

## Summary

This report summarizes the status of cancer in Minnesota, using cases reported to the Minnesota Cancer Surveillance System and deaths reported to the Minnesota Center for Health Statistics. 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 risks, early detection, and treatment.

- In 2002, 23,384 Minnesotans were diagnosed with cancer, and 9,198 Minnesotans died of this disease.
- More Minnesotans now die of cancer than heart disease. Heart disease mortality is declining at a substantially faster rate than cancer mortality, both in Minnesota and nationally. Minnesota was the first state with cancer as the leading cause of death because the heart disease mortality rate in Minnesota is 30 percent lower than the national average, while our cancer mortality rate is only six percent lower.
- 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 167,310 Minnesotans, or 3.3 percent of the population, were living with a history of cancer on January 1, 2002.
- In 2002, more Minnesotans died of lung cancer (2,327 deaths) than the next three most common cancers combined: colorectal (932 deaths), breast (642 deaths), and prostate (601 deaths). Lung cancer mortality among Minnesota women continues to increase by more than two percent each year, in contrast to stabilizing rates nationally.
- The overall cancer incidence rate increased by 1.1 percent per year among Minnesotans between 1995 and 2002. This was largely due to a significant increase in prostate cancer incidence among men and significant increases in lung and breast cancer incidence among women.
- The number of Minnesotans diagnosed with cancer increased by 32 percent between 1988 and 2002, reflecting the growth and aging of the Minnesota population as well as the increases in incidence described above.
- Despite an increase in the overall risk of developing cancer, the cancer mortality rate steadily declined by less than one percent each year among both men and women in Minnesota between 1988 and 2002. Mortality rates declined significantly for breast, prostate, and colorectal cancer, and for lung cancer among males.
- Even though the overall cancer mortality rate decreased over the 15-year period 1988-2002, the number of Minnesotans dying of cancer increased by approximately 13.5 percent because of the growth and aging of the Minnesota population.
- The overall cancer incidence rate in Minnesota is similar to the national rate for all races combined, and is five percent lower among non-Hispanic whites.
- Minnesotans have significantly higher incidence and mortality rates for leukemia (about 5% higher) and prostate cancer (about 10% higher) than reported nationally. The mesothelioma incidence rate among men is 24 percent higher in Minnesota than nationally, but is the same for women.
- Racial and ethnic differences in the burden of cancer are evident in Minnesota. Of special concern are cancer rates among American Indians in Minnesota. Nationally, American Indians have the lowest overall cancer rate, but in Minnesota they have the highest. They were 14 percent more likely to be diagnosed with cancer than non-Hispanic white Minnesotans and 46 percent more likely to die of the disease. The majority of the excess in cancer risk among American Indians in Minnesota was due to lung and colorectal cancer.

## Minnesota Cancer Alliance to Implement Cancer Plan Minnesota 2005-2010

*Cancer Plan Minnesota 2005-2010* is the state's first comprehensive cancer control plan. Developed over a two-year period through a broad-based collaboration of public, private and non-profit organizations, the plan was released in April 2005 and now serves as a common framework for action to reduce the burden of cancer for all Minnesotans.

The Minnesota Cancer Surveillance System (MCSS) was essential in the development of data-driven objectives for *Cancer Plan Minnesota*. The plan includes 24 objectives and numerous strategies covering all facets of cancer control: prevention, early detection, treatment, quality of life, cancer disparities, and data and research needs. Over the long run, MCSS will be the key source of population-based data to assess the outcome of cancer control efforts in Minnesota.

Now that *Cancer Plan Minnesota* is complete, planning partners have formed a coalition, the Minnesota Cancer Alliance, to provide 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. Alliance members are committed

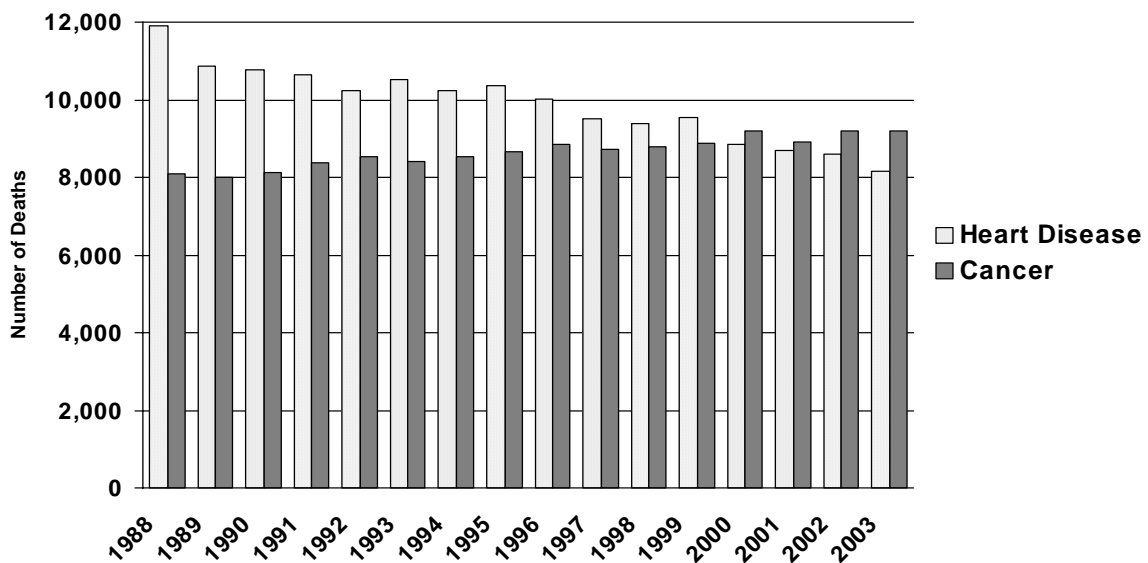
to supporting the plan's implementation.

Minnesota Cancer Alliance task forces are currently addressing the cancer plan's four priorities:

1. Increase the tobacco excise tax and expand clean indoor air policies.
2. Reduce racial, ethnic, and geographic disparities in cancer screening and treatment.
3. Improve access to information about services for cancer patients and their families.
4. Increase colorectal cancer screening.

The importance of working together to reduce the suffering caused by cancer is underscored by the fact that cancer became the leading cause of death in Minnesota in 2000. Volunteers representing a broad base of stakeholders are working together in project teams to take specific action to help achieve the cancer plan's objectives. 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.cancerplanmn.org> or contact Elizabeth Moe, Project Coordinator, at (651) 201-3608.

**Deaths due to Heart Disease and Cancer,  
Minnesota, 1988-2003**



Source: Minnesota Center for Health Statistics. All 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 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.

**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](http://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.

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