment facilities should be built and additional staff hired to serve patients who otherwise have to travel long distances to obtain treatment, and identify populations needing public education programs for cancer prevention.

## Statistical Methods

The statistical methods and constructs used in this report conform to standards established by the National Cancer Institute and are described in Appendix E.

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\* [www.cancerplanmn.org](http://www.cancerplanmn.org)

## Protection of Individual Privacy

Privacy of information that could identify an individual (e.g., name and address) is strictly protected by Minnesota law. Furthermore, this information is considered privileged in that the MDH cannot be compelled by court order to release any personal data collected by MCSS.

For more details on this issue, please see “Questions and Answers about MCSS Data Privacy” following the Summary section at the beginning of this report.

**Table I-1: North American Association of Central Cancer Registries certification results: quality, completeness, and timeliness of 2003 data, Minnesota Cancer Surveillance System**

Registry Element	Gold Standard	Silver Standard	MCSS Measure	Standard Achieved
1. Completeness of case ascertainment	95 %	90 %	100.8 %	Gold
2. Completeness of information recorded				
• Missing/unknown “age at diagnosis”	<= 2 %	<= 3 %	0.0 %	Gold
• Missing/unknown “sex”	<= 2 %	<= 3 %	0.0 %	Gold
• Missing/unknown “race”	<= 3 %	<= 5 %	2.1 %	Gold
• Missing/unknown “county”	<= 2 %	<= 3 %	0.5 %	Gold
3. Death certificate only cases	<= 3 %	<= 5 %	1.4 %	Gold
4. Duplicate primary cases	<= 0.1 %	<= 0.2 %	0.08 %	Gold
5. Passing EDITS	100.0 %	97 %	100.0 %	Gold
6. Timeliness	Data submitted within 24 months of close of calendar year			Gold

**Table I-2: Publications (2005-2006)****Table I-2a: Peer-Reviewed Publications co-authored by MCSS/MDH staff**

Chan JK, Gomez SL, O'Malley CD, Perkins CI, Clarke CA. Validity of cancer registry medicaid status against enrollment files: implications for population-based studies of cancer outcomes. *Medical Care* 2006; 44(10):952-5.

O'Malley CD, Shema SJ, Clarke LS, Clarke CA, Perkins CI. Medicaid status and stage at diagnosis of cervical cancer. *American Journal of Public Health*. 2006; 96(12):2179-85. Epub 2006 Oct 31.

Korn JE, Perkins CI. Taking a comprehensive approach to addressing Minnesota's leading cause of death. *Cancer Plan Minnesota 2005-2010*. *Minnesota Medicine* 2005; 88(4):36-9.

**Table I-2b: Other Publications co-authored by MCSS/MDH staff**

One Vision, One Voice: The Minnesota Cancer Alliance 2006 Year-End Report.

American Cancer Society, Midwest Division. *Minnesota Cancer Facts & Figures 2006*. Mendota Heights, MN: American Cancer Society, Midwest Division, 2006.

Perkins C, Bushhouse S. *Cancer in Minnesota, 2004: Preliminary report*. Minnesota Cancer Surveillance System, St. Paul, MN, March 2006.

Perkins C, Bushhouse S. *Cervical cancer control in Minnesota: assessing its effectiveness with data from the Minnesota Cancer Surveillance System*. St. Paul, MN: Minnesota Department of Health, December 2005.

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**Table I-2c: Publications incorporating data from MCSS**

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- Howe HL, Wu XC, Ries LA, Cokkinides V, Ahmed F, Jemal A, Miller B, Williams M, Ward E, Wingo PA, Ramirez A, Edwards BK. Annual report to the nation on the status of cancer, 1975-2003, featuring cancer among U.S. Hispanic/Latino populations. *Cancer* 2006;107:1711-42.
- Propp JM, McCarthy BJ, Davis FG, Preston-Martin S. Descriptive epidemiology of vestibular schwannomas. *Neuro-Oncology*. 8(1):1-11, 2006.
- Carozza SE, Howe HL. Patterns of cancer incidence among US Hispanics/Latinos, 1995-2000. *Cancer Causes Control* 2006;17(8):1067-75.
- Boscoe FP, Schymura MJ. Solar ultraviolet-B exposure and cancer incidence and mortality in the United States, 1993-2002. *BMC Cancer* 2006;6:264.
- Goodman MT, Tung KH, Wilkens LR. Comparative epidemiology of breast cancer among men and women in the U.S., 1996 to 2000. *Cancer Causes Control* 2006;17(2):127-36.
- Smigal C, Jemal A, Ward E, Cokkinides V, Smith R, Howe HL, Thun M. Trends in breast cancer by race and ethnicity: update 2006. *CA Cancer J Clin* 2006;56(3):168-83.
- Wu X, Chen VW, Ruiz B, Andrews P, Su LJ, Correa P. Incidence of esophageal and gastric cancers among American Asians/Pacific Islanders, Whites, and Blacks: subsite and histology differences. *Cancer* 2006;106:683-92.
- Samowitz WS, Albertsen H, Sweeney C, Herrick J, Caan BJ, Anderson KE, Wolff RK, Slattery ML. Association of smoking, CpG island methylator phenotype, and V600E BRAF mutations in colon cancer. *J Natl Cancer Inst*. 2006 Dec 6;98(23):1731-8.
- Tande AJ, Platz EA, Folsom AR. The metabolic syndrome is associated with reduced risk of prostate cancer. *Am J Epidemiol*. 2006 Dec 1;164(11):1094-102.
- Ruder AM, Waters MA, Carreón T, Butler MA, Davis-King KE, Calvert GM, Schulte PA, Ward EM, Connally LB, Lu J, Wall D, Zivkovich Z, Heineman EF, Mandel JS, Morton RF, Reding DJ, Rosenman KD; The Brain Cancer Collaborative Study Group. The Upper Midwest Health Study: a case-control study of primary intracranial gliomas in farm and rural residents. *J Agric Saf Health*. 2006 Nov;12(4):255-74.
- Slattery ML, Sweeney C, Murtaugh M, Ma KN, Caan BJ, Potter JD, Wolff R. Associations between vitamin D, vitamin D receptor gene and the androgen receptor gene with colon and rectal cancer. *Int J Cancer*. 2006 Jun 15;118(12):3140-6.
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**Table I-2c: Publications incorporating data from MCSS (continued)**


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**Table I-2c: Publications incorporating data from MCSS (continued)**

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**Table I-2c: Publications incorporating data from MCSS (continued)**


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**Table I-3: Applications requesting data for research; status as of January 2007**

<b>Year*</b>	<b>Nature of Study</b>	<b>Status (Institution)</b>
1989	International study of the effectiveness of screening for neuroblastoma at birth	Completed: Study period 1989-1998. Minnesota was one of the control areas. (U of MN)
1990	Population-based, case-control study of the epidemiology of childhood acute lymphoblastic leukemia	Completed: MCSS provided data on the completeness of ascertainment. (U of MN)
1991	International, population-based, case-control study of renal cell carcinoma	Completed: MCSS provided rapid ascertainment for identification of cases. (U of MN)
1991	National, multi-center, population-based, case-control study of colon cancer	Completed: MCSS provided rapid ascertainment for identification of cases. (U of MN)
1993	Record linkage with a 4,000-member cohort characterized for cardiovascular disease risk factors	Periodic linkage project. Fourth linkage completed fall 2003. (U of MN)
1994	Record linkage with a 14,000-member cohort who completed a nutrition survey (American Cancer Society CPS-II Nutrition study)	Completed: Pilot linkage to estimate sensitivity and specificity of cancer identification using central cancer registries. (American Cancer Society - National Home Office)
1994	Record linkage with the list of women screened through the Minnesota Breast and Cervical Cancer Control Program	Periodic linkage project. Most recent linkage completed Fall 2004. (MN Dept. of Health)
1995	Record linkage with Indian Health Service patient registries to characterize cancer incidence	Completed: Report describing cancer incidence in American Indians in Minnesota was released Fall 1996. (MN Dept. of Health)
1995	Multi-center, population-based, case-control study of gliomas in rural areas	Completed: MCSS provided rapid ascertainment for identification of cases. (U of MN)
1996	Multi-center, population-based, case-control study of proximity to toxic waste sites and occurrence of Wilms tumor	Application denied because of major methodological flaws. (Agency for Toxic Substances and Disease Registry)
1996	Randomized trial to assess whether risk-appropriate counseling increases utilization of screening by individuals with a first-degree relative who had colorectal cancer	Application withdrawn before peer review because study was not funded. (MN Dept. of Health)
1997	Multi-center, population-based, case-control study of acoustic neuromas and use of cellular phones	Application inactive because of funding issues. (U of IL - Chicago)
1997	Randomized, controlled clinical trial to determine whether screening for fecal occult blood reduces colorectal cancer mortality	Completed: MCSS validated cancer incidence in the 46,000 study participants via record linkage. MCSS also linked the study cohort with 1995 MCSS data. (U of MN)
1997	Population-based study of the role of aromatic amines in pancreatic cancer etiology	Completed: MCSS provided rapid ascertainment for identification and recruitment of cases. MCSS also linked the study cases with incidence and mortality data to assist in estimating response rates. (U of MN)

\* Year application submitted

<b>Year*</b>	<b>Nature of Study</b>	<b>Status (Institution)</b>
1997	Population-based pilot study of the quality of life in cancer survivors	Completed: MCSS identified and recruited a random sample of cases. (American Cancer Society - National Home Office)
1997	Occupational cohort linkage study to describe cancer incidence in a group of workers	Completed: MCSS linked a list of workers with MCSS data and provided aggregated results to the investigator. (3M)
1997	Occupational cohort linkage study to describe cancer incidence in two groups of workers, and to compare the results of incidence follow-up with the results of mortality follow-up	Completed: MCSS linked lists of workers with MCSS and death certificate data. (MN Dept. of Health)
1997, 2002	Identification and recruitment of families at high risk of colorectal cancer into a Familial Colorectal Cancer Registry (Re-applied in 2002 for extension of funding)	In process: MCSS is identifying individuals diagnosed with colorectal cancer between 1997 and 2007, who are then invited to provide information on familial cancer histories and possibly invited to participate in a national database which would be used to investigate the genetics of colorectal cancer. (Mayo Clinic and U of MN)
1998	Evaluation of Treatment Information in the Cancer Registry through Linkage	Completed: MCSS linked the list of cancer patients diagnosed in 1995 with lists of enrollees in several sets of claims and encounter data. Completeness of treatment information was compared between the two sources. (MN Dept. of Health)
1998	Mesothelioma Incidence in the Mining Industry: A Case Study	Completed: A list of 70,000 individuals who worked in the mining industry was linked with all individuals in MCSS who developed mesotheliomas. The goal was to ascertain if mesotheliomas among miners could be explained by occupational exposure to commercial asbestos. (MN Dept. of Health)
1999	Minnesota/Wisconsin Men's Health Study	Completed: MCSS identified individuals with prostate cancer diagnosed in 1999 and 2000. The study is looking for associations between genetic markers, exposure variables (pesticides, occupational, farming), and risk of prostate cancer. (U of MN)
1999	Pilot Test for Linking Population-Based Cancer Registries with CCG/POG Pediatric Registries	Completed: The MCSS list of cancer patients age 0 - 19 was linked with the CCG/POG databases for Minnesota to describe the completeness of ascertainment for both databases. (MN Dept. of Health)
2001	American Cancer Society CPS-II Nutrition study	Periodic linkage with more than 500 Minnesotans who completed nutritional surveys to verify and update their cancer status. (American Cancer Society - National Home Office)

*Introduction*

<b>Year*</b>	<b>Nature of Study</b>	<b>Status (Institution)</b>
2001	National Quality of Life Study	Completed: MCSS identified and invited cancer survivors to participate in this study of behavioral, psychosocial, treatment, and support factors that influence quality of life and cancer survivorship in the U.S. (American Cancer Society - National Home Office)
2002	Incidence of Endometrial Adenocarcinoma Following Endometrial Ablation in a Low Risk Population	Completed: The MCSS assisted in determining how many women who underwent endometrial ablation subsequently developed endometrial cancer. (St. Luke's Roosevelt Hospital)
2002	Family Health Study/Validation of a Family History of Cancer Questionnaire for Risk Factor Surveillance	Completed: MCSS assisted with assessing the validity of self-reported family history of cancer. (National Cancer Institute)
2003	Statistical Models for Cancer Control and Epidemiology	In Process: MCSS is improving its geocoding information so that cancer treatment and survival can be assessed in relationship to distance from appropriate medical facilities. (University of Minnesota)
2004	Relationship of Increasing Indoor Tanning Use to Melanoma Risk	In Process: MCSS is identifying patients diagnosed with melanoma skin cancer between April 2003 and March 2008. The study is looking for associations between genetic markers, indoor tanning booth use, and other known risk factors and melanoma skin cancer. (University of Minnesota)
2005	Predictors of Adult Leukemia	In Process: MCSS is using rapid ascertainment to identify patients diagnosed with chronic or acute myelogenous or monocytic leukemia between June 2005 and November 2009. The study is looking for associations with farming exposures, nonsteroidal antiinflammatory drug use, and genetic markers. (University of Minnesota)
2005	Annual Report to the Nation on the Status of Cancer, 1975-2003, with a Special Feature on Cancer in US/Hispanic/Latino Populations, 1999-2003.	Completed: The data was used to facilitate the statistical comparisons among the three population groups: Hispanic/Latino; non-Hispanic White; and non-Hispanic Black.(NAACCR)
2006	Birth Factors and Childhood cancers in Minnesota: A Data Linkage Study.	Completed: (University of Minnesota)