

Chapter I: Introduction

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This report contains information on the incidence and mortality of cancer in Minnesota from 1988-1999. 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 in this report are compiled by the Minnesota Cancer Surveillance System (MCSS), and mortality data are compiled by the Minnesota Center for Health Statistics (MCHS).

The MCSS is an ongoing program within the Chronic Disease and Environmental Epidemiology Section of the MDH. The MCSS systematically collects demographic and diagnostic information on all newly diagnosed, microscopically confirmed cancers among Minnesota residents. The primary objectives of the 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 the MCSS. The MCSS began operations on January 1, 1988.

Funds for the enhancement of the MCSS became available in 1994 through 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 2007. The support of the NPCR has

enabled the 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 six 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*; and *The Occurrence of Cancer in Minnesota 1992-1997*. These reports will be referenced as MCSS 1991, MCSS 1993, MCSS 1995, MCSS 1997, MCSS 1999, and MCSS 2001, respectively; they are available from the MCSS. MCSS 1999 and MCSS 2001 are available on the MCSS web site (<http://www.health.state.mn.us/divs/dpc/cdee/mcss.htm>).

Data Sources

Incidence Data

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

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The MCSS has three important characteristics: it is population-based, it is pathology-based, and it is an active (vs. passive) system. Population-based surveillance means that data are collected from a defined population base (i.e., the state of Minnesota) so that incidence rates (risk) can be calculated. Pathology-based surveillance means that cancers are identified through the pathology laboratories where tissues are examined and the diagnosis of cancer is made. Active surveillance means that cancers are required to be reported to the MCSS by Minnesota statutes and that pathology reports in the state and surrounding border referral centers are reviewed by MCSS Field Service staff to ensure completeness of ascertainment.

Enough information is collected so that the 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 the 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 566,000 reports of cancer representing approximately 339,000 different cancers were registered with the MCSS as of December 2002. For the period covered by this report, January 1, 1988 to December 31, 1999, 238,860 newly diagnosed, invasive cancers were registered. *In situ* cancers of the urinary bladder are included with invasive cancers so that Minnesota data is 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 the first legislative report on the MCSS (MCSS 1991), filed 12 years ago, 17,728 cancers were included in the analyses of 1988 data. The current database for 1988 contains information on 17,993 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 1988-1999 data included in this report was October 7, 2002.

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 for the years 1988 and 1989 were developed from the U. S. Census Bureau's 1980 and 1990 censuses. Linear interpolation between the two census years provided age-sex-region estimates for 1988 and 1989. Adjusted census counts were used for 1990. Age-, sex-, and county-specific intercensal population projections obtained from the U.S. Census Bureau were used for the years 1991-1999. For race-specific analyses, age-, sex-, and race-specific intercensal projections for the entire state were obtained from the U.S. Census Bureau's web site.

Completeness and Quality of Data

MCSS Field Service staff first identified 9.6 percent of all the cancer diagnoses reportable to the 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 1988-1999, 5.1 percent would have been missed without this review. It is estimated that more than 6 million pathology reports were reviewed during the 12-year period included in this report.

The 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. Only 1.2 percent of all cancers diagnosed between 1995 and 1999 (the years for which death clearance has been performed) had the death certificate as the source of casefinding. A high-quality cancer registry should have between 1 percent and 3 percent of its cases as DCO.

MCSS data are very complete and of very high quality. This is documented by several measures of data quality which are available for the MCSS. First, in December 2001 the MCSS submitted a nonidentified file of its provisional data for 1999 to the Registry Certification Committee of the North American Association of Central Cancer Registries (NAACCR). NAACCR is the organization in North America which develops standards and models for the collection of cancer data in central cancer registries. Table I-1 contains the results of the certification process. The MCSS achieved the highest rating, the Gold Standard, for all criteria.

Second, a contractor of the NPCR performed an external audit of the completeness and quality of MCSS data in July 2002. 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.

Third, the 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, 2000:1, and 2001:1). Special attention has been paid to the data fields that were new to the MCSS in 1995, stage at diagnosis and the information on the first course of cancer therapy.

Race is an important variable for cancer surveillance. Unfortunately, race is not always reported on data submitted to the MCSS, and prior to the 1995 diagnosis year the 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 9.7 percent of the cancers diagnosed during the period 1988-1994. The percentage can be improved by assuming that individuals are white if they live in counties that had more than 95 percent of residents listed as white in the 1990 census, and no other racial information is available. After making this assumption, race was “unknown” for only 2.4 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 1999 (3.3 percent before and 1.1 percent after making an assumption based on county of residence).

Ethnicity (Hispanic origin) is even more difficult to collect accurately in Minnesota. Even when medical records are reviewed, usually no mention is made of whether or not a person is of Hispanic origin. Exploratory analyses of the available data indicate that the MCSS does not have complete enough data to provide meaningful information on

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cancer incidence among Minnesota's Hispanic population at this time. Further work, including examining the usefulness of matching with Hispanic surname lists as is done in other states, is planned so that information can be available on cancer incidence in this growing population in Minnesota.

Despite recent improvements in the completeness of data on the patient's race, the ability of the MCSS to evaluate racial and ethnic differences in cancer risk among Minnesotans is limited by several factors. 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 are often incompletely or inaccurately reported in the medical record or on the death certificate, which can compound the instability of rates based on small numbers. And finally, the population estimates that are available to calculate rates may represent undercounts of persons of color during the national census or inaccurate population estimates during the intercensal period. For example, the Hispanic population in Minnesota was estimated by the Bureau of the Census to be about 81,000 in 1999; the number of Hispanics enumerated in the 2000 census was 143,382. Since it is unlikely that the Minnesota Hispanic population increased by 75 percent in one year, it is reasonable to think that the population projections prior to the 2000 census were too low. However, at the time this report was prepared, the Bureau of the Census had not yet revised the population estimates for 1995-1999 to be consistent with the counts from the 2000 census.

These three factors limit our confidence in race- and ethnic-specific cancer rates in Minnesota, and make it difficult 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 the MCSS, and is important in developing policies and interventions directed at cancer control. We have, therefore, aggregated data over the 5-year period, 1995-1999, 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, the MCSS has five primary objectives. The following is a brief summary of how the MCSS is accomplishing each objective.

Monitoring the occurrence of cancer in Minnesota and describing the risks of developing cancer. Sophisticated computer programs have been written to support MCSS epidemiologists in describing the risks of developing cancer. The results of these analyses are partially included in this report. Cancer mortality data have also been analyzed and included in this description of cancer occurrence in Minnesota.

MCSS staff also conduct special analyses of the surveillance data. Emphasis is placed on integrating these findings into an epidemiologic and public health context. Recent examples are included below.

Informing health professionals and educating citizens regarding specific cancers. In the past two years, 16 formal presentations have been made before local public health, community, academic, and regulatory groups on the occurrence of cancer in Minnesota. A report entitled, "Cancer in Minnesota: Racial and Ethnic Disparities" was released in October 2001; this report was produced in collaboration with staff of the Minnesota Breast and Cervical Cancer Control Program (MBCCCP). The *Disease Control Newsletter* is published bimonthly by the MDH Acute Disease Investigation

and Control program, and is distributed to more than 16,650 health care providers statewide. Articles on breast and cervical cancer (Jan/Feb 2002), colorectal cancer (Mar/Apr 2002), melanoma (May/June 2002), and smoking-related cancers (Oct 2002) have been published. A nonexhaustive list of publications in the scientific literature (2001 - 2002) authored by MCSS staff or including MCSS data is in Table I-2.

Answering the public's questions and concerns about cancer. The MCSS receives 100 to 150 requests per year 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 detailed record-linkage studies of a defined cohort.

Promoting cancer research. The MCSS has assisted cancer researchers by providing information and data needed for the planning and support of grant applications. The MCSS has also received 26 data use applications since 1988, which are described in Table I-3. The involvement of the 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.

Guiding decisions about how to target cancer control activities. 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 which could identify an individual (e.g., name and address) is strictly protected by Minnesota law. Personally identifying information may be released only by permission of the subject of the data. Furthermore, this information is considered privileged in that the MDH cannot be compelled by court order to release any personal data collected by the MCSS.

One of the most important uses of MCSS data is to promote research on the prevention and control of cancer. In Minnesota, a large majority of cancer patients and/or their families agree to participate in studies designed to learn more about reducing the impact of cancer on our society. These people welcome the opportunity to translate their personal experience into knowledge that may help their families and others. Yet, even these important activities are voluntary. The subject or guardian must specifically agree to participate.

It is absolutely necessary that personally identifying information be collected by the MCSS. Multiple clinical reports are generated during the care of cancer patients. Personally identifying information is required to link this information to ensure completeness and accuracy of the resultant data. Federal guidelines require collection of personal identifiers to prevent a significant over-counting of cancer. Without accurate linkage of multiple reports made possible by personally identifying information, cancer rates would appear two-thirds higher, greatly exaggerating differences between Minnesota and the rest of the U.S. Thus, personally identifying information is both necessary for and strictly protected by the 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 1999 data, Minnesota Cancer Surveillance System

Registry Element	Gold Standard	Silver Standard	MCSS Measure	Standard Achieved
1. Completeness of case ascertainment	95%	90%	103.8%	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%	0.6%	Gold
3. Death certificate only cases	<= 3%	<= 5%	2.0%	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: Scientific publications (2001-2002)

Publications co-authored by MCSS/MDH staff
Boland LL, Mink PJ, Bushhouse SA, Folsom AR. Weight and length at birth and risk of early-onset prostate cancer. Submitted December 2002.
Perkins CI, Hotes J, Kohler B, Howe H. Association between breast cancer laterality and tumor location, United States, 1994-1998. Submitted.
Perkins CI, Wright WE, Allen M, Samuels SJ, Romano PS. Effects of capitated managed care on breast cancer detection and treatment among Medicaid enrollees in California. <i>Medical Care</i> . Submitted September 2002.
Kiffmeyer WR, Kastel E, Davies SM, Envall J, Bushhouse S, Robison LL, Ross JA. Susceptibility to cancer in the Minnesota Hmong population. Submitted August 2002.
Short M, Carlin BP, Bushhouse SA. Using hierarchical spatial models for cancer control planning in Minnesota. <i>Cancer Causes and Control</i> . In Press.
Publications incorporating/based on data from the MCSS
U.S. Cancer Statistics Working Group. <i>United States Cancer Statistics: 1999 Incidence</i> . Atlanta (GA): Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2002.
Camp NJ, Slattery ML. Classification tree analysis: a statistical tool to investigate risk factor interactions with an example for colon cancer (United States). <i>Cancer Causes Control</i> . 2002 Nov;13(9):813-23.
CBTRUS. <i>Statistical Report: Primary Brain Tumors in the United States, 1995-1999</i> . Chicago, Illinois: Central Brain Tumor Registry of the United States, 2002.
Anderson KE, Sinha R, Kulldorff M, Gross M, Lang NP, Barber C, Harnack L, DiMagno E, Bliss R, Kadlubar FF. Meat intake and cooking techniques: associations with pancreatic cancer. <i>Mutat Res</i> . 2002 Sep 30; 506-507:225-31.
Slattery ML, Curtin K, Ma K, Schaffer D, Potter J, Samowitz W. GSTM-1 and NAT2 and genetic alterations in colon tumors. <i>Cancer Causes Control</i> . 2002 Aug;13(6):527-34.
Slattery ML, Curtin K, Ma K, Edwards S, Schaffer D, Anderson K, Samowitz W. Diet, activity, and lifestyle associations with p53 mutations in colon tumors. <i>Cancer Epidemiol Biomarkers Prev</i> . 2002 Jun;11(6):541-8.
Slattery ML, Potter JD. Physical activity and colon cancer: confounding or interaction? <i>Med Sci Sports Exerc</i> . 2002 Jun; 34(6):913-9.
Edwards BK, Howe HL, Ries LA, Thun MJ, Rosenberg HM, Yancik R, Wingo PA, Jemal A, Feigal EG. Annual report to the nation on the status of cancer, 1973-1999, featuring implications of age and aging on U.S. cancer burden. <i>Cancer</i> . 2002 May 15; 94(10):2766-92.
Woods WG, Gao RN, Shuster JJ, Robison LL, Bernstein M, Weitzman S, Bunin G, Levy I, Brossard J, Dougherty G, Tuchman M, Lemieux B. Screening of infants and mortality due to neuroblastoma. <i>N Engl J Med</i> . 2002 Apr 4; 346(14):1041-6.
McCarthy BJ, Surawicz T, Bruner JM, Kruchko C, Davis F. Consensus Conference on Brain Tumor Definition for Registration. November 10, 2000. <i>Neuro-oncol</i> . 2002 Apr; 4(2):134-45.

Table I-2: Scientific publications (2001-2002) (continued)

Publications incorporating/based on data from the MCSS: (continued)

Wu XC, Hotes JL, Fulton PJ, Cormier M, Correa CN, McLaughlin CC, Kosary C, Howe HL, Chen VW (eds). Cancer in North America, 1995-1999. Volume One: Incidence. Springfield, IL: North American Association of Central Cancer Registries, April 2002.

Shu X, Potter J, Linet M, Severson R, Han D, Kersey J, Neglia J, Trigg M, Robison L. Diagnostic X-rays and ultrasound exposure and risk of childhood acute lymphoblastic leukemia by immunotype. *Cancer Epidemiolo Biomarkers Prev.* 2002 Feb;11(2):177-85.

Slattery ML, Edwards SL, Caan B. Low-energy reporters: evaluation of potential differential reporting in case-control studies. *Nutr Cancer.* 2002; 42(2):173-9.

Slattery ML, Anderson K, Curtin K, Ma K, Schaffer D, Edwards S, Samowitz W. Lifestyle factors and Kras mutations in colon cancer tumors. *Mutat Res.* 2001 Nov 1; 483(1-2):73-81.

Slattery ML, Anderson K, Curtin K, Ma KN, Schaffer D, Samowitz W. Dietary intake and microsatellite instability in colon tumors. *Int J Cancer.* 2001 Aug 15; 93(4):601-7.

Slattery ML, Samowitz W, Ballard L, Schaffer D, Leppert M, Potter JD. A molecular variant of the APC gene at codon 1822: its association with diet, lifestyle, and risk of colon cancer. *Cancer Res.* 2001 Feb 1; 61(3):1000-4.

Slattery ML, Potter JD, Curtin K, Edwards S, Ma KN, Anderson K, Schaffer D, Samowitz WS. Estrogens reduce and withdrawal of estrogens increase risk of microsatellite instability-positive colon cancer. *Cancer Res.* 2001 Jan 1; 61(1):126-30.

Table I-3: Applications requesting data for research as of December 2002

Year^a	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 scheduled for early 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 Spring 2002. (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)

Table I-3: Applications requesting MCSS data for research as of December 2002 (continued)

Year^a	Nature of Study	Status (Institution)
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)
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	Identification and recruitment of families at high risk of colorectal cancer into a Familial Colorectal Cancer Registry	Renewal application in process: MCSS is identifying individuals diagnosed with colorectal cancer between 1997 and 2002, 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	In Process: MCSS linked the list of cancer patients diagnosed in 1995 with lists of enrollees in several sets of claims and encounter data. The goal is to compare completeness of treatment information 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)

Table I-3: Applications requesting MCSS data for research as of December 2002 (continued)

Year^a	Nature of Study	Status (Institution)
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	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	In Process: MCSS is identifying and inviting 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	In Process: The MCSS will assist 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	Letter of Intent received: MCSS is being asked to assist with assessing the validity of self-reported family history of cancer. (National Cancer Institute)

a. Year application submitted

