Cancer Plan Minnesota 2005–2010 Recommendations for policymakers, planners, providers, and advocates.



Developed by the collaborative efforts of individuals and organizations committed to reducing the burden of cancer among all Minnesotans. This plan is the culmination of work done by hundreds of Minnesotans who volunteered time and energy to serve on Cancer Plan Minnesota committees and work groups, who provided input at community forums around the state, and who participated in planning summits in 2003 and 2004.



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Executive Summary

Cancer is the leading cause of death in Minnesota. Each year, more than 23,000 Minnesotans are diagnosed with a potentially life-threatening cancer, and more than 9,000 die from the disease. Four types of cancer—lung, breast, colorectal, and prostate—account for more than half of all cancer cases and half of all cancer deaths in Minnesota. More than two-thirds of cancer deaths could be prevented through the adoption of healthier lifestyles and greater use of screening.

In the year 2000, an estimated 156,600 Minnesotans—3.2 percent of the state's population—were living with a history of cancer. This number is projected to grow dramatically as the population ages and as advances are made in early detection and treatment.

In 2002, with support from the Centers for Disease Control and Prevention (CDC), stakeholders in Minnesota initiated a process to develop the state's first comprehensive cancer control plan. Addressing the full spectrum of cancer care, from prevention and early detection to treatment and end-of-life care, this process provided the cancer community with an opportunity to build new partnerships, reduce unnecessary duplication, improve coordination of resources, and sow the seeds for the development of innovative strategies. Moreover, it presented an opportunity for public discourse about cancer-related issues facing Minnesotans, an impetus to look long and hard for evidence-based strategies to address those issues, and a challenge to create a plan with measurable outcomes to gauge success.

Cancer Plan Minnesota's five overarching goals are to:

- 1. Prevent cancer from occurring.
- 2. Detect cancer at its earliest stages.
- 3. Treat all cancer patients with the most appropriate and effective therapy.
- 4. Optimize the quality of life for every person affected by cancer.
- 5. Eliminate disparities in the burden of cancer

These goals, which were articulated by the plan's steering committee, helped to frame the development of the plan's objectives and to underscore its comprehensive nature.

As a strategic plan, Cancer Plan Minnesota is intended to be a framework for action to effectively reduce the burden of cancer among all Minnesotans. It is a five-year plan, with the majority of its measurable objectives written for 2010. To provide some focus for action over the next one to two years, initial priority will be given to supporting the following efforts:

1. Increasing the tobacco excise tax and expanding clean indoor air policies.

Tobacco use and exposure to tobacco smoke are responsible for more cancer deaths than any other single factor. Smoking rates in Minnesota have not decreased during the last decade. The CDC estimates that each pack of cigarettes costs \$7.18 in medical care costs and lost productivity.

A major tax increase on tobacco will significantly reduce the number of youth who take up smoking and will encourage many adults to quit. Minnesota currently taxes each pack of cigarettes \$0.48, compared to \$0.84 nationally, and ranks 37th lowest in tobacco taxes. Minnesota was the first state to mandate smoke-free areas in restaurants and bars, but now lags behind 16 other states in passing statewide smoking bans to protect patrons and employees from exposure to secondhand smoke.

2. Reducing disparities in cancer screening and treatment.

A critical component of reducing the unequal burden of cancer is to improve the use of cancer screening and access to state-of-the-art treatment among populations that are underserved due to race, ethnicity, socioeconomic status, lack of health insurance, or residence in rural areas. Minnesota is one of two states in the nation with a funded initiative to eliminate health disparities. It can build, therefore, on partnerships already in place and projects already in progress across the state to enhance its efforts for cancer prevention and control.

3. Improving access to information about locally available services for cancer patients and their families.

After receiving a cancer diagnosis, many people find the search for needed services and support to be an overwhelming task and, thus, a barrier to effective treatment and sustained quality of life. A comprehensive online portal to listings of available resources and support services, county by county, is needed to facilitate greater use of these services and to help identify resource gaps. This can build on the work of the American Cancer Society (ACS), the National Cancer Institute (NCI), and other organizations.

4. Increasing colorectal cancer screening.

Colorectal cancer is the second-leading cause of cancer deaths in Minnesota. Screening can identify colorectal cancer in its early stages and, in addition, can identify precancerous lesions when they can be removed easily, without additional treatment. Nonetheless, colorectal cancer screening occurs less frequently than screening for breast and cervical cancer. Increasing colorectal cancer screening has the potential to save the lives of hundreds of Minnesotans each year.

With its plan developed and published, Cancer Plan Minnesota now intends to take action. Its supporting infrastructure, which consists of people from many organizations, will transform itself into a formal partnership. New members will be recruited, and implementation teams will take shape.

By working together, coordinating resources where appropriate, and integrating the cancer prevention and control activities outlined in this plan into existing programs and activities across the state, we can and will reduce the burden of cancer among all Minnesotans.

Cancer Plan Minnesota Summit, November 2004



Guiding Principles

We believe that by seeking and acting on opportunities for collaboration we can accomplish more together than we can accomplish alone to reduce the burden of cancer in Minnesota.

We support science-based and evidence-informed approaches to address cancer control across the continuum of cancer care.

We value reaching out to and engaging all Minnesotans, regardless of age, race, ethnicity, gender, geography, education, language, sexual orientation, and socioeconomic status.

We respect cultural wellness practices and traditions and support the delivery of cancer services to all Minnesotans within a context of cultural values.

We believe that patients and their families must be empowered to make decisions based on information presented and shared in a manner they can understand.

We support equal access to cancer services for all Minnesotans.

We support the elimination of fragmented care for cancer patients.

We support efforts to more effectively and equitably use public and private resources to continuously, transparently, and measurably decrease suffering from cancer.

We believe in using population-based approaches, system changes, and interventions directed at individuals' behavior to help reduce the burden of cancer.

We believe that moving this plan to action will require strong leadership, adequate resources, and broad-based commitment.

-Cancer Plan Minnesota Steering Committee



Brian Rank



Thomas T. Amatruda



Alan Bender



David Benson



D. Doug Blanke



Jose William Castellanos



Lyn Ceronsky



Charles Fazio



Patrick J. Flynn



Katherine Hokanson



Coral Houle



Helen Jackson



Carol Johnson



Judith Salmon Kaur



DeAnn Lazovich



Gloria Lewis



Jennifer Lundblad



Marc Manley



Sheryl Ness



John F. O'Leary



Kim Orn



Dung Pham



Ruth Pierce



Cheri Rolnick



Lisa Stephens



Patricia Swanson



Maribeth Swenty



Pam Van Zyl York



Richard Zera

Steering Committee

CHAIR

Brian Rank, M.D. HealthPartners, Inc.

MEMBERS

Thomas T. Amatruda, M.D. Hubert H. Humphrey Cancer Center

Alan Bender, D.V.M., Ph.D. Minnesota Department of Health

David Benson Nobles-Rock Community Health Board

Cathy A. Berendts, M.S., R.N. St. Mary's Duluth Clinic

D. Doug Blanke, J.D. William Mitchell College of Law

Jose William Castellanos, M.D. Chicanos y Latinos Unidos en Servicio

Lyn Ceronsky, A.P.R.N., M.S. Fairview Health Services

Charles Fazio, M.D. *Medica*

DeAnna Finifrock, R.N., M.S.N., P.H.N. Fond du Lac Human Services Patrick J. Flynn, M.D. Minnesota Oncology Hematology, P.A.

Katherine Hokanson, R.N., B.S., C.A.N. *Minnesota Medical Association*

Coral Houle American Cancer Society, Midwest Division, Inc.

Helen Jackson Stairstep Foundation

Carol Johnson Community Member

Judith Salmon Kaur, M.D. Mayo Clinic Cancer Center

DeAnn Lazovich, Ph.D. University of Minnesota Cancer Center

Gloria Lewis *Minnesota Department of Health*

Jennifer Lundblad, M.B.A. Stratis Health

Marc Manley, M.D., M.P.H. Blue Cross and Blue Shield of Minnesota

Sheryl Ness, R.N., M.A. Mayo Clinic Cancer Center

John F. O'Leary, M.D., F.A.C.S. American College of Surgeons Kim Orn American Cancer Society, Midwest Division, Inc.

Dung Pham Vietnamese Social Services of Minnesota

Ruth Pierce Itasca County Health and Human Services

Christine Reisdorf, M.P.H. Minnesota Department of Human Services

Cheri Rolnick, Ph.D., M.P.H. HealthPartners Research Foundation

Lisa Stephens, M.S., C.H.E.S. NCI Cancer Information Service

Patricia Swanson, R.N. Kittson County Hospice

Maribeth Swenty American Cancer Society, Midwest Division, Inc.

Pam Van Zyl York, M.P.H., Ph.D., R.D., L.N. *Minnesota Department* of Health

Richard Zera, M.D., Ph.D. Hennepin County Medical Center

Introduction

Cancer Plan Minnesota, the state's first comprehensive cancer control plan, is the product of individuals and organizations working together to develop a common framework for action to reduce the burden of cancer in Minnesota.

The state has a wealth of resources and programs dedicated to cancer prevention and control, including one of the most forward-thinking healthcare systems in the nation, two National Cancer Institute-designated Comprehensive Cancer Centers, a top-ranked school of public health, cutting-edge medical research, an outstanding cancer surveillance system, and a highly-trained healthcare workforce. Yet lack of communication and coordination within and among these resources has yielded many missed opportunities for collaboration and synergy.

Recognizing the advantages of broad-based, comprehensive planning to enhance integration, coordination, and leveraging of resources for cancer control, the U.S. Centers for Disease Control and Prevention (CDC) has provided funding for state-based comprehensive cancer control planning nationwide. The State of Minnesota received seed money from the CDC in 2002 to undertake the development of a plan to address the full continuum of cancer care, from prevention to end-of-life care. The Minnesota Department of Health (MDH) and the American Cancer Society (ACS), Midwest Division took the lead in facilitating the process and recruited a steering committee from cancer centers, healthcare provider organizations, community-based organizations, public health institutions, cancer advocates, and the medical community. The role of the steering committee was to provide guidance and oversight.

How the Plan Was Developed

In April 2003, the steering committee began its work. Its members reached consensus on the purpose of a cancer plan for Minnesota, articulated the plan's guiding principles (see page 5), and developed the plan's overarching goals (see page 2). In October 2003, a public kick-off event was held. More than 200 people gathered at this initial Cancer Plan Summit to review the burden of cancer in Minnesota and to learn how they could become involved in developing the plan. In concurrent sessions organized across the continuum of cancer care, participants discussed Minnesota's cancer-related assets, needs, and key issues.

Immediately following the summit, five work groups were formed around the issues of prevention, detection, treatment, palliation, and survivorship. Two committees were created to address genomics and health disparities. A data review committee was convened to provide technical expertise to the work groups and steering committee in the areas of cancer epidemiology, surveillance, evaluation, data collection, and analysis. Ten community forums were held at various locations across Minnesota to provide additional opportunities for community input. The work groups considered the themes and ideas generated at these meetings as they developed issue statements, drafted objectives, discussed measurement issues, and recommended strategies. To avoid "reinventing the wheel," a concerted effort was made to dovetail this work with that already done by other chronic disease prevention and control initiatives in Minnesota, such as those directed at diabetes and cardiovascular disease.

The process was highly interactive, and at each step of the way there were opportunities for formal and informal feedback between the steering committee, the work groups, and the other committees. A draft plan was released for comment in October 2004.

A second Cancer Plan Summit, held in November 2004, gave stakeholders another opportunity to come together, this time to begin outlining steps for action. The dialogue was energetic and intense as groups coalesced around strategies for the plan. Summit participants expressed their priorities through a straw ballot. After the summit, the steering committee considered the participants' input as it selected the plan's initial priority areas for implementation. The committee also took into account its own overall assessment of Minnesota's most critical gaps in cancer prevention and care and its assessment of which of the identified cancer-related issues and strategies were most likely to have the greatest impact and were most ready to be put into action.

The Plan's Objectives

Cancer Plan Minnesota contains 24 objectives (see page 11), each with recommended strategies for implementation. The objectives have been organized into six chapters: prevention; early detection; treatment; quality of life; disparities; and data, surveillance, and research. Some are cross-referenced to more than one chapter.

Although work is expected to occur across the broad array of objectives and strategies put forth in the plan, particular emphasis will be given to supporting activities in the following four areas during the next one to two years.

Initial Priority Areas

- · Increasing the tobacco excise tax and expanding clean indoor air policies
- Reducing disparities in cancer screening and treatment
- Improving access to information about locally available services for cancer patients and their families
- Increasing colorectal cancer screening

A Commitment to Results

The Cancer Plan Minnesota initiative is committed to results. The success of the plan will ultimately be judged by the extent to which its goals and objectives are met. Over the long term, progress will be demonstrated by reductions in cancer incidence and mortality and improvements in cancer survival, as reflected in cancer surveillance data reported by the Minnesota Cancer Surveillance System (MCSS). In the intermediate term, progress will be demonstrated by movement toward targets suggested by the work groups and by the plan's data review committee. These targets, or indicators of success, are listed with each of the objectives in the plan.

Work groups were charged to develop specific, measurable, attainable, realistic, and time-measured objectives for the plan. This was particularly challenging on issues for which population-level indicators were limited, unpublished, or nonexistent. Consequently, proxy indicators were recommended for several of the plan's objectives. For other objectives, potential indicators were suggested—ones that would require special initiatives to gather the needed data. In its deliberations, the plan's steering committee and data review committee concluded that a lack of existing indicators should not preclude the inclusion of important objectives in the plan. Clearly, more work is needed at the state and national level to develop feasible population-based measures, particularly in the areas of survivorship and palliative care.

Over the next one to two years, the evaluation of Cancer Plan Minnesota will focus on the implementation of strategies in the priority areas. This evaluation will be accomplished through the collection and analysis of process and outcome data from the plan's implementation teams—the Cancer Plan Action Teams. In addition, an evaluation committee will be established to systematically inventory and report on the full spectrum of activities in the cancer community around the strategies in the plan.

From Planning to Action

The next steps for Cancer Plan Minnesota are to formalize its working partnerships, to launch and support its Cancer Plan Action Teams, and to strengthen and expand channels of communication for plan stakeholders. Cancer Plan Minnesota is an ambitious undertaking. Minnesota is consistently ranked one of the healthiest states in the nation, with one of the highest life expectancies.¹ If we focus our efforts on shared, achievable priorities, we can use these strengths to more effectively reduce the burden of cancer for all Minnesotans.

Cancer Plan Minnesota Objectives at a Glance

- 1. Reduce the use of tobacco.
- 2. Reduce exposure to secondhand smoke.
- 3. Increase the proportion of adults and children who meet recommended physical activity levels.
- 4. Improve the diet of adults and children.
- 5. Reduce the proportion of adults and children who are overweight or obese.
- 6. Reduce the exposure of adults and children to ultraviolet light.
- 7. Increase screening and follow-up for breast, colorectal, and cervical cancer.
- 8. Reduce disparities in screening for breast, colorectal, and cervical cancer.
- 9. Increase the number of healthcare providers who deliver consistent and appropriate messages to help men make informed decisions about prostate cancer screening and follow-up.
- 10. Increase the number of moderate- and high-risk individuals who receive appropriate screening and referral for cancer genetic services.
- 11. Improve the quality of cancer care in Minnesota.
- 12. Improve the quantity of information and support available to cancer patients and providers.
- 13. Reduce age, cultural, and geographic barriers to appropriate and effective cancer care.
- 14. Reduce financial barriers to appropriate and effective cancer care.
- 15. Increase participation of racial and ethnic minority patients in clinical trials.
- 16. Maximize the use of services that support the short- and long-term needs and that improve the quality of life of cancer survivors and their families.
- 17. Optimize continuity of care for cancer survivors.
- 18. Ensure that all cancer patients, their families, and their healthcare providers can access information about advance care planning and palliative care services.
- 19. Ensure that adults and children diagnosed with cancer can access appropriate palliative care and hospice care.
- 20. Eliminate financial barriers to the delivery of palliative care.
- 21. Improve the cultural competency of healthcare providers.
- 22. Increase the number of racial and ethnic minority workers in healthcare workforce.
- 23. Expand the application, scope, and quality of existing data sources and surveillance activities.
- 24. Collect new data and conduct research to inform and shape cancer control efforts in Minnesota.



Chapter 1 The Overall Cancer Burden in Minnesota

The following summary of the burden of cancer in Minnesota helped to inform the development of and setting priorities for Cancer Plan Minnesota. More detailed statistics can be found in the report "Minnesota Cancer Facts and Figures 2003."²

Cancer is very common.

More than 23,600 Minnesotans were diagnosed with a potentially serious cancer in 2002, the most recent year for which reporting is complete.³ This figure does not include individuals diagnosed with common skin cancers or early-stage, *in situ* tumors. The number of Minnesotans living with a history of a serious cancer is estimated to be 156,600, nearly seven times the number diagnosed with the disease each year.⁴

Based on current statistics, 52 percent of men and 45 percent of women in Minnesota will be diagnosed with an invasive cancer during their lifetime.⁵ It's very difficult not to know someone who has struggled or is struggling with the physical, emotional, and financial challenges of this disease.

More than half of Minnesotans diagnosed with cancer have lung, breast, prostate, or colorectal cancer (Figure 1). There are more than 100 different kinds of cancer, but these four types accounted for 56 percent of all cancers diagnosed among Minnesotans in 2002 and 49 percent of all cancer deaths.³

Cancer has become the leading cause of death in Minnesota.

Nearly 9,200 Minnesotans died of cancer in 2002.³ For the first time in 2000, and again in 2001 and 2002, more Minnesotans died of cancer than of heart disease^{6,7,8} (Figure 2). While Minnesota's heart disease mortality rate decreased by more than 40 percent between 1988 and 2000, its cancer mortality rate decreased by less than 5 percent.⁹

Figure 1

Ten Most Common Cancers, Minnesota, 2002



Preliminary Report.

Figure 2

Deaths Due to Heart Disease and Cancer, Minnesota, 1988–2002



Source: Minnesota Cance Surveillance System.

Figure 3

Actual and Projected Number of New Cancer Cases, Minnesota, 1988–2010



Source: Minnesota Cancer Surveillance System.

Figure 4

Cancer Mortality by Race and Gender, Minnesota, 1996–2000



Source: Adapted from *Minnesota Cancer Facts* and *Figures, 2003.*

Trends for heart disease and cancer mortality in Minnesota are similar to those in the United States as a whole, yet Minnesota was the only state in 2000 with a higher mortality rate for cancer than for heart disease.⁶ The crossover between cancer and heart disease mortality occurred earlier in Minnesota than in other states because heart disease mortality is about 30 percent lower in Minnesota than in the nation as a whole; cancer mortality, on the other hand, is only slightly lower in Minnesota than in the entire United States.⁶

Cancer will become more common as the Minnesota population ages.

The number of Minnesota residents is projected to increase by 11 percent between 2000 and 2010.¹⁰ However, the number of persons diagnosed with cancer will increase by 22 percent over the same period (Figure 3), even if cancer rates do not increase, because of the larger than usual number of persons born in the 15 to 20 years following the end of World War II who are reaching the age when cancer risk increases sharply.¹¹

The burden of cancer is unequal.

The risk of being diagnosed with and dying from cancer is not the same for each racial and ethnic group. Whether this disparity is primarily due to genetic, environmental, or socioeconomic differences is controversial. Racial and ethnic differences in the burden of cancer are evident nationally,¹² and despite the state's reputation for excellent health care, in Minnesota as well (Figure 4).²

Minnesota's cancer rates have become more similar to national ones, although the state's rates were once lower.

From 1988 to 1992, the overall cancer incidence rate in Minnesota was 8 percent lower than among the white population in the geographic areas in the United States participating in the Surveillance, Epidemiology, and End Results (SEER) Program.^{12,13} During the same five-year period, Minnesota's overall cancer mortality rate was 6 percent lower than among whites in the United States as a whole.^{9,13} In recent years, however, cancer rates in Minnesota have become more similar to those for the nation (Figure 5), primarily because lung cancer rates among women have begun to decline nationally but are still increasing in Minnesota. The decline in lung cancer among men is slower in Minnesota than nationally.

Progress has been made, but we can accomplish much more.

The overall cancer mortality rate among men in Minnesota is declining, as are breast and colorectal cancer mortality rates among women in the state. More Minnesotans are being screened for cancer than a decade ago. That's the good news.

The bad news is that tobacco smoke causes nearly 30 percent of cancer deaths,¹⁴ and, according to annual surveys of Minnesota adults, smoking rates in Minnesota did not decline between 1990 and 2002.¹⁵ Another 30 percent of cancer deaths are attributable to poor diet, lack of exercise, and obesity,¹⁴ but the proportion of obese Minnesota adults has more than doubled during the last decade or so.¹⁵

In addition, national data have shown that

persons of color and the poor are less likely to have their cancers detected early, receive recommended treatment, and survive the disease.¹⁶ And far too little information is available to assess and systematically address the services that are needed by, and the quality of life of, the estimated 156,600 cancer survivors in Minnesota.

Figure 5





Source: Minnesota Cancer Surveillance System. SEER is the Surveillance, Epidemiology and End Results Program. Rates for SEER/U.S. are for white persons, including Hispanics.



Chapter 2 Prevention

Over the long run, preventing cancer by reducing health risk behaviors will have an enormous impact on the burden of cancer in Minnesota. It has been estimated that close to two-thirds of all cancers are attributable to risk factors that can be modified.¹⁷ Research has identified effective strategies to change behaviors known to increase cancer risk, such as cigarette smoking.¹⁷ The challenge is to organize public and private resources around the strategies that have the greatest impact.

Many of the common types of cancer share behavioral risk factors with other chronic diseases, such as heart disease, diabetes, and chronic obstructive lung disease. Coordinating efforts to address these common risk factors will help advance Minnesota's strategic health objectives not only for cancer, but also for stroke, heart disease, diabetes, arthritis, and asthma.

Tobacco is a leading preventable cause of cancer.

About 30 percent of cancer deaths are associated with tobacco use.¹⁴ Despite the highly publicized link between cigarette smoking and cancer, about 21 percent of adults in Minnesota habitually smoked cigarettes in 2003, and smoking rates in the state have not decreased significantly during the last decade (Figure 6).¹⁵ The toll is economic as well as human: each pack of cigarettes costs \$7.18 in medical care costs and lost productivity.¹⁸



and will encourage many adults to quit.^{19,20} However, Minnesota currently taxes each pack of cigarettes \$0.48, compared to \$0.84 nationally, and ranks 37th lowest in tobacco taxes.²¹

To reduce exposure to secondhand smoke, many citizens have advocated for smokefree environments in homes, daycare homes or centers, schools, workplaces, recreation areas, motor vehicles, and public places.^{22,23} Although Minnesota was the first state to mandate smoke-free areas in restaurants and bars, it now lags behind 16 other states in passing statewide smoking bans to protect patrons and employees from exposure to secondhand smoke.²⁴



Trends in Adult Smoking, Minnesota, 1990–2003



Source: Behavioral Risk Factor Surveillance System. Smokers in this survey are defined as adults who have smoked at least 100 cigarettes in their lifetime and now smoke every day or some days.

Poor diet, physical inactivity, and obesity are responsible for about another 30 percent of cancer deaths in the United States.^{14,25}

Figure 7 Trends in Adult Obesity, Minnesota, 1990–2003



Source: Behavioral Risk Factor Surveillance System. Obese persons have a body mass index (BMI) of 30.0 or higher. Evidence indicates that the cancer incidence would decrease if people ate healthier foods, maintained a healthy weight, and included more physical activity in their daily lives.^{26,27} Yet the trends are not moving in a healthy direction. The proportion of obese adults in Minnesota, for example, has risen from 10 percent in 1990 to 23 percent in 2003 (Figure 7).¹⁵

Effective community-wide campaigns can provide people with the support they need to change unhealthy behaviors; they can also promote supportive environments and community norms for regular physical activity and healthy eating.²⁸ Such campaigns include support and self-help groups, counseling, risk factor screening and education, community events, and access to or development of facilities for physical activity and healthy eating. When covered by the media, community-wide campaigns have an even broader reach and impact.

Overexposure to ultraviolet (UV) light, and sunlight in particular, is the main cause of skin cancer.

Sunburn in childhood is strongly associated with an increased risk of both melanoma and non-melanoma skin cancers in adulthood,²⁹ although sunburns in adulthood are also a risk factor. Reducing exposure to UV light can be achieved by increasing awareness about the use of sun protection measures, educating individuals of all ages about best practices and policies to promote sun protection, and implementing environmental changes to reduce ultraviolet light exposure.³⁰

Reduce the use of tobacco.



Indicators:

- Proportion of adults who currently smoke cigarettes (Target: 17%; Baseline: 21.1%; Source: MBRFSS 2003)
- Proportion of young adults who currently smoke cigarettes (Target: 29%; Baseline: 39.0%; Source: MATS 2003)
- Proportion of adolescents who currently smoke cigarettes as measured in grades 9–12 (Target: 23%; Baseline: 28.9%; Source: MYTS 2002)
- Proportion of American Indians who currently smoke cigarettes (Target: σ^a:44%; ♀: 50%; Baseline: σ^a: 48.4%, ♀: 55.2%; Source: MBRFSS 1996–2000)

- Advocate for an increase in the state cigarette tax and taxes on other tobacco products, and for limiting or prohibiting discounting of wholesale prices for tobacco products.
- Advocate for funding for "comprehensive tobacco prevention programs" at the funding levels recommended by the U.S. Centers for Disease Control and Prevention.
- Provide culturally appropriate tobacco-cessation interventions.
- Maintain and coordinate effective statewide telephone tobacco-cessation counseling programs.
- Challenge and engage all insurers, employers, and purchasers to include evidence-based tobacco-dependence treatment (counseling and pharmacotherapy) as part of their basic health benefits package.
- Publicly recognize health insurance plans and healthcare facilities that meet or exceed smoking cessation guidelines.
- Advocate for increased legislative funding to expand the Minnesota Department of Health's Population-At-Risk tobacco grantees' program.
- Increase funding for community-based programs that address commercial tobacco use within racial and ethnic minority communities.
- Support current efforts to develop a strong statewide tribal tobacco coalition.



Reduce exposure to secondhand smoke.

Indicators:

- Proportion of adults exposed to secondhand smoke (Target: 46%; Baseline: 65.3%; Source: MATS 2003)
- Proportion of young adults exposed to secondhand smoke (Target: 58%; Baseline: 82.5%; Source: MATS 2003)
- Proportion of adolescents in grades 9–12 exposed to secondhand smoke (Target: 50%; Baseline: 71.8%; Source: MYTS 2002)

Strategies:

- Advocate for clean indoor air policies that require all workplaces to be smoke-free.
- Increase public awareness about raising children in completely smoke-free environments.



Increase the proportion of adults and children who meet recommended physical activity levels.

Indicators:

- Proportion of adults who engage in moderate or vigorous physical activity for 30 minutes or more on at least 5 days of the week (Target: 53%; Baseline: 48.5%; Source: MBRFSS 2001)
- Proportion of children who participate in vigorous physical activity for at least 20 minutes on at least 5 days of the week (Target: 6th graders: 45%, 9th graders: 37%, 12th graders: 33%; Baseline: 6th: 41%, 9th: 43%, 12th: 30%; Source: MSS 2001)
- Proportion of children who participate in moderate physical activity for at least 30 minutes on at least 5 days of the week (Target: 6th graders: 48%, 9th graders: 56%, 12th graders: 40%; Baseline: 6th: 44%, 9th: 51%, 12th: 37%; Source: MSS 2001)
- Proportion of children who participate in moderate or vigorous physical activity for 60 minutes on at least 5 days of the week (Source: to be identified)

Strategies:

- Conduct worksite programs to promote physical activity.
- Conduct physical activity and healthy eating programs, specifically for African American, American Indian, and Latino populations.
- Conduct school-based programs that promote regular physical activity for students, staff, and the community.
- Provide quality, daily physical education for children from pre-kindergarten through grade 12.
- Increase the availability of safe and accessible recreational facilities in the community, and support the development and operation of community-based recreation centers for all people, including the elderly.
- Promote regular physical activity through counseling and education from healthcare providers and organizations.
- Conduct community-wide campaigns to promote physical activity.
- Encourage mixed-use zoning with homes situated within walking and bicycle-riding distance of attractive, walker-friendly commercial, business, and community facilities.

Improve the diet of adults and children.

Indicators:

- Proportion of adults who consume 5 or more servings of fruits and vegetables daily (Target: 25%; Baseline: 22.7%; Source: MBRFSS 2002)
- Proportion of all adults who do not consume alcohol or, if they do consume alcohol, use alcohol in moderation (less than 2 drinks per day for men, less than 1 drink per day for women) (Target: σ³: 97%, ♀: 100%; Baseline: σ³: 93.2%, ♀: 95.7%; Source: MBRFSS 2002)
- Proportion of children aged 2–18 years who consume 5 or more servings of fruits and vegetables daily (Target: 6th graders: 24%, 9th graders: 17%, 12th graders: 13%; Baseline: 6th: 22%, 9th: 15%, 12th: 12%; Source: MSS 2001)
- Proportion of children and adults who choose a diet that is low in caloric density and high in nutrient density (Source: to be identified)
- Proportion of children and adults who consume 3 or more servings of whole grain foods daily (Target: 10% increase over baseline; Source: to be identified)

OBJECTIVE 4

- Proportion of children and adults who consume less than 10% of their daily calories from added sugars (Target: 10% increase over baseline; Source: to be identified)
- Proportion of children and adults who consume 30% or less of their daily calorie intake from fat (Target: 10% increase over baseline; Source: to be identified)
- Proportion of children and adults who consume 10% or less of their daily calorie intake from saturated plus trans fat (Target: 10% increase over baseline; Source: to be identified)
- Proportion of adults who consume 1 serving or less (3 ounces or less) of red meat per day (Target: 10% increase over baseline; Source: to be identified)
- Proportion of children and adults who consume the recommended servings of calcium-rich foods daily based on recommendations for age and gender (Target: 10% increase over baseline; Source: to be identified)

- Conduct community-wide campaigns to promote healthy, low-fat eating, including promoting the daily consumption of 5 or more servings of fruits and vegetables, 3 or more servings of whole grains, and adequate calcium intake.
- Conduct school-based programs to promote healthy, low-fat eating, including promoting the daily consumption of 5 or more servings of fruits and vegetables, 3 or more servings of whole grains, and adequate calcium intake.
- Develop school policies requiring that a variety of healthy choices be provided in vending machines, school stores, and other venues within the school's control.
- Provide counseling and education by healthcare providers and organizations to promote healthy, low-fat eating, including promoting the daily consumption of 5 or more servings of fruits and vegetables, 3 or more servings of whole grains, and adequate calcium intake.
- Conduct worksite programs to promote healthy, low-fat eating, including promoting the daily consumption of 5 or more servings of fruits and vegetables, 3 or more servings of whole grains, and adequate calcium intake.

Reduce the proportion of adults and children who are overweight or obese.

OBJECTIVE 5

Indicators:

- Proportion of adults aged 18 years and older who are obese (body mass index [BMI] greater or equal to 30.0) (Target: 20%; Baseline: 22.4%; Source: MBRFSS 2002)
- Proportion of adults aged 18 years and older with BMI below 25.0 (Target: 45%; Baseline: 41.1%; Source: MBRFSS 2002)
- Proportion of children aged 2–18 years with a BMI less than the 95th percentile for age and gender (Source: to be identified)

- Partner with existing coalitions or groups working to increase physical activity, decrease obesity, and encourage a healthy diet, particularly among racial and ethnic minority communities.
- Conduct social marketing campaigns to promote healthy weight management for adults.



OBJECTIVE 6

Reduce the exposure of adults and children to ultraviolet light.

Indicators:

- Proportion of adults aged 18 years and older who report one or more sunburns in the past year (Target: 30%; Baseline: 39%; Source: MBRFSS 1999)
- Proportion of adults aged 18 and older who use indoor tanning devices (Target: 30%; Baseline: 38%; Source: Lazovich, unpublished data)
- Proportion of adolescents aged 14–17 years who use indoor tanning devices (Target: 30%; Baseline: 40%; Source: Lazovich, unpublished data)
- Proportion of children and adolescents who experience sunburns (Source: to be identified)
- Proportion of adults and children who consistently use sun protection measures (Target: increase to 75%; Source: to be identified)

- Establish partnerships to promote sun protection policies, encourage sun protection product development and availability, and support educational efforts to increase awareness and behavior change towards greater sun protection.
- Promote adoption of sun protection curricula in primary schools.
- Advocate for sun protection policies at primary schools.
- Educate the public and staff at recreational and tourism settings about sun protection.
- Advocate for sun protection policies in recreational and tourism settings.
- Promote counseling by primary care physicians to their patients and their patients' family members about the need for sun protection practices.
- Educate adolescents, their parents, and young adults about the potential harm caused by use of indoor tanning.
- Advocate for school policies that prohibit high schools from accepting promotional materials from commercial tanning businesses.
- Enforce commercial tanning facility compliance with existing state licensure regulations that support inspections, enforcement, and penalties.





Chapter 3 Early Detection

The early detection of cancer and premalignant disease is a mainstay of local, state, and national efforts to reduce morbidity and mortality from cancer. A large body of evidence supports the effectiveness of routine screening for several of Minnesota's most commonly occurring cancers.

For colorectal, breast, and cervical cancers, evidence-based consensus guidelines support a recommendation for population-based screening.³¹ For prostate, ovarian, and other cancers, consensus is lacking. Identification of persons at elevated risk due to their family's cancer history may help target those who need screening or more intense surveillance for the disease beginning at younger ages.

Colorectal cancer is the secondleading cause of cancer death in Minnesota.³

The good news is that the vast majority of colorectal cancers can be prevented through screening. Fecal occult blood testing (FOBT), sigmoidoscopy, air contrast barium enema, and/or colonoscopy can detect premalignant polyps and early-stage cancer. Routine screening with FOBT has been shown to reduce the incidence of colorectal cancer by at least 20 percent and deaths from the disease by 33 percent.^{32,33} Although the use of colorectal cancer screening by Minnesotans has increased during the last five years, one-third to one-half of those over age 50 are not routinely screened in accordance with nationally recognized guidelines (Figure 8).³⁴

Figure 8

Percent of Minnesotans Who Were Up-to-Date on Colorectal Cancer Screening, 2001–2002



Source: Minnesota Behavioral Risk Factor Surveillance System. Urban counties are in Metropolitan Statistical Areas of the 2000 Census. Up-to-date means the person had a fecal occult blood test within the previous year and/or had a sigmoidoscopy or colonoscopy within the previous five years.

Breast cancer is the most commonly diagnosed cancer among Minnesota women.³

Widespread use of mammography, along with advances in breast cancer treatment, has led to significant reductions in breast cancer mortality during the last decade.³⁵

Despite these gains, African American and American Indian women in Minnesota are considerably less likely to survive breast cancer than white women (Figure 9).² The poorer survival of these women is due, in part, to the fact that their disease is more likely to be diagnosed at a late stage^{16,36}; however, differences in tumor characteristics, use of medical services, and the care delivered may also play a role.^{37,38}

Figure 9



Female Breast Cancer by Race, Minnesota, 1996–2000

Source: Minnesota Cancer Facts and Figures, 2003.

Figure 10

Cervical Cancer Incidence by Age and Race, Minnesota, 1996–2001



Source: Minnesota Cancer Surveillance System.

Free mammography has been widely available throughout Minnesota to uninsured and underinsured women for more than a decade through the Sage Screening Program (formerly known as the Minnesota Breast and Cervical Cancer Control Program). Although free Pap smears and mammograms have been provided to almost 100,000 Minnesota women through Sage, many eligible women are not receiving regular breast cancer screening.

Virtually all deaths from cervical cancer could be eliminated through screening and early detection.

Its cause, human papillomavirus (HPV), is known, and the tools to detect very early, premalignant signs of the disease have been available and in use for half a century. Although fewer than 50 women die each vear in Minnesota from cervical cancer, women of color are diagnosed with a disproportionate number of cases (Figure 10).³⁹ National data indicate that about half of women diagnosed with invasive cervical cancer have never been screened, and that older women are the least likely to be screened.³⁶ Women aged 50 and older comprise about 40 percent of new cases of invasive cervical cancer, but 69 percent of all deaths from the disease.⁵ Currently, the best way to reduce needless deaths from cervical cancer is to combine Pap test screening with prompt and appropriate follow-up for any detected abnormalities.

Prostate cancer mortality rates are higher in Minnesota than in the United States as a whole.²

African American men have the highest prostate cancer rates in Minnesota.² While there is convincing evidence that prostate specific antigen (PSA) screening can detect prostate cancer in its earliest stages, considerable uncertainty remains in the scientific community about whether detection and treatment of early-stage disease improves health outcomes. Many older men die with prostate cancer rather than from it, and aggressive treatment is not without significant side effects.

Data from clinical trials currently underway may shed light on these issues in the next few years. In the meantime, most health experts agree that men of average risk aged 50 and older should discuss the potential risks and benefits of PSA screening with a healthcare provider.

Knowledge gained from family history and genetic testing can also play an important role in early detection.

A detailed family history can help to identify an inherited predisposition for cancer and can guide people to an appropriate referral for genetic counseling and testing. Individuals who have an elevated risk for cancer based on family history or a genetic test will benefit from tailored advice about their options for prevention and surveillance.

Increase age-appropriate screening and follow-up for breast, colorectal, and cervical cancer.

OBJECTIVE 7

Indicators:

- Proportion of adults aged 50 years and older who have had a fecal occult blood test within the previous 12 months or colonoscopy or sigmoidoscopy within the previous 5 years (Target: 74%; Baseline: 62%; Source: MBRFSS 2002)
- Proportion of women aged 21 years and older who have had a Pap smear within the previous 3 years (Target: 98%; Baseline: 85%; Source: MBRFSS 2002)
- Proportion of women aged 40 years and older who have had a mammogram within the previous 2 years (Target: 90%; Baseline: 81%; Source: MBRFSS 2002)
- Proportion of women aged 50 years and older who have had a mammogram within the previous 2 years (Target: 92%; Baseline 84%; Source: MBRFSS 2002)

- Adopt a common set of breast, colorectal, and cervical cancer screening and follow-up guidelines to be promoted by all healthcare plans and health delivery systems.
- Disseminate screening and follow-up guidelines to all primary care providers.
- Determine the nature and scope of problems related to timeliness and completeness of follow-up for abnormal screening tests.

OBJECTIVE 8

Reduce disparities in screening for breast, colorectal, and cervical cancer.

Indicators:

- Proportion of breast cancers diagnosed at an early stage (*in situ* or localized) among African American women (Target: 72%; Baseline 55%; Source: MCSS 1998–2000)
- Proportion of breast cancers diagnosed at an early stage (*in situ* or localized) among American Indian women (Target: 72%; Baseline 67%; Source: MCSS 1998–2000)
- Proportion of breast cancers diagnosed at an early stage (*in situ* or localized) among Asian/Pacific Islander women (Target: 72%; Baseline 67%; Source: MCSS 1998–2000)

- Develop sources of free or low-cost colorectal cancer screening for people without access to medical coverage.
- Advocate for ongoing or increased funding for programs that support free and low-cost cervical cancer screening for younger women (under age 40).
- Advocate for increased funding for programs that support free and low-cost mammography.
- Create targeted awareness campaigns, educational programs, and interventions to improve cancer screening rates.
- Develop innovative interventions to reach women who are not being screened for cervical cancer.
- Create strategic partnerships to reach women who are not being screened for breast cancer.
- Develop targeted social marketing campaigns to reach "hard to reach women" for breast cancer screening.



Increase the number of healthcare providers who deliver consistent and appropriate messages to help men make informed decisions about prostate cancer screening and follow-up.

Indicators:

No indicators identified.

Strategies:

- Identify and encourage the use of quality patient and provider-directed training tools to facilitate shared decision making about prostate cancer screening.
- Educate providers and the public on the risks and benefits of prostate cancer screening.
- Promote participation in prostate cancer screening and prevention trials.
- Educate medical and nursing school students about the debate surrounding prostate cancer screening.

Increase the number of moderate- and high-risk individuals who receive appropriate cancer screening and referral for cancer genetic services.

Indicators:

No indicators identified.

- Work with the Institute for Clinical Systems Improvement (ICSI) to develop recommendations for risk-appropriate screening and referral for cancer genetic services.
- Educate healthcare providers about the implications of a cancer diagnosis for cancer risk among family members.
- Advocate for health insurance coverage of cancer risk assessment.
- Develop and promote a family history cancer risk assessment tool for use in primary care settings.
- Create awareness campaigns regarding the importance of family history as a risk factor for cancer.





Chapter 4

In 2001, more than 23,600 Minnesotans were diagnosed with a potentially serious cancer.³ Each of these individuals and their families grappled with new and sometimes overwhelming information and choices about how the illness would be treated. Some were fortunate and found the information, care, and emotional and financial support they needed. Many, however, did not find all the resources they needed due to limited access to quality care, insufficient information to make informed decisions, or other barriers to optimal care. Assuring that all Minnesotans with cancer receive the most appropriate and effective therapy is an essential component of comprehensive cancer control.

Cancer treatment has improved greatly during the past three decades.

The proportion of cancer patients alive five years after diagnosis, adjusted for expected mortality from other causes, increased from 50 percent among patients diagnosed in 1974–1976 to 64 percent among patients diagnosed in 1995–2000.¹² For several common cancers, five-year survival is close to 95 percent when the disease is diagnosed early.¹²

Innovative treatment modalities currently under development may eventually turn cancer from a life-threatening illness into a chronic disease. Yet, not all patients benefit from these advances. As the National Cancer Policy Board (NCPB), which undertook a comprehensive review of the quality of cancer care in the United States, concluded: "Even as new scientific breakthroughs are announced ... many cancer patients may be getting the wrong care, too little care, or too much care The consequences of these lapses in care are, in some cases, reduced survival and, in others, compromised quality of life."⁴⁰

The ability to develop data-driven objectives for improving the quality of cancer care in Minnesota is limited.

What is the quality of cancer care in Minnesota? How does cancer survival in our state compare to patients living elsewhere? What is the quality of life for Minnesota cancer survivors? Population-based information to answer these questions is hard to find. The Minnesota Cancer Surveillance System (MCSS) was initially implemented to track cancer rates but not to monitor treatment or survival, which would require considerably more resources. Efforts are being made to collect, consolidate, enhance, and analyze data on MCSS so that treatment and survival outcomes can be measured in the near future. These issues are discussed in more detail in chapter 7, "Data, Surveillance, and Research."

The limited data available indicate that women living in rural Minnesota are less likely to receive the recommended radiation therapy following breast-conserving surgery for breast cancer.⁴¹ We also know from national data that poor people and members of racial and ethnic minorities are less likely to survive many cancers, even if diagnosed at the same stage as their white counterparts, and that these same groups are often less likely to receive recommended treatment.¹⁶ Although similar data for Minnesota are not available, community forums held by Cancer Plan Minnesota suggested that lack of interpreters, cultural sensitivity, and healthcare coverage are problems for members of racial and ethnic minorities in the state. A wide range of voices throughout the state proclaimed the need for better communication between patients and physicians, more patient navigators (trained individuals who help guide cancer patients through treatment), and better coordination of care.

We know what is needed to achieve excellence in cancer care.

According to the NCPB,⁴⁰ excellence in cancer care would be achieved if individuals had:

- access to comprehensive and coordinated services;
- · confidence in the experience and training of their providers;
- a belief that providers respected them, listened to them, and advocated on their behalf;
- an ability to ask questions and voice opinions comfortably, to be full participants in all decisions regarding care;
- a clear understanding of their diagnosis and access to information to aid this understanding;
- awareness of all treatment options and of the risks and benefits associated with each;
- confidence that recommended treatments are appropriate and offer the best chance of a good outcome consistent with personal preferences;
- a prospective plan for treatment and palliation;
- a healthcare professional responsible (and accountable) for organizing this plan in partnership with each individual; and
- assurances that agreed-upon national standards of quality care are met at their site of care.

The NCPB concluded that for many Americans with cancer, there is a wide gulf between this ideal and the reality of their experience with cancer care. The following objectives and strategies, if implemented, will move Minnesota closer to this ideal.



Improve the quality of cancer care in Minnesota, including the delivery of appropriate and effective treatment, symptom management, and follow-up care.

Indicators:

- The 5-year relative survival rate for Minnesotans diagnosed with cancer
 (Potential source: MCSS)
- The proportion of pediatric and adult cancer patients who are seen by an oncologist (Potential sources: MCSS, administrative data)
- The proportion of cancer patients who receive annual follow-up care by an oncologist (Potential source: administrative data)
- The proportion of cancer patients who complete recommended treatment (Potential sources: MCSS, administrative data)

- Identify, build consensus on, and disseminate a minimal set of "best practices" guidelines for cancer treatment, symptom management, and follow-up care.
- Enhance communication between cancer specialists and primary care providers (e.g., via multidisciplinary care coordinators, telemedicine, patient navigators).
- Improve access to quality care for patients with rare cancers.
- Ensure that all children diagnosed with cancer are seen by a pediatric oncologist.
- Educate patients and healthcare professionals about complementary and alternative medicine.
- Educate medical and nursing students about medical genetics as it relates to cancer treatment and follow-up.
- Obtain a family history of cancer from every cancer patient to guide treatment and follow-up and to advise family members on their own cancer risk.

OBJECTIVE 12

Improve the quantity of information and support available to cancer patients and providers to foster informed decision making regarding cancer treatment.

Indicators:

- The proportion of cancer patients in Minnesota who have access to patient navigators (Potential sources: MCSS, maps of cancer patient navigator locations)
- The proportion of cancer patients in Minnesota who receive information about cancer clinical trials (Potential source: special surveys)
- The proportion of cancer patients in Minnesota who are satisfied with the level of information they received to make treatment decisions (Potential source: special surveys)

Strategies:

- Develop and promote a Web site with links to comprehensive resources in Minnesota for cancer patients, healthcare providers, and the public.
- Broaden the availability of navigation services for cancer patients and their families, especially for those who may experience cultural or linguistic barriers to care.
- Enhance the skills of cancer care providers to present tailored treatment options that support informed decision making.
- Provide all cancer patients with information about clinical trials.

OBJECTIVE 13

Reduce age, cultural, and geographic barriers to appropriate and effective cancer care.

Indicators:

- The 5-year relative survival rate among elderly, rural, and racial and ethnic minority cancer patients (Potential source: MCSS)
- The proportion of elderly, rural, and minority cancer patients who receive recommended treatment (Potential source: MCSS, Medicare, Medicaid, other administrative data)

Strategies:

- Educate healthcare providers about the special needs of the elderly undergoing cancer treatment.
- Provide culturally and linguistically appropriate healthcare services in diverse healthcare settings, following guidelines recommended by the Office of Minority Health.⁴²
- Increase the availability of free or low-cost transportation services and lodging for cancer patients, especially in rural settings.
- Promote family-centered cancer treatment environments.
- Develop targeted marketing campaigns to improve the use of cancer treatment services in communities experiencing cancer-related health disparities.

Reduce financial barriers to appropriate and effective cancer care.

Indicators:

• The proportion of Minnesotans who are uninsured or underinsured (Source: MNHA)

Strategies:

- Support the Institute of Medicine's call to achieve universal health care by 2010.43
- Enroll eligible uninsured and underinsured individuals in available public healthcare plans (e.g., Medicaid, Veterans Administration, and supplemental Medicare programs).
- Provide cancer treatment services through MinnesotaCare to uninsured or underinsured patients to ensure that they receive equitable treatment within the cancer care system.
- Remedy gaps in coverage that are barriers to appropriate and effective cancer care for those who already have insurance.
- Conduct targeted awareness campaigns in racial and ethnic minority communities regarding the availability of programs and coverage for cancer-related services.

OBJECTIVE 14

OBJECTIVE 15

Increase participation of racial and ethnic minority patients in clinical trials.

Indicators:

• The number of racial and ethnic minority patients in Minnesota enrolled in federally funded clinical trials (Potential source: Community Clinical Oncology Program data)

- Conduct outreach programs in racial and ethnic minority communities that communicate the results as well as the benefits of clinical trials to individuals and communities.
- Expand the clinical trial infrastructure into racial and ethnic minority communities, including the employment of culturally diverse staff.
- Use community lay health educators to increase awareness of clinical trials in community settings.
- Solicit participation from racial ethnic minority communities on Institutional Review Boards (IRBs).





Chapter 5 Quality of Life

Improvements in the early detection of cancer and the effectiveness of cancer treatment have resulted in more people living longer after being diagnosed with the disease. In January 2000, an estimated 156,620 Minnesotans, or 3.2 percent of the population, were living with a history of cancer (Figure 11).⁴

A cancer diagnosis remains a life-changing event for individuals and for their family members, friends, and caregivers. People who have been diagnosed with cancer — and others in their lives — face a host of short- and long-term issues affecting their quality of life, including the physical effects of cancer treatment, spiritual and emotional needs, pain control, and, for some, decisions about end-of-life care.

Treatment, survivorship, and palliative care are closely intertwined.

At what point in the cancer continuum does the term survivor apply? According to the National Coalition for Cancer Survivorship, cancer survivorship begins at the time of diagnosis and continues through the remaining years of life.⁴⁴ And while the term palliative care is often used in the context of support for those dying from cancer, the World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."⁴⁵

This is consistent with the National Cancer Policy Board's recommendation that palliative care should begin at the time of diagnosis.⁴⁰ The term hospice should not be used synonymously with palliative care. A component of palliative care at the end of life, hospice care is underused and commonly misunderstood.

Identifying measurable outcomes in the areas of cancer survivorship and palliative care is hampered by a lack of agreed-upon standards and indicators.

The ongoing work of groups such as the National Quality Forum, whose mission is to develop and implement a national strategy for healthcare quality measurement and reporting, will help bolster state-based efforts to measure progress in these areas.

Figure 11

Ten Cancers with the Largest Number of Survivors, Minnesota, 2000



Source: Adapted from *Estimated Minnesota Cancer* Prevalence, January 1, 2000.

OBJECTIVE 16

Maximize the use of services that support the short- and long-term needs (e.g., symptom control and emotional, economic, and spiritual needs) and that improve the quality of life of cancer survivors and their families.

Indicators:

- Duration of enrollment in hospice (Potential source: hospice program enrollment data)
- Proportion of cancer patients who receive palliative care consultations Potential source: administrative data)

Strategies:

- Develop, maintain, and promote an inventory of resources that support the short- and long-term needs (e.g., symptom control and emotional, economic, and spiritual needs) of cancer survivors and their families.
- Assess the extent to which various support services are needed and used by cancer survivors and their families (by race/ethnicity, geography, socioeconomic status, etc.).
- Determine and address gaps and barriers to the use of support services by cancer survivors.
- Educate healthcare providers, patients, and employers about the short and long-term issues that affect the quality of life of cancer survivors and their families following initial treatment.

OBJECTIVE 17

Optimize continuity of care for cancer survivors during and beyond the initial course of treatment.

Indicators:

• Proportion of primary care physicians who receive information about their patients' cancer treatment and follow-up recommendations from their patients' oncologists. (Potential source: special surveys)

Strategies:

- Develop and promote methods to facilitate the exchange of information among all healthcare providers involved in the care of cancer survivors.
- Educate cancer survivors and their families about the importance of seeking information about the short- and long-term plans for their treatment and follow-up.
- Build on existing community collaborations that address coordinated community cancer care.

Ensure that all cancer patients, their families, and their healthcare providers can access information about advance care planning and palliative care services.

Indicators:

• The proportion of cancer patients who know how and where to get information about advance care planning and palliative care (Potential source: special surveys)

- Develop a database of hospice and palliative care providers that is readily accessible to patients, families, and healthcare providers.
- Educate patient navigators about advance care planning, symptom management, and programs available for palliative and hospice care.
- Educate community health workers about how to access culturally relevant information on advance care planning, palliative care, and hospice services.
- Distribute information about advance care planning and palliative care along with educational materials to all cancer patients and their families.



OBJECTIVE 19

Ensure that adults and children diagnosed with cancer can access appropriate palliative care and hospice care though all phases of cancer treatment.

Indicators:

- The distribution of hospice services in Minnesota in relation to cancer cases (Potential sources: MCSS, hospice organizations)
- The distribution of certified palliative care programs and providers in Minnesota in relation to cancer cases (Potential sources: MCSS, certification data)

- Integrate the palliative care guidelines of the National Comprehensive Cancer Network (NCCN) into routine, state-of-the-art cancer care.
- Support the recommendations of the Minnesota Commission on End of Life Care.
- Increase the number of physicians, advanced practice nurses, registered nurses, and home health aides credentialed in hospice and palliative care.
- Increase content on palliative care in medical and nursing education and training programs and in continuing education for healthcare professionals.
- Increase the number of palliative care providers who belong to racial/ethnic communities.
- Create centers of excellence in symptom management at cancer centers.

Eliminate financial barriers to the delivery of palliative care for children and adults with cancer.

OBJECTIVE 20

Indicators:

- The number of health insurers in Minnesota that offer a palliative care benefit (Potential source: special surveys)
- The number of Minnesotans who have palliative care coverage (Potential source: special surveys)

- Assess the status of existing policies around coverage and reimbursement for palliative care.
- Advocate for changes in healthcare financing to include palliative care in all benefit plans, including plans for self-insured employers.
- Advocate for changes in eligibility for benefit programs that limit financial access to palliative care.
- Integrate reimbursement for palliative care into standard cancer treatment programs.





Chapter 6 Disparities

Disparities or inequalities in cancer incidence, mortality, and survival are most readily described in terms of race and ethnicity, socioeconomic status, gender, age, and geography. According to statewide surveillance data, African Americans and American Indians in Minnesota suffer a disproportionate share of the burden for many cancers (Figure 12).³⁹ A recent report by the Institute of Medicine suggests that members of racial and ethnic minority groups are less likely than whites to receive needed medical services.46 This may partially explain some cancer-related health disparities. The extent to which other factors, such as income, education, health insurance coverage, access to services, language, and culture, contribute to observed differences in cancer incidence and mortality in Minnesota is not known.

Many of the issues related to health disparities involve prevention, early detection, treatment, quality of life, and data surveillance. As a result, most of the objectives and strategies regarding disparities have been integrated into other chapters of this plan, as noted below.

Improve the cultural competency of healthcare providers.

Indicators:

- Proportion of healthcare providers who have undergone cultural competency training (Potential source: special surveys)
- Proportion of clinics with adequate interpreter services (Potential source: special surveys)

Strategies:

- Provide cross-cultural education to students and clinicians in healthcare professions.
- Increase the availability of interpreters in healthcare settings for all major languages.

Figure 12

Cancer Mortality by Race for the Most Common Cancers, Minnesota, 1996–2000



Source: Minnesota Cancer Surveillance System.



OBJECTIVE 22

Increase the number of racial and ethnic minority workers in the healthcare practitioners and technical occupations workforce.

Indicators:

• Proportion of minority workers in the healthcare practitioners and technical occupations workforce in Minnesota (Target: 10%; Baseline 6.2%; Source: Minnesota Workforce Center, Department of Employment and Economic Development)

- Work with schools to educate high school students and families from racial and ethnic minority communities about opportunities to enter the healthcare workforce.
- Assist immigrants who are qualified medical professionals in their countries of origin to become certified to practice in the United States.



The objectives related to cancer health disparities listed below have been incorporated into other chapters in this plan.

NOTE

Reduce disparities in screening for breast, colorectal, and cervical cancer. (See Objective 8.)

Reduce age, cultural, and geographic barriers to appropriate and effective cancer care. (See Objective 13.)

Increase participation of racial and ethnic minority patients in clinical trials. (See Objective 15.)

Ensure that all cancer patients, their families, and their healthcare providers can access information about advance care planning and palliative care services. (See Objective 18.)

Expand the application, scope, and quality of existing data sources and surveillance activities to better assess cancer control efforts in Minnesota. (See Objective 23.)



Chapter 7 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.

- 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.

OBJECTIVE 24

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

- 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.

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Data Review Committee CHAIR

Alan Bender, D.V.M., Ph.D. Minnesota Department of Health

MEMBERS

Thomas Arneson, M.D., M.P.H. *Stratis Health*

David Benson American Cancer Society, Midwest Division, Inc.

Erik Bergstralh, M.S. Mayo Clinic

Hung Ching Chan, M.P.H. Medica

Steven Foldes, Ph.D. Blue Cross and Blue Shield of Minnesota

Susan Gentilli HealthPartners Research Foundation

Greg Gifford, Ph.D. *Minnesota Department of Health*

Margaret Hargreaves Hennepin County

Carol Janney, M.S. Mayo Clinic

Ann Kinney, Ph.D. Minnesota Department of Health

DeAnn Lazovich, Ph.D. University of Minnesota Cancer Center

John Oswald, Ph.D. Minnesota Department of Health Gregory S. Rachu, M.P.H. Great Lakes Inter-Tribal Council

Cheri Rolnick, Ph.D., M.P.H. HealthPartners Research Foundation

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Abbreviations for Data Sources

MATS

The Minnesota Adult Tobacco Survey obtains information on tobacco use and exposure to secondhand smoke among Minnesotans aged 18 years and older. Data is collected anonymously through telephone interviews of randomly selected adults. MATS was conducted in 1999 and 2003, with approximately 8,800 participants in 2003. See *www.health.state.mn.us/divs/hpcd/tpc*.

MBRFSS

The Minnesota Behavioral Risk Factor Surveillance System has obtained information on a broad range of health-related behaviors through telephone interviews of randomly selected adults in Minnesota each year since 1984 in collaboration with the Centers for Disease Control and Prevention. Surveys are conducted anonymously. Approximately 4,500 Minnesotans aged 18 years and older participated in 2002. See *www.cdc.gov/brfss*.

MCHS

The Minnesota Center for Health Statistics is part of the Minnesota Department of Health. It is responsible for administering MATS, MBRFSS, and MYTS as well as the registration of vital statistics. See *www.health.state.mn.us/divs/chs/top_2.htm*.

MCSS

The Minnesota Cancer Surveillance System has collected information on all cancers diagnosed in Minnesota since 1988. It is administered by the Minnesota Department of Health. Reporting is mandated by law and data privacy is stringently protected. See *www.health.state.mn.us/divs/hpcd/cdee/mcss*.

MNHA

The Minnesota Health Access Survey is a random digital dial telephone survey that has been conducted in Minnesota periodically since 1990. The purpose of the survey is to measure access to health insurance coverage and the potential reasons for lack of coverage among Minnesotans. The survey was conducted in 1990, 1995, 1999, 2001, and 2004 and has been funded through a variety of federal, state, local, and private sources.

MSS

The Minnesota Student Survey collects information on a broad range of health-related beliefs and behaviors among adolescents in Minnesota through surveys of randomly selected public school students in grades 6, 9, and 12. Surveys are completed anonymously. MSS has been conducted every three years since 1989, with approximately 134,000 participants in 2001. See *www.mnschoolhealth.com/resources.html?ac=data*.

MYTS

The Minnesota Youth Tobacco Survey obtains information on tobacco use among randomly selected Minnesota public school students in grades 6–12. Surveys are completed anonymously. MYTS was conducted in 2000 and 2002; the next MYTS will be in 2005. Approximately 12,000 students participated in 2002. See *www.health.state.mn.us/divs/hpcd/tpc/TobaccoReports.html*.

NHANES

The National Health and Nutrition Examination Survey is administered by the National Center for Health Statistics (NCHS) to assess the health and health-related behaviors of a representative sample of randomly selected U.S. residents. A home interview is followed by a physical examination in a mobile examination center. Conducted periodically starting in 1960–1962, the NHANES became continuous in 1999, with data released every two years. Approximately 17,000 examinations were conducted during 1999–2002. See *www.cdc.gov/nchs/nhanes.htm*.

SEER

The Surveillance, Epidemiology and End Results Program is administered by the National Cancer Institute and has collected information on all cancers diagnosed in selected geographic areas of the United States since 1973. Currently about 14 percent of the U.S. population resides in SEER program areas. MCSS is not part of SEER. See *seer.cancer.gov*.





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For additional copies of this document, contact

American Cancer Society Midwest Division, Inc. 2520 Pilot Knob Road, Suite 150 Mendota Heights, MN 55120-1158 tel 651 255.8131

For more information, contact

Minnesota Department of Health Health Promotion and Chronic Disease Division PO Box 64882 St. Paul, MN 55164-0882 tel 651 215.5800