

Summary

This report summarizes the status of cancer in Minnesota, using cases reported to the Minnesota Cancer Surveillance System (MCSS) and deaths reported to the Minnesota Center for Health Statistics. Cancer surveillance plays a critical role in protecting and improving public health. These data enable the Minnesota Department of Health (MDH) 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.

- More than 22,000 Minnesotans were diagnosed with cancer in 1999, excluding cancers that are rarely life-threatening, such as common skin cancers and *in situ* cancers.
- Nearly 8,900 Minnesotans died of cancer in 1999, accounting for one of every four deaths.
- Prostate, breast, lung, and colorectal cancers are the most common, accounting for 56 percent of cancer diagnoses and 49 percent of cancer deaths.
- Over the 12-year period 1988-1999, the overall cancer incidence rate among males in Minnesota decreased somewhat, largely due to significant decreases in colorectal, stomach, and several smoking-related cancers (lung, larynx, and oral cavity).
- Over the same period, the overall cancer incidence rate among women in Minnesota increased by about 8 percent, largely due to significant increases in breast and lung cancer. These increases were large enough to outweigh significant decreases in colorectal, stomach, and cervical cancer.
- Although the overall cancer incidence rate in Minnesota did not increase significantly between 1988 and 1999, the number of persons diagnosed with cancer increased by more than 20 percent because of the growth and aging of the Minnesota population.
- The cancer mortality rate declined among both men and women, but more sharply among men. For women, continuing increases in lung cancer mortality largely offset decreasing mortality rates in other sites, including breast cancer.
- Despite a 4 percent decrease in the cancer mortality rate in Minnesota between 1988 and 1999, the number of persons dying of cancer increased by 10 percent because of the growth and aging of the Minnesota population.
- Cancer rates in Minnesota are about 5 percent lower than reported nationally, largely due to lower rates of cancers caused by tobacco use.
- Race disparities in the burden of cancer are evident in Minnesota. Black men have the highest cancer rates in Minnesota—their incidence rate is 30 percent higher and their mortality rate is 60 percent higher than among white males. Of special concern are cancer rates among American Indians. Nationally, the overall cancer mortality rate is 40 percent lower among American Indians than whites; in Minnesota, their rate is 30 percent higher than whites. Among American Indian men, lung cancer mortality is two times higher in Minnesota than in the U.S. as a whole; among American Indian women, it is three times higher in Minnesota. Other smoking-related cancers appear to be unusually common among American Indians in Minnesota, as well as prostate, colorectal, and cervical cancer.
- The mesothelioma incidence rate among men in Minnesota increased by 70 percent between 1988, when statewide cancer reporting was implemented, and 1999. Rates did not increase among women. Mesothelioma incidence in Minnesota is 14 percent higher among men than reported for the nation, but is the same for women.

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 one 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 2 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 data 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 nearly 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 in to consideration when the legislature mandated the creation of the 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 are 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/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, give the challenges facing patients coping with new cancer diagnoses, and the physicians'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

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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 nearly 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, (<http://www.health.state.mn.us/divs/dpc/cdee/mcss.htm>), by telephoning the MCSS office at (612) 676-5216, or by writing to: MCSS, P.O. Box 9441, Minneapolis, MN 55440-9441.