

Data, Surveillance, and Research

High-quality data are necessary to identify where cancer prevention and control efforts should be targeted, to establish measurable and achievable objectives, and to evaluate progress. During the planning process, nearly every Cancer Plan Minnesota work group identified key issues that lacked sufficient data to create specific, measurable objectives. Because of the importance of these data gaps to the future of cancer control in Minnesota, they have been consolidated into one chapter.

Minnesota is fortunate to have high-quality population-based cancer incidence data from the Minnesota Cancer Surveillance System (MCSS). Cancer became a reportable disease in Minnesota in 1988, and MCSS has repeatedly met the highest standards for data quality, timeliness, and completeness. Because of the investment of Minnesota citizens in MCSS, we know how cancer rates in Minnesota compare to those for the nation, the trends in specific types of cancers, and how those rates and trends vary by region, age, gender, race, and ethnicity.

These data provide the framework upon which Cancer Plan Minnesota is constructed; without MCSS, we would not be able to measure progress in meeting our goals. However, MCSS was not initially designed to monitor cancer treatment or survival, a process that requires considerably more resources. Using funds from the National Program of Cancer Registries, MCSS has begun to collect, consolidate, enhance, and analyze treatment and vital status information on cancer patients. Additional resources would greatly increase the ability of MCSS to examine patterns of care and survival rates among Minnesota residents who are diagnosed with cancer.

A second valuable data resource for cancer control is the Minnesota Behavioral Risk Factor Surveillance System (MBRFSS), an ongoing telephone survey of randomly selected adults, conducted in Minnesota in collaboration with the U.S. Centers for Disease Control and Prevention for more than 15 years. Many questions on the survey are related to cancer control—access to health care, cancer screening utilization, and prevalence of known risk factors such as smoking. There is room for improvement, however. Analyses of these data could be greatly expanded, questions could be added to fill data gaps, and the validity of these self-reported data should be evaluated.

Organizations involved in cancer research throughout Minnesota, whether affiliated with public agencies, healthcare insurers, universities, or cancer centers, are a third valuable data resource. Collaborating on common objectives could make better use of data maintained by individual organizations.

In addition to the above existing data resources, there are important areas for which no or only limited data exist to inform cancer control activities. This is especially true for measures of post-diagnosis quality of life, family histories of cancer, the use of and access to cancer care following initial treatment, and cancer risk factors among children. In fact, relatively little is known, even at a national level, about the quality of cancer care

for cancers other than the most common types. Health services research in Minnesota should be expanded to better understand the costs of cancer care, to identify where the cancer care system could be improved, and to evaluate the state's progress in meeting the objectives of Cancer Plan Minnesota.

With these concerns in mind, the following data-related objectives that are necessary to assess and/or complete many of the other Cancer Plan Minnesota goals have been identified.



OBJECTIVE 23

Expand the application, scope, and quality of existing data sources and surveillance activities to better assess cancer control efforts in Minnesota.

Strategies:

- Advocate for increased funding for the population-based statewide cancer registry (MCSS) to enhance data collection and analysis of treatment choices and survival rates by race/ethnicity, socioeconomic status, family history, and geographic area.
- Standardize the way in which socio-demographic data are collected in the hospital record to describe and monitor cancer-related health disparities.
- Develop innovative approaches to use administrative claims data to describe and monitor patterns of care for cancer prevention, screening, treatment, follow-up, and use of cancer support services.
- Measure breast cancer screening rates among women from racial/ethnic groups that experience disparities in breast cancer mortality.
- Assess regional variations in colorectal cancer screening rates.
- Use mapping techniques to assess gaps in the availability and use of cancer-related support services such as hospice, particularly in rural areas and in racial/ethnic minority communities.
- Increase the analysis and dissemination of data from ongoing surveys that collect data relevant to cancer control (e.g., MBRFSS and the Minnesota Student Survey [MSS]).
- Evaluate adding questions to fill data gaps and over-sampling minority populations in ongoing surveys to ensure reliable estimates of healthcare access, screening, and behaviors for these groups.
- Undertake studies to assess the validity of data related to cancer control collected by the MBRFSS.

Collect new data and conduct research to inform and shape cancer control efforts in Minnesota.

OBJECTIVE 24

Strategies:

- Conduct a state-based survey — modeled on the National Health and Nutrition Examination Survey (NHANES) — every 5 years to collect more detailed data on risk factors for cancer, such as weight, physical activity, nutrition, and sun exposure.
- Develop a common approach to assess and monitor the quality of life for cancer survivors in Minnesota.
- Include quality of life measures in research on palliative care.
- Convene a broad-based health data research group to develop a model of cancer care costs in Minnesota.
- Collect data on family history to estimate the proportion of Minnesotans who are at moderate or high risk for cancer based on family history.
- Describe the nature and scope of problems related to timeliness and completeness of follow-up for abnormal screening tests.
- Evaluate the adequacy of the healthcare workforce and services infrastructure to meet current and future demands for quality cancer care (especially in rural areas).
- Characterize the needs and use of specific support services by cancer survivors by socio-demographic characteristics.
- Develop and evaluate innovative approaches to reaching women who are not currently being screened for cervical cancer.
- Identify the proportion of children and adolescents who report 1 or more sunburns in the past year.
- Identify the proportion of children and adults who practice 1 or more sun protection activities.
- Develop a core set of quality measures to measure and monitor the quality of care along the cancer continuum through a coordinated public-private effort.