

Cancer in Minnesota 1988 - 2006



Minnesota Department of Health
Minnesota Cancer Surveillance System

September 2010





Protecting, maintaining and improving the health of all Minnesotans

December 2010

Dear Colleague:

The Minnesota Department of Health (MDH) is pleased to present the tenth biennial report of the Minnesota Cancer Surveillance System (MCSS) on the occurrence of cancer in Minnesota, in accordance with Minnesota Statute 144.672 Subdivision 2.

This report demonstrates continued and substantial progress in reducing the burden of cancer in our state. The female breast cancer incidence rate was 13 percent lower in 2006 than in 2000, when it peaked. Incidence rates are also declining significantly for colorectal and stomach cancers among both men and women, for lung and laryngeal cancers among men, and for ovarian and cervical cancers among women. Overall, the rate of increase in cancer incidence is slowing down. Overall cancer mortality is declining significantly among both men and women in our state, primarily due to declines in colorectal, prostate, and breast cancer, which together accounted for 21 percent of cancer deaths in Minnesota in 2006.

Nonetheless, much work remains to be done. An estimated 195,250 Minnesotans are living with a history of cancer. Cancer is our leading cause of death, causing the deaths of 20 percent more Minnesotans than heart disease in 2006. Half of all Minnesotans will be diagnosed with a potentially serious cancer during their lives. Persons of color experience a disproportionate burden of cancer in our state. Of special concern are American Indians, whose risk of dying of cancer in Minnesota is twice that of American Indians in the United States as a whole.

The MCSS is a powerful tool for public health, and its value increases with each year of data collection. The MDH is an active partner in the Minnesota Cancer Alliance, a collaboration of public, private and non-profit organizations created to implement *Cancer Plan Minnesota 2005-2010*, our state's first comprehensive cancer control plan. We encourage all organizations and individuals interested in cancer control to join with us and the Alliance to reduce the burden of cancer for all Minnesotans.

This report was prepared by MCSS staff under the direction of Dr. Sally Bushhouse. Questions and comments on the report can be directed to the MCSS at 651-201-5900.

Sincerely,

A handwritten signature in black ink, appearing to read "Jeanne M. Danaher", is written over a horizontal line.

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Cancer in Minnesota, 1988-2006

Report to the Minnesota Legislature 2010

September 2010

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As requested by Minnesota Statute 3.197: This report cost approximately \$10,600 to prepare, including staff time, printing, and mailing expenses.

Upon request, this publication will be made available in alternative formats, such as large print, Braille, or cassette tape.

Printed on recycled paper.

ACKNOWLEDGEMENTS

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Sincere thanks to the cancer registrars, laboratory personnel, and health care providers throughout the state whose diligence in data collection and reporting make this report possible. Collection of Minnesota cancer data was supported by Cooperative Agreement Number U58/0P000802-04 from the Centers for Disease Control and Prevention. The contents of this work are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

On the Cover

Photo of the Minnesota state flower, the Pink Lady Slipper, from the State of Minnesota website,
<http://www.sos.state.mn.us/student/flower.html>

SUGGESTED CITATION:

Brown M, Perkins C, Soler J, Bushhouse S. *Cancer in Minnesota, 1988-2006*. St. Paul, Minnesota: Minnesota Cancer Surveillance System, Minnesota Department of Health, September 2010.

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Summary

This report summarizes the status of cancer in Minnesota. These data enable the Minnesota Department of Health to detect public health problems, to target goals for cancer control, and to inform citizens and health care professionals about cancer risks, early detection, and treatment.

- In 2006, 24,916 Minnesotans were diagnosed with cancer, and 9,065 Minnesotans died of this group of diseases.
- Heart disease is the leading cause of death in the U.S., but cancer has been the leading cause of death in Minnesota since 2000. In 2006, 20 percent more Minnesotans (1,559 persons) died of cancer than heart disease.
- Despite these sobering facts, the rate of increase in cancer incidence is slowing down. The overall cancer incidence rate among males was increasing by 1.1 percent per year when trends were evaluated through the end of 2002, but now is increasing by 0.5 percent per year. Among females, the overall cancer incidence rate increased by 1.4 percent per year from 1995 to 2000, but then stabilized from 2000 to 2006.
- The invasive breast cancer incidence rate among women in Minnesota declined significantly by 3.9 percent per year from 2000 to 2004, and then stabilized. Breast cancer incidence was 13 percent lower in 2006 (124.6 new cases per year per 100,000 women) than in 2000 (142.6).
- The prostate cancer incidence rate increased modestly from 1995 to 2006, but the trend was not statistically significant.
- The overall cancer mortality rate is steadily declining. Among males in Minnesota it declined by 0.8 percent per year from 1988 to 2002, and then by 2.9 percent per year from 2002 to 2006. The cancer mortality rate among men was 18 percent lower in 2006 (207.6 deaths per year per 100,000 men) than in 1988 (252.3). Overall cancer mortality among Minnesota women decreased significantly by 0.6 percent per year from 1988 to 2006; the rate was 12 percent lower in 2006 (147.3) than in 1988 (166.8).
- Mortality rates are declining significantly for many cancers, including breast, colorectal, ovary, prostate, and stomach cancers and non-Hodgkin lymphoma, and lung cancer among males.
- In 2006, lung cancer killed almost as many Minnesotans (2,353 deaths) as the next four leading cancers combined: colorectal (822), breast (614), pancreas (564), and prostate (484).
- Lung cancer mortality among women continues to increase by 0.9 percent each year in Minnesota. U.S. lung cancer mortality among women stabilized in 2002, and among non-Hispanic white women is decreasing significantly by 0.6 percent per year.
- In general, Minnesotans have a lower risk of developing or dying from most types of cancer than the nation as a whole. Over the five-year period 2002-2006, the exceptions were leukemia (both genders), non-Hodgkin lymphoma (males), and uterine and prostate cancers, which were significantly elevated among non-Hispanic whites in Minnesota compared to those in the SEER Program.
- However, among American Indians the overall cancer incidence rate in Minnesota is 68 percent higher than in the SEER Program, and overall cancer mortality is twice as high as in the U.S. as a whole. Much of the increase in risk is due to lung and colorectal cancers.
- The mesothelioma incidence rate among men is significantly higher in northeast Minnesota than in the state as a whole, while among women, the rate in northeast Minnesota is among the lowest.
- Disparities in the burden of cancer are evident in Minnesota. American Indians were 13 percent more likely to develop cancer than non-Hispanic white Minnesotans and 40 percent more likely to die of these diseases. Similarly, African Americans were 6 percent more likely to develop cancer than non-Hispanic whites and 30 percent more likely to die of cancer.
- Based on current rates, about one out of two Minnesotans will be diagnosed with a potentially serious cancer during his or her lifetime, and one out of four will die of cancer.
- An estimated 195,250 Minnesotans, or 3.8 percent of the population, were living with a history of cancer on January 1, 2006.

The Minnesota Cancer Alliance and Cancer Plan Minnesota 2005-2010

The state’s first comprehensive cancer control plan, *Cancer Plan Minnesota 2005-2010* was developed through a broad-based collaboration of public, private and non-profit organizations. Released in April 2005 it serves as a common framework for action to reduce the burden of cancer for all Minnesotans. The plan includes objectives and strategies covering all facets of cancer control: prevention, early detection, treatment, quality of life, cancer disparities, and data and research needs. An updated version will be released in early 2011.

The Minnesota Cancer Alliance was formed to implement *Cancer Plan Minnesota*. Comprising more than 100 member organizations, it has served as a forum through which cancer control activities can be better coordinated to make optimal use of limited resources and to more fully realize opportunities for innovation.

Minnesota Cancer Alliance task forces and work groups have spent the past five years focusing on activities that address the cancer plan’s four initial priority areas

1. Increase colorectal cancer screening.
2. Promote policies to reduce the harmful effects of tobacco.

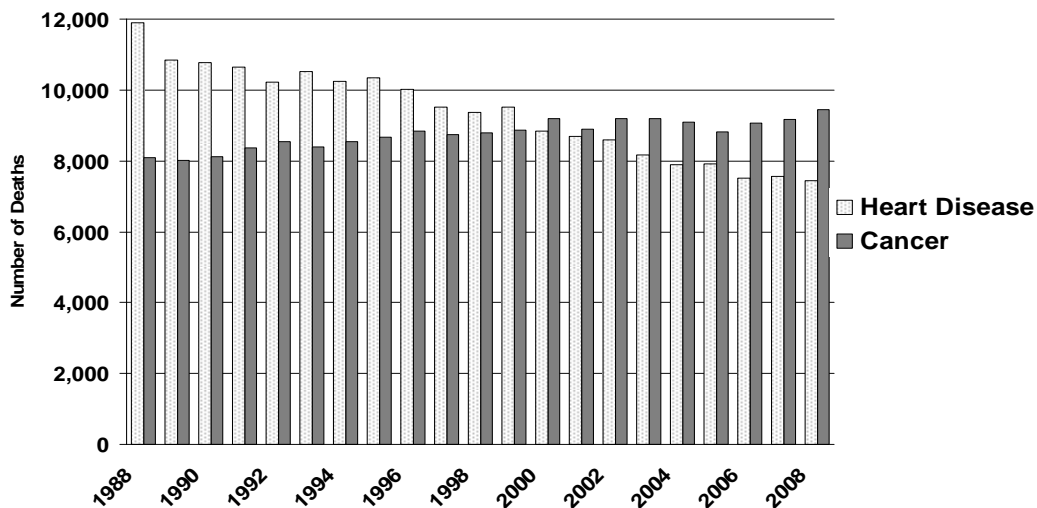
3. Reduce disparities in cancer screening and treatment.
4. Enhancing quality of life for cancer survivors and their caregivers.

Notable successes have been passing a comprehensive smoke free policy (Freedom to Breathe), securing state and federal funding to support a colorectal cancer screening program for the under and un-insured, developing a cancer training for community health workers and creating a cancer survivor care plan.

The Minnesota Cancer Surveillance System (MCSS) has been instrumental in developing data-driven objectives for *Cancer Plan Minnesota* and continues to serve as the key source of population-based data to assess the outcome of cancer control efforts in Minnesota. In addition to this biennial report, MCSS works closely with the American Cancer Society to produce *Minnesota Cancer Facts and Figures* in alternate years.

If you are interested in joining the Minnesota Cancer Alliance or one of its project teams, or to order a copy of *Cancer Plan Minnesota*, go to <http://www.mncanceralliance.org> or contact Elizabeth Moe, Project Coordinator, at 651-201-3608.

**Deaths due to Heart Disease and Cancer,
Minnesota, 1988-2008**



Source: Minnesota Center for Health Statistics. Analyses were conducted by MCSS.

Questions and Answers about MCSS Data Privacy

The Minnesota Cancer Surveillance System (MCSS) is Minnesota's statewide, population-based cancer registry. It was mandated by the state legislature in 1987 to collect information on all newly diagnosed cancers among Minnesota residents. By law, new cancer cases must be reported to the MCSS, including the name, date of birth, and social security number of the person diagnosed with cancer. These data enable the Minnesota Department of Health (MDH) to protect and improve public health by monitoring cancer rates throughout the state and over time. The MCSS also benefits all Minnesotans by serving as a resource for education and research to prevent, detect, treat, and cure cancer.

Why does the MCSS need to obtain the names of individuals diagnosed with cancer? There are five primary reasons why MCSS functions depend on having information identifying individuals:

1. Most cancer cases are reported to the MCSS more than once. To determine how many new cancers have been diagnosed, multiple reports must be combined into a single summary of the case. Without personal information, separate reports from laboratories, physicians, treatment facilities, and hospitals could not be identified as representing the same case. Using patient names and other personal information to link multiple reports on the same person is essential to maintain the accuracy of the MCSS. Inaccurate data would undermine the public's investment in cancer registration and render it ineffective in protecting public health.
2. No single source of information captures all cancer diagnoses or provides all the information needed for cancer surveillance. For example, pathology reports do not contain critical information such as stage at diagnosis or treatment received. The name of the patient allows this information to be obtained from the hospital or from the physician, if the patient was not admitted to a hospital. Since an increasing number of cancer patients are treated on an outpatient basis, the ability to request additional information from physicians and treatment facilities is very important to obtain complete and unbiased data.
3. Personal identifiers are needed to link MCSS cases with death certificates. This is done to make sure that all cancer cases have been reported, and to lay the groundwork for assessing cancer survival. About two percent of MCSS cases, and a higher proportion of certain cancers, would not be identified without this linkage. The MCSS hopes to have sufficient resources in the future to evaluate cancer survival, which is a critical element in identifying disparities in cancer care. This cannot be done in a cost-effective manner without linkage to death certificates.
4. Names are needed if cancer patients are to be given the opportunity to contribute to knowledge about their disease by participating in research. The MCSS is authorized to contact cancer patients, after obtaining consent from their physician, to see if they are interested in participating in specific cancer research projects. Participation is completely voluntary. MCSS data have enabled research to be conducted on such questions as the efficacy of colorectal cancer screening, the causes of pancreatic cancer, associations between cancer and occupational exposures such as mesothelioma and mining, and the epidemiology of childhood leukemia.
5. To protect the health of Minnesotans, the MCSS must be able to evaluate whether communities or workplaces are experiencing a higher occurrence of cancer than would be expected. Although names are never released in these investigations, they are vitally important to their conduct. For example, when a concern arises in an occupational setting, names of former and current employees can be linked to the MCSS by MDH staff to determine whether workers are experiencing an excess of cancer. Because personal identifiers enable MCSS to be highly complete and accurate, as discussed above, the MDH can be confident that investigations

of cancer occurrence reflect reality, and not the artifacts of poor data collection.

Do other cancer registries obtain the names of people diagnosed with cancer? Yes. All 50 states and the District of Columbia have statewide cancer registries. All of them obtain personally identifying information on cancer cases for the reasons discussed above. Nine geographic areas (states or metropolitan areas) in the U.S. have been participating in the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute since 1973. Each of the SEER registries has collected personally identifying information for more than three decades.

How does the MCSS protect the privacy of cancer patients? Protecting data privacy is a high priority for the MCSS and is mandated by Minnesota law. The MCSS is housed in a guarded, key-pass protected location that is not accessible to the general public. MCSS employees must sign confidentiality pledges as a condition of employment, and they are subject to criminal penalty for any breach of privacy. MCSS employees are given access to personally identifying information only as needed to perform their duties, and they are trained and monitored to keep private data secure. Data encryption, passwords, and computer firewalls are used to protect electronic data. By law, MCSS data are considered private. Data are only released in accordance with the Minnesota Government Data Practices Act. Minnesota law also protects the data from being discovered (i.e., released) during litigation without consent of the patient.

Was patient privacy taken into consideration when the legislature mandated the creation of MCSS? Yes. Prior to establishing the MCSS, the Commissioner of Health empanelled an advisory committee charged with assessing whether the benefits of statewide cancer registration to the citizens of Minnesota outweighed the potential costs to individual privacy. The committee consisted of members from the legal profession, business, labor, medicine, government, patient advocates such as the American Cancer Society, and the community. It deliberated for more than a year. Based on the importance of the proposed

system to protecting public health and the ability to protect individually identifying medical data, the committee unanimously concluded that the benefits far outweighed the costs. On their recommendation, statutes that provided for both the collection of personal medical information and its stringent protection were adopted by the state.

Are patients asked for consent to have information about their cancer reported to the MCSS? No. Patient consent is not required by Minnesota statutes. Requiring consent would undermine the public's investment in cancer registration and render it ineffective in protecting public health. Federal standards require that at least 95 percent of the expected number of cases must be reported before cancer registration is complete. MCSS completeness currently meets that standard. If even 10 percent of people with cancer refused to have their information reported to the MCSS, Minnesota cancer rates would appear to be much lower than they are. In addition, persons refusing consent would likely differ from those giving consent in unknown ways, such as gender, age, race and ethnicity, location of residence, type of cancer, or year of diagnosis. Because of this, data would be biased. It would be impossible to reliably compare rates among these important factors, which is the basis of cancer surveillance. In fact, the refusal rate could be even higher, given the challenges facing patients coping with new cancer diagnoses, and the physician's need to discuss treatment, prognosis and quality of life issues with the patient. Obtaining consent for cancer reporting in this context arguably represents an unnecessary and inappropriate burden on both patients and physicians.

Do other states require informed consent for cancer registration? No. For the same reasons as discussed above, no cancer registry in the U.S. requires informed consent for cancer reporting.

How are Minnesota cancer patients given an opportunity to participate in research projects? Before a patient is invited to participate in research, his or her physician is contacted by the MCSS to determine if there is any reason why the patient or the patient's family should not be approached. This step is required by the statute

that created the MCSS. If the physician consents, the patient is invited to participate, as specified in the study protocol. Participation is always voluntary, and the MCSS does not inform the patient's physician of his or her decision. Patients may request that they are never approached by the MCSS to participate in research by contacting the MCSS (see contact information below).

Cancer patients who are approached to participate in research are sometimes unaware that their names have been reported to the MCSS. The invitation may, therefore, come as a surprise and cause concern. Although first consulting the physician is intended to prevent patients and their families from being contacted at inappropriate times, this unfortunately can happen despite the best of intentions. Nonetheless, experience indicates that most cancer patients welcome the opportunity to contribute to knowledge about their illness.

How is data privacy protected by researchers?

Data from the MCSS are only provided to a researcher whose project has been reviewed and approved both by the MCSS Peer Review Committee, which evaluates proposed studies for social and scientific merit, and by a federally approved Committee for the Protection of Human Subjects. These latter committees, also called Institutional Review Boards (IRBs), carefully review research protocols, including the provision of informed consent and methods to protect data confidentiality, to determine whether potential risks have been well explained prior to obtaining consent and are justified by potential benefits. Failure to protect confidentiality can result in the termination of the project and its funding. Research projects are reviewed annually, and complaints must be reported to the governing IRB. Researchers who receive private patient information from the MCSS are also contractually bound to protect the information under all the requirements of Minnesota law.

Does cancer reporting represent a risk to patient privacy?

Yes, although the risk is small. Any time that data are exchanged, whether between individuals, between health care providers, between providers and insurers, or between providers and the MCSS, it is possible

for breaches in data privacy, either inadvertent or intentional, to occur. The state legislature and MDH have taken extreme care to minimize these risks by the protections described above, with an outstanding record of success.

The underlying issue today is the same as deliberated by the Commissioner's advisory committee more than 15 years ago: "Are the benefits of cancer surveillance greater than its costs?" The answer remains an emphatic "Yes." The lifetime risk of developing a life-threatening cancer is approximately 50 percent. Thus, each of us will be affected directly or indirectly by this group of diseases. The methods used by the MCSS to collect and release data effectively balance the need to protect public health through cancer surveillance, the desire of the public for progress in preventing, detecting, and treating cancer, and the rights of individuals to privacy. The MCSS can only fulfill its legal mandates and provide the information required for cancer control and for protection of the public health through collection and protection of this critical and sensitive individual information.

Where can more information about the MCSS be obtained?

More information can be obtained by visiting the MCSS website, (www.health.state.mn.us/divs/hpcd/cdee/mcss), by telephoning the MCSS office at (651) 201-5900, or by writing to MCSS, P.O. Box 64882, St. Paul, MN 55164-0882.