Chapter I:
Introduction

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This report contains information on the incidence and mortality of cancer in Minnesota from 1988-2006. 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. The Minnesota Cancer Surveillance System (MCSS) collects incidence data, and the Minnesota Center for Health Statistics (MCHS) collects mortality data. MCSS conducted 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 Minnesota legislature recognized the need for accurate information about the occurrence of cancer 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.

Previous MCSS reports entitled, *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*; *Cancer in Minnesota 1988-2002*; and *Cancer in Minnesota 1988-2004* will be referenced in this document as MCSS 1991, MCSS 1993, MCSS 1995, MCSS 1997, MCSS 1999, MCSS 2001, MCSS 2003, MCSS 2005 and MCSS 2008, respectively; they are available from MCSS. MCSS 1999, 2001, 2003, 2005 and MCSS 2008 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), nor *in situ* carcinomas of the uterine cervix.

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,

* www.health.state.mn.us/divs/hpcd/cdee/mcss

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. MCSS obtains information about the patient, cancer, stage, and treatment that the pathology laboratory cannot provide 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 880,000 reports of cancer representing approximately 509,000 different cancers were registered with MCSS as of September 18, 2009. For the period covered by this report, January 1, 1988 to December 31, 2006, 404,152 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 19 years ago, 17,728 cancers were included in the analyses of 1988 data. The current database for 1988 contains information on 18,011 cancers (some of the increase is because the initial report of data for 1988 did not include *in situ* cancers of the bladder). MCSS is 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 1988-2006 data included in this report was September 18, 2009.

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.[*] They are calculated using a modified version of the annual time series of July 1 county population estimates by age, sex, race, and Hispanic origin that are produced by the Population Estimates Program of the US Census Bureau[†] with support from the NCI through an interagency agreement. Descriptions of the methodologies employed by the Census Bureau for various sets of estimates may be found on the same website. County population estimates for 2000 and later years must be bridged from 31 race categories used in Census 2000 to the four race categories specified under earlier OMB standards in order to report long-term cancer trends. Bridged estimates attempt to re-categorize those selecting more than one race on the Census form 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

[*] www.seer.cancer.gov/popdata
[†] www.census.gov/popest/estimates.php
[‡] www.cdc.gov/nchs/nvss/bridged_race.htm

according to the 2nd edition (ICD-O-2), and 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 (see Appendices A and B) 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 data for all cancer sites combined. 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 2,239 diagnoses over the period 2001-2006. 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 reports. 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 forward, 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 1975. Four more areas were added in 1992, and an additional four areas in 2000. 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 26 percent of the U.S. population, as

presented in race-specific tables in their report *SEER Cancer Statistics Review*. 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 3.6 percent of the Minnesota population during 2002-2006 and approximately 20 percent of the overall population in the 17 SEER areas. This means that for many sites, cancer rates for all races combined will be higher in Minnesota than 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 2002-2006, 3.8 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 3.8 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 liver (24% of cases reported as clinically diagnosed in SEER), pancreas (17%), brain (11%), Kaposi sarcoma (10%), 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 9.6 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 1988-2006, 4.7 percent (over 21,000 cancers) 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 reportable cancers diagnosed between 1995 and 2006 (the years for which death clearance has been performed), 4,290 or 1.4 percent would not have been identified without the death certificate, and another 3,874 or 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 2008 MCSS submitted a de-identified file of its provisional data through 2006 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.

Third, in March-April 2008 a contractor of NPCR performed an external audit of the completeness and quality of MCSS data. Estimated case completeness was 99.7 percent, with 3 missed cases. Data accuracy was also very high, with an overall accuracy of 96.5 percent (197 errors identified out of 5,688 data items reviewed). A copy of the full report is available from MCSS.

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 most recent 4 reports are available on-line at the MCSS web site.[*] Special attention was 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. MCSS has not had the resources to conduct its own audits in more recent years.

Data on Race and Ethnicity

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 6.9 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 2006 (3.1 percent before and 1.2 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 has been participating in this linkage project, and cancers newly diagnosed through 2006 were linked with the IHS roster. The number of cancers in American Indians in the MCSS database for the years 1995-2006 increased by 48 percent because of the linkage. Minnesota death certificates were also linked with the IHS roster for the same years, increasing the number of cancer deaths among American Indians by 10 percent.

Despite these efforts, it is likely that cancer rates among American Indians statewide continue to be underestimated, especially outside of the IHS Contract Health Service Delivery Area

[*] www.health.state.mn.us/divs/hpcd/cdee/mcss

(CHSDA), where fewer American Indians use IHS health services and fewer are likely to be noted in the medical record as American Indian. Therefore, cancer incidence and mortality rates among American Indians are presented in this report for two geographic areas: statewide, and for residents of CHSDA counties. The IHS has designated 29 Minnesota counties as part of CHSDA. Over the five-year period 2002-2006, these counties are estimated to have included 51 percent of the American Indian population in the state. Overall cancer incidence and mortality rates are approximately 20 percent higher for American Indians in CHSDA counties than statewide. Cancer rates calculated for the CHSDA counties are thought to provide a more accurate picture of cancer rates among American Indians, but this is difficult to establish.

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. Failing to count Hispanic individuals as such results in calculated rates that are lower than the true rates. MCSS adapted the NAACCR Hispanic Identification Algorithm (NHIA) to work in Minnesota. Briefly, NHIA, which is described on the NAACCR web site,[*] 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

[*] http://www.naaccr.org/DataandPublications/CallforData.aspx (click on "NHIA v2.2")

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 49 (0.02 percent) cases with more than one reported race. 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, 2002-2006, 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,* 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 software designed by SEER and 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 2007 - 2008, 9 formal presentations were made before local public health, community, academic, and regulatory groups on the occurrence of cancer in Minnesota and related topics. An example of other activities to inform and educate are the biennial *Minnesota Cancer Facts & Figures*,† authored by an MCSS epidemiologist and published by the American Cancer Society. A list of publications (2007 - 2008) authored by MCSS staff is found in Table I-2a, b.

Answering the public's questions and concerns about cancer. MCSS received over 100 requests

* www.seer.cancer.gov/software
† http://www.mncanceralliance.org/Minnesota_Cancer_Facts_and_Figures_2009.html

for information on cancer rates or cancer risks. These inquiries represent all geographic regions of the state. Although most of these inquires 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 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 41 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. The current plan, written for 2005-2010, is in the process of being updated for 2011-2015. 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.

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 2006 data, Minnesota Cancer Surveillance System

Registry Element	Gold Standard	Silver Standard	MCSS Measure	Standard Achieved
1. Completeness of case ascertainment	95 %	90 %	106.6 %	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 %	1.6 %	Gold
• Missing/unknown “county”	<= 2 %	<= 3 %	0.6 %	Gold
3. Death certificate only cases	<= 3 %	<= 5 %	1.9 %	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 (2006, not previously reported; 2007; and 2008)

Table I-2a: Peer-Reviewed Publications co-authored by MCSS/MDH staff

Johnson KJ, Puumala SE, Soler JT, Spector LG. Perinatal characteristics and risk of neuroblastoma. Int J Cancer. 2008 Sep 1;123(5): 1166-72.

Spector LG, Johnson KJ, Soler JT, Puumala SE. Perinatal risk factors for helpatoblastoma. Br J Cancer. 2008 May 6;98(9):1570-3.

Puumala SE, Soler JT, Johnson KJ, Spector LG. In J Cancer. 2008 Mar 15;122(6): 1368-73.

Johnson KJ, Soler JT, Puumala SE, Ross JA, Spector LG. BMC Pediatr. 2008 Feb 25;8-7.

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

Cancer in Minnesota 1988-2004. St. Paul, Minnesota: Minnesota Cancer Surveillance System, Minnesota Department of Health, September 2008.

Cancer Incidence in Dakota and Washington Counties. St. Paul, Minnesota: Minnesota Cancer Surveillance System, Minnesota Department of Health, June 7, 2007.

Table I-2c: Publications incorporating/based on data from MCSS

Jemal A, Thun MJ, Ries LA, Howe HL, Weir HK, Center MM, Ward E, Wu XC, Eheman C, Anderson R, Ajani UA, Kohler B, Edwards BK. Annual report to the nation on the status of cancer, 1975-2005, featuring trends in lung cancer, tobacco use, and tobacco control. J Natl Cancer Inst. 2008 Dec 3;100(23):1672-94.

Watson M, Saraiya M, Ahmed F, Cardinez CJ, Reichman ME, Weir HK, Richards TB. Using population-based cancer registry data to assess the burden of human papillomavirus-associated cancers in the United States: overview of methods. Cancer. 2008 Nov 15;113(10 Suppl):2841-54.

Table I-2c: Publications incorporating/based on data from MCSS

Ryerson AB, Peters ES, Coughlin SS, Chen VW, Gillison ML, Reichman ME, Wu X, Chaturvedi AK, Kawaoka K.Burden of potentially human papillomavirus-associated cancers of the oropharynx and oral cavity in the US, 1998-2003. Cancer. 2008 Nov 15;113(10 Suppl):2901-9.

Brunner WM, Williams AN, Bender AP. Investigation of exposures to commercial asbestos in northeastern Minnesota iron miners who developed mesothelioma. Regul Toxicol Pharmacol. 2008 Oct;52(1 Suppl) :S116-20.

Slattery ML, Wolff RK, Curtin K, Fitzpatrick F, Herrick J, Potter JD, Caan BJ, Samowitz WS. Colon tumor mutations and epigenetic changes associated with genetic polymorphism: Insight into disease pathways. Mutat Res. 2008 Oct 15.

Li J, Thompson T, Miller JW, Pollack LA, Stewart SL. Cancer incidence among children and adolescents in the United States, 2001-2003. Pediatrics. 2008 Jun;121(6):e1470-7.

Yamamoto JF, Goodman MT. Patterns of leukemia in the United States by subtype and demographic characteristics, 1997-2002. Cancer Causes Control 2008 May;19(4):379-90.

Slattery ML, Folson AR, Wolff R, Herrick J, Caan BJ, Potter JD. Transcription factor 7-like 2 polymorphism and colon cancer. Cancer Epidemiol Biomarkers Prev. 2008 Apr;17(4): 978-82.

Harper S, Lynch J, Meersman SC, Breen N, Davis WW, Reichman ME. An overview of methods for monitoring social disparities in cancer with an example using trends in lung cancer incidence by area-socioeconomic position and race-ethnicity, 1992-2004. Am J Epidemiol. 2008 Apr 15;167(8):889-99.

Carozza SE, Li B, Elgethun K, Whitworth R. Risk of childhood cancer associated with residence in agriculturally intense areas of the United States. Environ Health Perspect 2008 Apr;116(4):559-65.

Stewart SL, Wike JM, Foster SL, Michaud F. The incidence of primary fallopian tube cancer in the United States. Gynecol Oncol 2007; 107:392-397.

Stewart SL, Sabatino SA, Foster SL, Richardson LC. Decline in breast cancer incidence—United States, 1999-2003. MMWR 2007; 56(22):549-552.

Goodman MT. Descriptive study of gallbladder, extrahepatic bile duct, and ampullary cancers in the United States, 1997-2002. Cancer Causes Control 2007; 18(4):415-22.

Pickle LW, Hao Y, Jemal A, Zou Z, Tiwari R, Ward E, Hachey M, Howe HL, Feuer EJ. A new method of predicting U.S. and state-level cancer incidence counts for the current calendar year. Ca Journal for Clinicians. 2007 57(1):30-42.

Larson T, Melnikova N, Davis S, Jamison P. Incidence and descriptive epidemiology of Mesothelioma in the United States, 1999-2002. Int J Occup Environ Health 2007; 13:398-403.

Goodman MT, Hernandex BY Shvetsov YB. Demographic and pathological differences in the incidence of invasive penile cancer in the United States, 1995-2003. Cancer Epidemiol Biomarkers Prev 2007 Sep;16(9):1833-9.

Wu XC, Chen VW, Andrews PA, Ruiz B, Correa P. Incidence of esophageal and gastric cancers among Hispanics, non-Hispanic whites and non-Hispanic blacks in the United States: subsite and histology differences. Cancer Causes Control 2007 Aug;18(6):585-93.

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Table I-2c: Publications incorporating/based on data from MCSS

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Table I-3: Applications requesting data for research as of December 2009

Year*	Nature of Study	Status (Institution)
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	Biennial 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	Annual 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 deter mine 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)
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)

* Year application submitted

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)	Completed: MCSS identified individuals diagnosed with colorectal cancer between 1997 and 2007, who were then invited to provide information on familial cancer histories and possibly invited to participate in a national database that will 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. The study compared completeness of treatment information between the two sources. (MN Dept. of Health)
1998	Mesothelioma Incidence in the Mining Indus try: 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 Regis tries	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	Completed: Linkage with more than 500 Minnesotans who completed nutritional surveys to verify and update their cancer status. (American Cancer Society - National Home Office)
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	Completed: MCSS improved its geocoding information so that cancer treatment and survival could be assessed in relationship to distance from appropriate medical facilities. (U of MN)
2004	Relationship of Increasing Indoor Tanning Use to Melanoma Risk	Completed: MCSS identified patients diagnosed with melanoma skin cancer between April 2003 and March 2008. The study looked for associations between genetic markers, indoor tanning booth use, and other know risk factors and melanoma skin cancer. (U of MN)
2005	Predictors of Adult Leukemia	Completed: MCSS used rapid ascertainment to identify patients diagnosed with chronic or acute myelogenous or monocytic leukemia between June 2005 and November 2009. The study looked for associations with farming exposures, nonsteroidal antiinflammatory drug use, and genetic markers. (U of MN)
2005	Breast and Prostate Cancer Data Quality and Patterns of Care	Completed: A collaborative agreement between CDC and seven population-based cancer registries or affiliated research institutions to determine the proportion of patients diagnosed with breast or prostate cancer who received first course of therapy in accordance with guidelines issued by the National Comprehensive Cancer Network. (MN Dept. of Health)
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: MCSS submitted data to NAACCR with a county identifier to be used to link with the Bureau of the Census files that include the percent of the county residents that live below poverty, and to the US Department of Agriculture Beale codes to designate urbanicity of the county of the patient's residence at the time of diagnosis. 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: A linkage study of over 2400 cases of cancer diagnosed in children in Minnesota to their birth files and additionally to select controls from the birth files to identify certain birth risk factors and the development of cancer.

2007	Mayo Mammography Health Study Linkage	Ongoing: MCSS will be linking its database at intervals with records of more than 21,000 women who received routine mammography and consented to participate in the study. The aim is to assess whether changes in breast density over time are associated with breast cancer. The secondary aim is to examine whether breast density responses that accompany HRT initiation are associated with breast cancer risk. (Mayo Clinic)
2007	Forteo Post-Approval Surveillance Study: Case Series	Ongoing: MCSS is identifying cases of adult osteosarcoma and inviting them or their next-of-kin to participate in an interview. The goal is to discover whether this type of cancer might be associated with the use of a drug called Forteo, a biosynthetic human parathyroid hormone used to treat osteoporosis. (RTI Health Solutions, for Eli Lilly)
2007	Occupational and Demographic Factors of Iron Miners that Developed Mesothelioma in Minnesota (1988-2006)	Completed: Linkage study to establish the detailed protocol for a future case-control study to evaluate the role (if any) of historical exposure to taconite dust as a factor in mesothelioma occurrence and to describe, within data privacy limitations, the miners that have developed mesothelioma. (MN Dept. of Health)
2008	American Cancer Society CPS-II Nutrition Survey	Completed: Linkage with more than 500 Minnesotans who completed nutritional surveys to verify and update their cancer status. (American Cancer Society - National Home Office)
2009	Mortality and Cancer Incidence Studies of Workers in the Minnesota Taconite Industry	In process: A cohort of taconite workers is being linked to MCSS to investigate 1) whether taconite industry workers have an increased risk of mesothelioma specifically associated with exposure to mineral fibers in the dust from mining and processing taconite, and 2) the incidence of other cancers is associated with exposure to dust from the taconite industry. (U of MN)
2009	Cancer Incidence in 3M Chemical Workers	In process: MCSS will link its database with a list of fluorochemical-exposed workers (approximately 7,500) to identify any increased cancer risks. (U of MN)
2009	Cancer Epidemiology in Adventists, a low risk group	Completed: MCSS oversaw a linkage between its database and a list of Adventists who had consented to participate in the study, to identify incident cancers among cohort members and investigate cancer risk associated with dietary and other lifestyle factors. (Loma Linda University)