# WISCONSIN'S COMPREHENSIVE CANCER CONTROL PLAN

2010 - 2015

Prevention • Screening • Treatment
Survivorship • Palliative Care • Data Collection & Reporting

# **Acknowledgements**

## **A Special Thank You**

To all the cancer survivors, family members and caregivers who shared your experiences with us. This Plan is dedicated to your strong spirits and determination.

The Wisconsin Comprehensive Cancer Control Plan acknowledges the organizations and individuals on the following page for their expertise, time, and energy. Without them this plan could not have been developed. The consensus process was used to develop this Plan. Each individual or organization may not agree with every point within this document, but they all support comprehensive cancer control for Wisconsin. We look forward to each partner's continued involvement and support. Together we will reduce the burden of cancer in Wisconsin.

# Organizations Involved in the Wisconsin Comprehensive Cancer Control Plan 2010-2015

ABCD: After Breast Cancer Diagnosis

American Cancer Society

Amgen

Angel on My Shoulder

Ann's Hope Foundation

Aspirus Regional Cancer Center

Aurora Health System

Aurora BayCare Medical Center

Aurora Sinai Medical Center

Aurora St. Luke's Medical Center

Bellin Memorial Hospital

Bluemound Business Center

Breast Cancer Recovery Foundation

Breast Surgery Experts of NE Wisconsin, LLC

City of Milwaukee Health Department

Community Care, Inc.

Community Memorial Hospital

Dean Health Systems

Froedtert Hospital

Gilda's Club

Madison

Southeastern Wisconsin

Great Lakes Inter-Tribal Council

Gundersen Lutheran

HOPE of Wisconsin

HospiceCare, Inc.

Lac Courte Oreilles Tribe

La Crosse County Health Department

Leukemia and Lymphoma Society

Madison and Dane County Public Health

Marathon County Health Department

Marshfield Clinic

Medical College of Wisconsin

Memorial Hospital - Prairie du Chien

Memorial Medical Center

MetaStar, Inc.

Mid-State Technical College

Ministry Health Care - St Joseph's Hospital

Monroe Clinic

NCI's Cancer Information Services-North Central Region

Oncology Alliance S.C.

Pfizer

Planned Parenthood of Wisconsin

Prairie du Chien Memorial Hospital

ProHealth Care System

Quintessence Biosciences, Inc.

Regional Hospice Service

Richland Hospital

Riverview Hospital Association

Scott Consulting

Southeastern Oneida Tribal Services

St. Vincent Hospital

Stillwaters Cancer Support Services

Susan G. Komen for the Cure

Central Wisconsin

Madison

Milwaukee

ThedaCare

Unity Hospice

University of Wisconsin - Cancer Center Riverview

University of Wisconsin - La Crosse

University of Wisconsin - Madison

American Indian Studies and Family Studies

Applied Population Laboratory

Carbone Cancer Center

Center for Patient Partnerships

Center for Tobacco Research & Intervention

Collaborative Center for Health Equity

Department of Population Health Sciences

Hospital and Clinics

Population Health Institute

School of Business

School of Medicine and Public Health

School of Social Work

Survey Center

Waupaca Co. Dept. of Health and Human Services

WEA Trust

Wheaton Franciscan Health Care

Wisconsin Breast Cancer Coalition

Wisconsin Cancer Council

Wisconsin Collaborative for Healthcare Quality

Wisconsin Department of Health Services:

Bureau of Community Health Promotion

Nutrition, Physical Activity & Obesity Prevention Program

Regional Offices

Tobacco Prevention & Control Program

Wisconsin Cancer Reporting System

Wisconsin Well Women Program

Wisconsin Hospital Association

Wisconsin Medical Society

Wisconsin Ovarian Cancer Alliance

Wisconsin Primary Health Care Association Wisconsin Women's Health Foundation

WPS Health Insurance

In addition to these listed organizations, many cancer survivors from Wisconsin played an important role throughout the development of the WI CCC Plan 2010-2015.



# How Can You Use the Wisconsin Comprehensive Cancer Control Plan 2010-2015?

The Wisconsin Comprehensive Cancer Control Plan 2010-2015 (WI CCC Plan) was developed in collaboration with partners across Wisconsin. Strategies and action steps across the cancer continuum are presented throughout the WI CCC Plan for organizations to implement over the next five years to reduce the burden of cancer in the state.

Below are a few examples of strategies and action steps from the Plan that could be implemented by you and/or your organization. By no way is this list exhaustive of all the possible ways you or your organization might work to reduce the burden of cancer in Wisconsin over the next five years. Refer to the complete WI CCC Plan 2010-2015 for all the proposed strategies and action steps. The WI CCC Plan 2010-2015 can be accessed at www.wicancer.org.

## If you are a COMMUNITY BASED ORGANIZATION

- Decrease youth tobacco use in your community through programs and policy.
- Create a local level action plan to eliminate barriers to cancer screenings.
- Provide community based educational forums to address specific and unique needs of cancer survivors.
- Work with health systems to improve health literacy resources for patients.
- Inform cancer patients that quality symptom management is an expected part of their cancer care.

# If you are a STATE OR LOCAL PUBLIC HEALTH AGENCY

- Decrease youth tobacco use in your community through programs and policy.
- Promote physical activity and healthy balanced diets to those living in your community.
- Promote programs that cover recommended screenings for the underinsured or uninsured.
- Promote the use of existing cancer-related data and relevant reports.
- Collect data to measure emerging needs identified within the chapters of WI CCC Plan.

#### If you are a HEALTH CARE SYSTEM

- Implement office based reminders that identify patients due for cancer prevention and screening services.
- Seek and apply for accreditation by the American College of Surgeons.
- Increase the availability of culturally appropriate patient navigation systems within your health system.
- Practice shared decision making between providers, patients and family at your health system.

- Put survivorship best practice models into practice system wide.
- Promote advanced directives conversations with providers, patients and families.
- Ensure all cancer cases are reported as mandated to the Wisconsin Cancer Reporting System.

## If you are a HEALTH CARE PROVIDER

- Ask all your patients if they smoke and provide tobacco cessation interventions to patients who do smoke.
- Screen patients for obesity and work with those that are receiving treatment.
- Encourage patients to get their recommended cancer screenings.
- Follow nationally validated practice guidelines when treating a cancer patient.
- Provide cancer patients with a written synopsis of their coordinated care plan.
- Pursue continued education to increase understanding of survivor needs and available best practices.
- Talk with your patients about the benefits of palliative care.

## If you are an ADVOCACY ORGANIZATION

- Advocate for legislation to increase funding for survivorship services, research and surveillance.
- Advocate for the completion of advance care documents for all cancer patients.
- Advocate for full funding of the WI Cancer Reporting System.

## If you are a LEGISLATOR

- Support full funding of the WI Tobacco Prevention & Control Program.
- Support the regulation of tanning beds.
- Support legislation that provides full insurance coverage and funding for recommended cancer screenings.
- Support legislation to improve funding for survivorship services, research and surveillance.
- Support full funding of the WI Cancer Reporting System.

## If you are a PROFESSIONAL ORGANIZATION

- Inform professional members of the importance and benefits of providing cancer clinical trials.
- Educate professional members on survivor needs and available best practices.
- Support policy changes and increase funding for survivorship services.
- Train professional members on standard cancer symptom management.
- Partner with other professional organizations to provide cancer risk assessments and counseling.

## If you are an INSURANCE COMPANY OR PAYER

- Provide full coverage for tobacco addiction treatments.
- Reimburse for nutrition and physical activity counseling and interventions.
- Provide full coverage for HPV vaccination services.
- Provide incentives to members who get recommended cancer screenings.
- Provide full coverage for recommended cancer screenings.
- Reimburse providers for their time to discuss the importance of advance directives with patients.
- Provide full coverage for cancer risk assessments and genetic testing.

## If you are a BUSINESS AND/OR EMPLOYER

- Provide a smoke-free work environment and access to tobacco addiction treatment for employees.
- Encourage employees to be physically active and eat a healthy balanced diet.
- Provide sun-protective gear or products to those working outside.
- Provide full coverage for recommended cancer screenings and time off for employees to get screened.
- Implement a cancer screening event at the workplace.
- Provide information on return to work transition issues to survivors and their co-workers.

## If you are an ACADEMIC OR RESEARCH INSTITUTION

- Assess possible environmental issues as they relate to cancer.
- Increase awareness of the connection between alcohol consumption and cancer risk.
- Train professionals on how to address cancer survivorship issues.
- Identify indicators and useful sources of data for monitoring quality symptom management.
- Collect data to measure emerging needs identified within the chapters of WI CCC Plan.
- Create a database to capture data on Wisconsin survivors.

## If you are an EDUCATOR OR SCHOOL

- Promote healthy lifestyles behaviors to students and staff.
- Provide information on return to school transition issues to survivors and those in their school environment.

## If you are a SURVIVOR

- Share your experience to help educate the public about the needs of survivors and co-survivors.
- Mentor survivors and co-survivors to be active participants in their medical decision making teams.
- Encourage employers or schools to provide information on transition issues to survivors and others.
- Consider joining an advocacy group or organization working to improve survivors' experiences.

## If you are a WISCONSIN RESIDENT

- Incorporate healthy lifestyles for you and your family.
- Get and follow recommended cancer screenings.
- · Complete an advance directive.

#### **Online Information & Resources**

The following Appendices can be viewed and downloaded at www.wicancer.org:

How You Can Use the WI CCC Plan 2010-2015.

Appendix A: Cancer Screening Guidelines

Appendix B: Wisconsin Demographics

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Appendix A: Cancer Screening Guidelines

Appendix B: Wisconsin Demographics

## Introduction

## Why did Wisconsin develop a comprehensive cancer control plan 2010-2015?

Cancer is the second leading cause of death in Wisconsin with an average of 10,841 cancer deaths each year. In 2006, almost 27,000 new cases of cancer were diagnosed. Even though residents of Wisconsin are still developing and dying from cancer, it is not the death sentence it once was. More than half of those who have cancer will survive and each year the number of cancer survivors grows.

Comprehensive cancer control is defined by the Centers of Disease Control and Prevention (CDC) as "an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation." CDC's National Comprehensive Cancer Control Program (NCCCP) provides funding and technical assistance to states for developing and implementing comprehensive cancer control (CCC).

State cancer plans are the stepping stones for advancing state CCC programs. Each state or tribal health agency develops an individual cancer plan to address its unique cancer burden. In September 2002, Wisconsin's Department of Health Services was awarded a comprehensive cancer control planning grant from the Centers for Disease Control and Prevention. With this grant, diverse partners

from all over the state came

together in 2003 -2004 to develop the Wisconsin

Comprehensive

2005-2010.

Cancer Control Plan (WI CCC Plan)

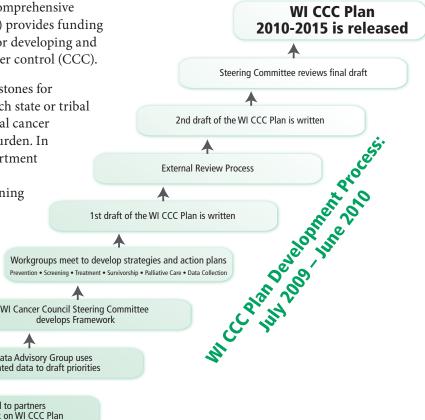
Cancer Data Advisory Group uses cancer related data to draft priorities

Survey administered to partners to gather their feedback on WI CCC Plan

As the successful implementation of the WI CCC Plan 2005-2010 came to a close, a larger network of partners convened to develop the WI CCC Plan 2010-2015, addressing new and existing concerns of cancer control in Wisconsin.

## **The Development Process**

The WI CCC Plan 2010-2015 was developed by almost 200 partners across the state which included advocates, nurses, physicians, public health professionals, researchers, social workers, survivors and more. These partners represented approximately 90 different organizations throughout Wisconsin that are dedicated to reducing the burden of cancer in the state. This process occurred over the course of one year from July 2009 - June 2010. It is illustrated below.



## WI CCC Plan 2010-2015 Components

**Vision:** A healthier Wisconsin by reducing the impact of cancer.

**Mission:** To engage diverse public, private and community partners to develop, implement and promote a statewide comprehensive approach to cancer control.

**Goals** define what Wisconsin hopes to achieve over five years in a specific area of cancer control. The WI CCC Plan 2010-2015 goals are:

- Reduce the risk of developing cancer.
- Increase early detection through appropriate screening for cancer.
- Reduce death and disability from cancer.
- Improve the quality of life for cancer survivors.
- Reduce suffering from cancer.
- Improve the quality of cancer-related data.

**Priorities** represent changes needed in order to reduce the burden of cancer in Wisconsin. They are listed by chapter below.

## **Chapter 1: Prevention**

- I. Decrease tobacco use and exposure to tobacco smoke
- II. Decrease the rate of obesity
- III. Decrease high risk alcohol consumption
- IV. Increase protective behaviors from sun/UV exposure
- V. Increase HPV vaccine utilization

#### **Chapter 2: Screening**

- I. Increase public awareness of recommended cancer screenings
- II. Implement health system based strategies to increase cancer screening rates
- III. Increase access to cancer screenings

### **Chapter 3: Treatment**

- I. Increase access to quality cancer care
- II. Increase participation in cancer clinical trials
- III. Improve patient satisfaction with their cancer care

### **Chapter 4: Survivorship**

- I. Raise awareness of survivors' needs
- II. Educate and empower survivors
- III. Increase access to quality care and services
- IV. Increase survivorship related data through surveillance and research

## **Chapter 5: Palliative Care**

- I. Improve advance care planning
- II. Increase access to quality symptom management
- III. Increase access to quality end of life care

## Chapter 6: Data Collection and Reporting

- I. Improve the WI Cancer Reporting System
- II. Improve WI specific cancer related data sources
- III. Monitor emerging cancer data issues

Besides a goal and priorities, each chapter includes a parameter, strategies, action steps and targets for change. These chapter components are defined below.

Chapter parameters were developed to give construct to the beginning and ending points of the Plan's chapter. They are only used for the writing of the Plan and do not suggest stages across the continuum of cancer care begin and complete at discrete points.

A **Strategy** is an evidence-based approach to address the priorities of the Plan. **Action steps** are the activities that lead the implementation of each strategy. To allow for flexibility in the implementation of the Plan by many different stakeholders, it was necessary to keep strategies and action steps broad. Although action steps were generated to provide direction to those who implement the Plan, they will also allow organizations to tailor specific implementation projects to match their own goals and mission.

Targets for Change are the changes we are striving to achieve with the implementation of Plan over the next 5 years. They are purposefully written at a long term outcome level. When a strategy is implemented from the Plan, short and intermediate outcomes that lead to the Targets for Change will need to be developed as a part of the implementation project's evaluation.

## **Cross Cutting Issues**

The Plan also has cross cutting issues that encompass the continuum of cancer care. These cross cutting issues do not have a separate goal but instead are threaded throughout the chapter to ensure that priorities and strategies developed in this Plan include:

- **Disparities:** Differences in the incidence, prevalence, mortality, and burden of diseases and other adverse conditions that exist among specific population groups.
- Access to Health Care: Equal access to services throughout the continuum of cancer for all Wisconsin residents.
- Public Policy and Advocacy: Populationbased and system changes through public policy and advocacy.
- Workforce Development: Address labor needs to better serve Wisconsin residents across the continuum of cancer.
- Evaluation: Systematic way to improve and account for actions that are useful, feasible, ethical, and accurate.

The Wisconsin Comprehensive Cancer Control Plan 2010-2015 will serve as a common framework for action in cancer prevention and control over the next several years. It will provide program leaders, policy makers and researchers with a carefully crafted vision of what needs to be done and the resources needed to reduce the burden of cancer on the people of Wisconsin.

## **Implementation and Evaluation**

Strategies and action steps from the WI CCC Plan 2010-2015 will be prioritized annually for implementation by the Steering Committee through a systematic process using specific, measurable criteria (e.g., the magnitude of the burden, the strength of evidence suggesting an effective solution exists, the likelihood that interventions will lead to significant improvements, the presence of major gaps in current efforts, and the existence of disparate burden). The resulting priorities will set the direction for the implementation efforts of the statewide coalition for the following year.

Implementation of the Plan will also take place through organizations dedicated to cancer control all across Wisconsin. Each organization can use the Plan as a guide for specific strategies and action steps they choose to implement over the next five years. To ensure the continued implementation of this Plan, the current coalition of public and private partners must be maintained and expanded to develop, implement, and promote the WI CCC Plan. With this group, successful implementation will include:

- Sustaining and growing the current coalition to include key decision-makers in cancer prevention and control.
- Assuring leadership and accountability with implementation of the Plan.
- Promoting the WI CCC Plan with key stakeholders in Wisconsin.
- Obtaining additional funding for comprehensive cancer control efforts in Wisconsin.
- Continually evaluating implementation progress and adjusting implementation efforts as needed.

A five year evaluation plan will be developed as an accompanying piece to the WI CCC Plan 2010-2015. The Plan's Targets for Change will also be tracked annually to monitor long term progress. Implementation projects that develop from the Plan will be evaluated annually with the help of an external evaluation contractor. An evaluation report on the progress of the Plan will be presented annually. The purpose of developing and implementing the WI CCC Plan is ultimately to reduce cancer incidence, morbidity, and mortality and to improve the quality of life for those affected by the disease.

# Wisconsin Cancer Mortality and Incidence 2015 Goals

Healthy People 2010 national cancer mortality goals were adopted for Wisconsin Comprehensive Cancer Control Plan 2005-2010. The partners creating that first Plan thought the reductions in mortality rates for lung, colorectal, breast, cervical, and prostate over the period were reasonable goals for Wisconsin. The Healthy People 2020 goals were not finalized in time to be included in this revised Plan so we have used the following formula to adopt similar relative improvement goals in these mortality rates over the next five years:

Mortality Goal(2015) = Mortality Baseline(2010) - [Mortality Baseline(2010) \* (Annual goal % reduction) \* 5 years]

Example: the lung cancer mortality rate in 2005 was 49.5 per 100,000 and the 2010 goal was 44.9 per 100,000. To achieve this goal, lung cancer mortality would have needed to decline by 0.9 per 100,000 per

year or 1.86% of the baseline rate annually. Applying the same 1.86% annual reduction to the 2010 baseline of 48.7 per 100,000, we can project a 2015 goal of 44.2 per 100,000.

Healthy People 2010 (HP2010) did not set incidence goals, but partners creating the revised Plan decided Wisconsin should track cancer incidence rates as an indicator of progress in cancer control. With no national incidence goals to use as guidance, we adopted a pace for decline based on the goals for mortality reductions. With the understanding that cancer development is long-term, complex process with many influences, we decided to set the slope of incidence reductions between 2010 and 2015 to half the relative decline proposed for the mortality goal. We used the following formula to set incidence goals for 2015:

Incidence Goal(2015) = Incidence Baseline(2010) -[Incidence Baseline(2010) \* (Annual goal % reduction in mortality) \* 50% \* 5 years]

## **Wisconsin Cancer Mortality and Incidence 2010 Rates and 2015 Goals**

	MORTALITY		INCIDENCE	
Cancer Type	2010 Rate <sup>12</sup>	2015 Goal	2010 Rate <sup>12</sup>	2015 Goal
ALL CANCERS	184.3	150.6	470.3	427.3
Lung	48.7	44.2	64.8	61.8
Colorectal	17.2	11.4	49.4	41.0
Breast	23.4	19.7	122.7	113.0
Cervical	1.9	1.7	6.6	6.2
Prostate	27.8	23.3	156.9	144.3
Melanoma	2.5	2.3	15.3	13.8

Rates are expressed per 100,000 people and age-adjusted to the 2000 US Standard Population.

# Chapter 1: PREVENTION

# **Chapter 1: Prevention**

# Goal: Reduce the risk of developing cancer

## Parameter for the WI CCC Plan 2010-2015:

The Prevention Chapter includes activities designed to reduce the development of cancer in the population.

## **Definitions for this Chapter:**

Binge drinking is defined as five or more drinks on one occasion for men and four or more drinks on one occasion for women, one or more times in the past 30 days.

**Built environment** includes all the building spaces and products created by people that provide the setting for human activity. It includes homes, the workplace, neighborhoods, and methods of transportation.

CDC: Centers for Disease Control and Prevention

**Heavy drinking** is an as average consumption of two or more drinks per day or 60 or more alcoholic drinks a month for men and one or more drinks per day or 30 or more drinks a month for women.

HPV: Human Papillomavirus

Overweight adults and high school students include those individuals at or above the 85th percentile but below the 95th percentile for body mass index.

**Obese adults and high school students** include those individuals at or above the 95th percentile for body mass index.

Children (ages 2-4 years old) at risk of overweight include those individuals with a body mass index in the 85th to 94th percentile of children.

Overweight children (ages 2-4 years old) include those individuals with a body mass index at or above the 95th percentile of children.

**Tobacco use** includes the smoking, chewing, or snuffing of commercial tobacco or commercial tobacco-related products.

## Introduction:

Researchers estimate that between 50-75% of cancer deaths in the United States are caused by human behaviors.¹ Based on this information, simple changes in individual lifestyles can reduce the number of new cancer cases, and many cancer deaths can be prevented. The majority of cancer risk can be reduced by decreasing tobacco use and exposure, decreasing obesity, decreasing high risk alcohol consumption, increasing protective behaviors from sun and UV exposure, and increasing human papillomavirus (HPV) vaccine utilization.

Smoking is responsible for an estimated 30% of all cancer deaths and an estimated 87% of lung cancer cases.<sup>2</sup> In addition to lung cancer, smoking causes cancers of the larynx, mouth, esophagus, pharynx, and bladder, and contributes to cancers of the pancreas, kidney, and cervix.<sup>2</sup> There is a disparate burden of tobacco use by age, race, income and education. 55% of high school students reported trying a cigarette at least one time in their life.3 American Indians have the highest smoking rates (56%) of all racial/ethnic groups in Wisconsin, followed by Black/African Americans (29%), Whites (20%), Hispanic/Latinos (19%), and Asian/ Pacific Islanders (13%).4 Persons with an average household income of less than \$25,000 per year have a smoking prevalence rate (34%) more than double the rate of persons with a household income over \$75,000 (13%).4

Secondhand smoke has also been shown to cause cancer among non-smokers as well. As of July 2010, all Wisconsin workplaces will be smoke free. The continued protection of the statewide smoke free air law is important in reducing the incidence of tobacco related cancers in Wisconsin. Despite this advancement in the protection of smoke free air, more must be done to prevent individuals, especially those at disparate risk, from starting to smoke. Additionally, individuals who want to stop smoking must have access to the tools and resources to do so.

Obesity increases the risk of many chronic diseases. It is estimated to account for 30% of all cancer deaths.<sup>2</sup> Obesity has reached epidemic proportions in the United States and in Wisconsin. The percentage of the population carrying excess body weight has increased dramatically in the last decade, such that two out of three Wisconsin adults are now overweight or obese (64%).<sup>5</sup> Among Wisconsin public high school students, 14% are overweight and 9% are obese.<sup>6</sup> For children 2-4 years participating in the Women, Infants and Children (WIC) Program, 14% are overweight.<sup>7</sup> Due to its epidemic level in the state's population, it is crucial to decrease the level of obesity in Wisconsin. In order to decrease obesity in Wisconsin, it is important to increase physical activity, consumption of healthy balanced diets, and screening of and treatment for obesity.

Alcohol consumption causes approximately 3% of total cancer deaths. High risk alcohol consumption is a cause of liver cancer and oral cancers. It is linked to the increased risk of breast and colorectal cancers. Wisconsin leads the United States in the highest levels of binge drinking (24%), current alcohol use (69%), and heavy drinking (8%) among adults. Considering Wisconsin's high level of alcohol consumption, informing providers and the public about the link between high risk alcohol consumption and cancer is imperative to reduce the risk of alcohol-related cancers in Wisconsin.

Nearly all skin cancers are preventable by limiting direct exposure to the sun all year round. The number of melanomas diagnosed in the U.S., as well

as Wisconsin, is increasing. Since 1990, the number of melanomas diagnosed annually in Wisconsin has almost doubled from 360 to 700 cases and causes approximately 79% of skin cancer deaths. <sup>2</sup> Indoor tanning beds have also shown to increase the risk of developing skin cancer. In 2009, the World Health Organization (WHO), which developed the most widely used system for classifying carcinogens, elevated tanning beds to the Level 1 cancer risk category, the highest risk category among all carcinogens. <sup>10</sup> Increasing educational and policy approaches in schools and outdoor settings, in addition to decreasing the use of artificial tanning devices, can all be used to decrease the incidence of skin cancer caused by sun and ultraviolet exposures.

Human papillomavirus (HPV) is the most common sexually transmitted infection in the United States and causes almost all of cervical cancers.8 Two FDA approved vaccines (Cervarix and Gardasil) target the HPV strains that cause about 70% of all cervical cancers, and therefore are effective tools to protect women against most cervical cancers. The CDC recommends the HPV vaccine be administered to 11 and 12 year-old girls although the vaccine series can be started at 9 years of age. Catch-up vaccination is recommended for 13 through 26 year-old females who have not yet received or completed the vaccine series. It is important to note that all women still need cervical cancer screenings at regular intervals whether they received the HPV vaccine or not, as the vaccine does not protect against all cervical cancers.

In order to prevent the occurrence of cervical cancer, it is important to increase HPV vaccine utilization. By increasing accessibility of HPV vaccination services, increasing community awareness of the vaccine's benefits, and encouraging health systems to increase vaccination rates, the cervical cancers caused by the HPV strains in the vaccines can be prevented. It is also important to assemble and increase the collection of data regarding the use of the HPV vaccine in Wisconsin to properly track the vaccine's impact on cancer incidence and mortality in the state.

## Priority I: Decrease tobacco use and exposure to tobacco smoke

Strategy A: Decrease youth tobacco use.			
Action steps to implement this strategy	Support the implementation of a diverse statewide youth activism program and media campaign.		
	Support youth tobacco cessation services.		
	Support WI Wins to decrease youth access to tobacco products.		
	Increase the cigarette tax by \$1.00 per pack and other tobacco products by 75% of their price.		
	Fully fund a WI comprehensive tobacco prevention and control program consistent with CDC funding recommendations.		

Strategy B: Increase access to and use of evidence-based tobacco addiction treatment.			
Action steps to implement this strategy	Sustain, expand and promote services available through the WI Tobacco Quit Line to CDC recommended levels.		
	Implement targeted cessation activities, including increased access to medication, for the un/underinsured.		
	Sustain and increase tobacco dependence treatment insurance benefits and promote those benefits.		
	Make health care system changes to incorporate tobacco dependence assessment and treatment into routine medical care.		
	Educate health care providers on how to provide brief intervention for their patients.		

Strategy C: Implement and protect a statewide smoke free air law.		
Action step to implement this strategy	Support an enforcement and compliance plan for the statewide smoke free law.	

## **Priority II: Decrease the rate of obesity**

Strategy A: Increase physical activity.			
Action steps to implement this strategy	Improve safe, built environments to encourage physical activity.		
	Improve access to and utilization of programs that promote physical activity within targeted populations in communities, workplaces and schools.		
	Develop and promote planning, zoning and transportation policies that build physical activity into daily routines.		
	Develop a social marketing campaign that emphasizes the benefits of sustained physical activity.		
	Adopt, implement and enforce standards for physical activity in childcare, after school care and schools.		

Strategy B: Increase healthy balanced diets.			
Action steps to implement this strategy	Increase the availability and affordability of safe, healthy food and beverages in communities, workplaces and schools.		
	Adopt, implement and enforce nutrition and nutrition education standards to promote healthy food and beverages in childcare, after school care and schools.		
	Limit advertising of less healthy foods and beverages.		
	Develop a social marketing campaign that emphasizes the benefits of healthy foods and beverages.		
	Support policies and programs that increase breastfeeding initiation, duration and exclusivity.		

Strategy C: Increase screening of and treatment for obesity.			
Action steps	Train health care providers on how to use a lifestyle assessment protocol with patients annually and accurately screen for obesity.		
to implement this strategy	Promote reimbursement of nutrition and physical activity counseling and interventions.		
	Provide patients with tools for self-assessment and tracking of eating and physical activity habits.		

## **Priority III: Decrease high risk alcohol consumption**

Strategy A: Increase awareness of the connection between alcohol consumption and cancer risk.		
Action steps to implement this strategy	Educate health professionals about the relationship between high risk alcohol consumption and cancer.	
	Train health care providers on how to screen and treat their patients for high risk alcohol consumption.	
	Promote reimbursement of high risk alcohol consumption screening and treatment.	
	Support the implementation of a social marketing media campaign to increase public awareness of the link between high risk alcohol consumption and certain cancers.	

## Priority IV: Increase protective behaviors from sun/ultraviolet exposure

Strategy A: Increase educational and policy approaches regarding sun/ultraviolet protective behaviors in schools.		
Action steps to implement this strategy	Promote curriculum on sun protective behaviors in school health education.	
	Provide children with appropriate sun-protective gear or products for outside activities.	
	Increase sun-safety training for school staff.	
	Increase availability of shaded areas on school grounds.	
	Promote sun safety behaviors at school athletic and other outdoor events.	

Strategy B: Increase educational and policy approaches regarding sun/ultraviolet protective behaviors in outdoor settings.		
	Develop a public awareness campaign for adults, especially parents, on sun safety behaviors.	
Action steps to implement this strategy	Increase education on and use of sun/ultraviolet exposure protective behaviors targeted at outside workers.	
	Provide sun-protective gear or products to those working outside.	
	Increase availability of shaded areas at recreational sites such as parks, pools and other settings.	

Strategy C: Decrease use of tanning beds by adolescents and adults.	
Action steps	Advocate for regulation of tanning beds, including banning indoor tanning for minors.
to implement this strategy	Develop & implement a public awareness campaign to highlight the dangers of indoor tanning use.

## **Priority V: Increase HPV vaccine utilization and surveillance**

Strategy A: Increase access to vaccination services.		
	Support Wisconsin's Vaccines for Children program infrastructure to increase the number of health care providers that administer the HPV vaccine and to appropriately monitor and track its distribution.	
Action steps to implement	Advocate for insurance coverage of HPV vaccine according to CDC's HPV vaccine recommendations.	
this strategy	Promote legislation that increases access to the HPV vaccine for all females in the recommended age group.	
	Increase access to the HPV vaccine within populations most at risk for HPV infection and cervical cancer development.	

Strategy B: Increase community awareness of the benefits of HPV vaccine.	
Action steps	Educate the public about the dangers of HPV infection and the benefits of HPV vaccination.
to implement this strategy	Target public awareness campaigns to parents, school age girls, and young women about HPV recommendations.

Strategy C: Implement health care system based strategies to increase vaccination rates.	
Action steps	Educate health care providers about HPV vaccination recommendations.
to implement this strategy	Implement office-based reminders for patients due for HPV vaccination.

# Strategy D: Assemble data regarding use of the HPV vaccine in Wisconsin. Action steps to implement this strategy Partner with the Wisconsin Immunization Registry to develop an effective and efficient way to assemble HPV vaccine related data. Collaborate with the Wisconsin Immunization Registry and other partners to increase reporting of HPV vaccine related data to the registry.

## **Targets for Change**

REDUCE ADULT SMOKING RATES		
Baseline: 20%	2015 Goal: 16%	
Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2008.	Wisconsin Tobacco Prevention and Control Program's State Plan 2009-2014. WI Department of Health Services, Division of Public Health. Madison, WI. 2009.	

REDUCE HIGH SCHOOL TOBACCO USE RATES (any tobacco product)		
Baseline: 28%	2015 Goal: 15%	
Wisconsin Tobacco Prevention and Control Program. Wisconsin Youth Tobacco Survey (YTS) High School Fact Sheet. Wisconsin Department of Health Services, Division of Public Health. Madison, Wl. 2008.	Wisconsin Tobacco Prevention and Control Program's State Plan 2009-2014. WI Department of Health Services, Division of Public Health. Madison, WI. 2009.	

REDUCE MIDDLE SCHOOL TOBACCO USE RATES (any tobacco product)		
Baseline: 7%	2015 Goal: 4%	
Wisconsin Tobacco Prevention and Control Program. Wisconsin Youth Tobacco Survey (YTS) High School Fact Sheet. Wisconsin Department of Health Services, Division of Public Health. Madison, WI. 2008.	Wisconsin Tobacco Prevention and Control Program's State Plan 2009-2014. WI Department of Health Services, Division of Public Health. Madison, WI. 2009.	

REDUCE THE PERCENTAGE OF ADULTS WHO ARE OBESE		
Baseline: 26%	2015 Goal: 20%	
Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2008.	The goal was developed by the WI CCC Program, WI Nutrition, Physical Activity & Obesity Program and partners for purposes of the WI CCC Plan 2010-2015.	

## **Targets for Change**

# REDUCE THE PERCENTAGE OF HIGH SCHOOL STUDENTS WHO ARE OVERWEIGHT OR OBESE

Baseline: 23%	2015 Goal: 18%
Wisconsin Youth Risk Behavior Survey: Trends Graphs 1993-2009. Wisconsin Department of Public Instruction. Madison, WI. 2009.	The goal was developed by the WI CCC Program, WI Nutrition, Physical Activity & Obesity Program and partners for purposes of the WI CCC Plan 2010-2015.

# REDUCE THE PERCENTAGE OF CHILDREN (AGES 2-4) ENROLLED IN WIC WHO ARE AT RISK OF BEING OVERWEIGHT OR ARE CURRENTLY OVERWEIGHT

Baseline: 31%	2015 Goal: 25%
Pediatric Nutrition Surveillance System Wisconsin Summary 2000-2008, Table 8c. US. Centers for Disease Control and Prevention. 2009.	The goal was developed by the WI CCC Program, WI Nutrition, Physical Activity & Obesity Program and partners for purposes of the WI CCC Plan 2010-2015.

REDUCE THE PERCENTAGE OF ADULTS WHO BINGE DRINK		
Baseline: 23%	2015 Goal: 16%	
Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2008.	The goal was developed by the WI CCC Program and its partners for purposes of the WI CCC Plan 2005-2010. 16% is the national rate of adults who binge drink.	

# INCREASE THE PERCENTAGE OF 11-18 YEAR OLD FEMALES WHO RECEIVED 3+ DOSES OF THE HPV VACCINATION

Baseline: 20%	2015 Goal: 50%
Wisconsin Immunization Registry. Wisconsin Department of Health Services. Madison, WI. 2009.	The goal was developed by the WI CCC Program and its partners for purposes of the WI CCC Plan 2005-2010.



# **Chapter 2: SCREENING**

# **Chapter 2: Screening**

# Goal: Increase early detection through appropriate screening for cancer

## Parameter for the WI CCC Plan 2010-2015:

The Screening Chapter includes detecting existing cancer or its precursors (polyps, pre-cancerous cells) up to the time a cancer is diagnosed. Priorities in this Plan are focused on breast, cervical and colorectal cancer screenings. Screening for these three cancers has been proven to reduce mortality.

## **Definitions for this Chapter:**

Patient navigation in cancer care refers to individualized assistance offered to patients, families, and caregivers to help identify and eliminate barriers that prevent individuals from getting the right care, at the right time, and by the right person. Cancer patient navigation works with a patient from pre-diagnosis through all phases of the cancer experience.

Genetic Counselors are specially trained health care professionals with skills in medical genetics and counseling who work in a variety of settings including cancer genetic risk assessment. They work with a health care team to identify individuals and families at increased risk of cancer for the purpose of promoting awareness, early detection and cancer prevention.

## Introduction:

Screening for the early detection of cancer has shown to decrease mortality from breast, cervical and colorectal cancers. Unfortunately, some screening rates are decreasing. In Wisconsin, the percent of women age forty and older who had a mammogram in the past two years decreased from 80.2% in 2002 to 76.3% in 2008 and the percentage of women age 18 and older who had a pap smear in the past three years decreased from 89.6% in 2001 to 83.1% in 2008. <sup>5</sup> On a positive note, the

percentage of Wisconsin adults age fifty and older who had a colonoscopy/sigmoidoscopy to screen for colorectal cancer increased from 46% to 57% from 2001 to 2008.<sup>5</sup> Although colorectal cancer screening rates have increased, colorectal cancer in Wisconsin remains the third most prevalent cancer among men and second among women.<sup>2</sup> In addition to traditional cancer screenings, genetic counseling with appropriate genetic testing can aid in the identification of high risk individuals and families who need increased screening for earlier cancer detection. According to the National Cancer Institute, approximately 5 to 10 percent of all cases of cancer are hereditary.<sup>11</sup>

While screening for breast, cervical and colorectal cancers have shown to decrease cancer mortality, not all medical experts agree that screening for prostate cancer will save lives. Currently, there is not enough credible evidence to determine if the potential benefit of prostate cancer screening outweighs the potential risks. The potential benefit of prostate cancer screening is the early detection of cancer, which may make treatment more effective. However, potential risks include false positive test results (the test says you have cancer when you do not), treatment of prostate cancers that may never affect your health, and mild to serious side effects from treatment of prostate cancer. Most organizations recommend that men discuss with their doctors the benefits and risks of prostate cancer screening. The WI CCC Plan, along with the CDC, supports informed decision making, which encourages men to talk with their doctors to learn the nature and risk of prostate cancer, understand the benefits and risks of the screening tests, and make decisions consistent with their preferences and values.

Recommended methods of screening can prevent disease and offer a powerful opportunity for the detection and elimination of pre-cancerous lesions as well as the early detection and successful treatment of certain cancers. Raising public awareness, implementing health care system-based strategies, increasing access to screening tools, and increasing the number of high risk individuals who receive personal risk assessments are potential strategies to effectively increase cancer screening rates in Wisconsin.

Limited public knowledge of recommended screening guidelines and techniques has contributed to low screening rates. As guidelines and screening tools modify, the public must be made aware of these changes. Accessible, culturally appropriate communication tools targeted to specific populations within Wisconsin may be used by residents to identify the value of cancer screenings. Additionally, group and individual educational strategies are important to inform residents of cancer screening options and recommendations.

The implementation of various health care system based strategies may be used to increase cancer screening rates within health systems. With an increasing number of health care systems implementing electronic medical records, clinics and hospitals should utilize reminder systems for patients due for screenings. As the point of contact with patients and the deliverer of cancer screenings, health care providers must stay informed about issues regarding cancer screening recommendations and guidelines, including the importance of personalized provider-patient conversations based on cultural, heritable, and population-based needs and concerns of patients. Health plans also have a unique opportunity to engage with patients, employers and providers to offer incentives and reminders for patients to receive screenings and inform employers on the importance of encouraging employees to be screened.

Lack of access to cancer screenings has also contributed to the decline of screening rates. There are common barriers such as lack of insurance coverage and unique barriers based on community and cultural perceptions, preventing individuals from receiving recommended cancer screenings. An increase in public and private funding, the overall reduction in common and unique barriers, and implementation of culturally appropriate patient navigation systems are effective strategies to increase the number of individuals that receive cancer screenings.

To complement the benefits of traditional screenings, genes that carry and increased susceptibility for breast, ovarian, colon, and other cancers have been identified. Identifying a gene mutation may help prevent and detect cancer in high-risk individuals at an earlier stage, leading to more effective therapy. Due to the complexities of testing, genetic testing is recommended to be done in conjunction with genetic counseling. Personalized cancer risk assessments are used to determine an individual's chance of developing cancer based on family history, environmental exposures, and lifestyle choices. Individuals who are at high risk of developing cancer due to a family history may benefit from genetic testing and counseling. To increase the number of high risk individuals who receive a cancer risk assessment, it is important to increase access to such assessments, educate providers and patients about assessing cancer risk, and increase the number of professionals who offer cancer risk assessments.

## Priority I: Increase public awareness of recommended cancer screenings

Strategy A: Utilize communication tools that will show the value of cancer screenings to individuals.	
Action steps to implement this strategy	Assess existing and/or develop culturally appropriate communications tools.
	Gather screening communication tools and information in an accessible portal.
	Develop a local level action plan within targeted communities that includes a multi- dimensional media campaign to raise awareness of cancer screenings options and what it means to be above average risk for screenable cancers.
	Link with national and state advocacy groups that have media campaigns & websites to promote local screening opportunities.

	Strategy B: Implement group and one-on-one educational strategies to inform individuals of their cancer screening options.	
	Assess and share models of best practice for educational strategies.	
Action steps to implement	Utilize and support the outreach efforts of community health professionals and lay community health workers.	
this strategy	Partner with communities to create a local level action plan that incorporates appropriate educational strategies.	

# Priority II: Implement health care system based strategies to increase cancer screening rates

Strategy A: Encourage the use of office based systems to inform patients of screening options and ensure follow through with screenings.		
	Create an office environment where all staff are involved with ensuring that patients receive their recommended screenings.	
Action steps	Implement provider reminder systems that identify patients due for cancer screenings.	
to implement this strategy	Reward clinics & providers that routinely recommend and/or screen patients for cancer.	
uno suategy	Utilize client reminder tools to inform patients they are due for cancer screenings.	
	Provide incentives for patients to follow through on screening recommendations.	

Strategy B: Increase health care provider knowledge about cancer screenings.		
	Offer training & tools to providers on how to educate their patients about recommended screenings and their value.	
Action steps	Educate providers on cultural and population based issues that affect screening.	
to implement	Educate providers on cancer risks for patients that fall outside of routine screening guidelines.	
this strategy	Encourage providers to discuss the heritability/family risk with patients.	
	Encourage providers to include a cancer-related check up in a patient's periodic health examination.	

The state of the s	urage health plans to educate patients and providers on recommended er screenings.
	Provide incentives to members who get recommended cancer screenings.
Action steps	Provide information on cost savings to the plan and providers.
to implement this strategy	Utilize client reminder tools to inform health plan members they are due for their recommended cancer screenings.
	Encourage employers to provide full coverage of recommended cancer screening in their health plans and support time off for their employees to get their cancer screenings.

## **Priority III: Increase access to cancer screenings**

## Strategy A: Support coverage for recommended cancer screenings for those that are underinsured or uninsured.

# Action steps to implement this strategy

Advocate for increased funding for WI Well Woman Program to include:

- Public awareness/outreach funds to facilitate the pathway to the WI Well Woman Program.
- Coverage for screenings for women age 35-49.

Advocate for funds for colorectal cancer screening to create a statewide colorectal screening program.

Support legislation that provides for full insurance coverage for recommended cancer screenings, including diagnostic screenings.

## Strategy B: Reduce barriers that can make it difficult for individuals to seek cancer screenings.

# Action steps to implement this strategy

Define common screening barriers and identify barriers to screening that are unique to underserved communities.

Partner with communities to create a local level action plan that works to eliminate identified barriers to cancer screenings.

Implement and support community and employer based screening events.

Increase availability of clinic based extended hours screening appointments.

# Strategy C: Increase the availability of culturally appropriate patient navigation systems within communities and health systems.

## Action steps to implement this strategy

Assess current status of patient navigator programs in Wisconsin, including their impact on patient behavior & satisfaction.

Gain support from health systems & providers on the need for and value of patient navigators.

Support collaborative approaches to promoting patient navigation, such as the WI Community Health Worker initiative.

Work with higher education systems to review model community health worker training programs.

Recruit & train members within communities to be navigators in the community they represent.

# Priority IV: Increase the number of high risk individuals who receive a cancer risk assessment

## Strategy A: Increase access to cancer risk assessments.

Action step to implement this strategy

Advocate for health insurance coverage of cancer risk assessment and genetic testing.

## Strategy B: Educate providers and patients about assessing cancer risk.

Action steps to implement this strategy Educate providers about the implications of family history in cancer risk and about the benefits of cancer risk assessment and genetic counseling.

Create an awareness campaign regarding the importance of family history as a risk factor for cancer.

Provide culturally appropriate risk assessment materials to providers and patients.

## Strategy C: Increase the number of qualified professionals who offer cancer risk assessment.

Action steps to implement this strategy Advocate for the licensing of genetic counselors.

Partner with other professions, such as nurse educators, to provide cancer risk assessments and counseling.

Integrate genetic counseling into the patient teams at oncology clinics.

## **Targets for Change**

# INCREASE PERCENT OF PEOPLE 50 YEARS AND OLDER WHO HAD A COLONOSCOPY OR SIGMOIDOSCOPY IN PAST 5 YEARS

Baseline: 57% 2015 Goal: 75%

Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. Atlanta. GA. 2008.

American Cancer Society. Cancer Prevention & Early Detection Facts & Figures 2009. Atlanta, GA. 2009.

# INCREASE THE PERCENT OF ADULTS 50 YEARS & OLDER WHO HAD A BLOOD STOOL TEST WITHIN THE PAST TWO YEARS

Baseline: 17% 2015 Goal: 22%

Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2008.

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

## INCREASE PERCENT OF WOMEN 40 YEARS AND OLDER WHO HAD A MAMMOGRAM IN PAST TWO YEARS

Baseline: 76% 2015 Goal: 90%

Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2008.

American Cancer Society. Cancer Prevention & Early Detection Facts & Figures 2009. Atlanta, GA. 2009.

## INCREASE PERCENT OF WOMEN AGE 18+ WHO HAD PAP SMEAR IN PAST 3 YEARS

Baseline: 83% 2015 Goal: 90%

Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2008. The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# **Chapter 3: TREATMENT**

# **Chapter 3: Treatment**

# Goal: Reduce death and disability from cancer

## Parameter for the WI CCC Plan 2010-2015:

The Treatment Chapter focuses on the time of diagnosis through the end of active treatment when the goal is to cure the disease and prolong life.

## **Definitions for this Chapter:**

Patient navigation in cancer care refers to individualized assistance offered to patients, families, and caregivers to help to identify and eliminate barriers that prevent individuals from getting the right care, at the right time, and by the right person. Cancer patient navigation works with a patient from pre-diagnosis through all phases of the cancer experience.

WI ACT 194-2005 prohibits a health care policy, plan, or contract from excluding coverage for the cost of any routine patient care that is administered to an insured in a cancer clinical trial satisfying certain criteria and that would be covered under the policy, plan, or contract if the insured were not enrolled in a cancer clinical trial.

**ACCESS:** Assessment of Cancer Care and Satisfaction Study

**WICaRE:** Wisconsin Cancer Registry Evaluation: Patterns of Care Study

## Introduction:

From 2002 through 2006, approximately 27,200 cancers were diagnosed annually among Wisconsin residents. It is the second highest cause of death in the state, following heart disease. Access to quality, patient centered cancer treatment is critical to reduce death and disability from cancer in Wisconsin. This can be achieved through increased access to quality cancer care, increased enrollment in cancer clinical trials and improved patient satisfaction with their care.

Quality improvement efforts in cancer treatment would ensure that Wisconsin residents with cancer receive the best possible care. Credible, evidence-based guidelines can be used to reduce variation in the provision of cancer care, with resulting improvements in outcomes and cost-effectiveness of care. American College of Surgeons (ACoS) accreditation requires approved cancer programs to adhere to certain treatment guidelines. As of 2010, there are 38 ACoS approved cancer programs in Wisconsin. Increasing the number of professionally accredited cancer care facilities in Wisconsin would improve adherence to cancer treatment guidelines within cancer programs and ensure most cancer patients receive state of the art treatment.

Participation in cancer clinical trials gives patients: access to health care provided by leading physicians in the field of cancer research; new drugs and interventions before they are widely available; and an opportunity to make a valuable contribution to cancer research. There are 41 institutions that offer clinical trials in Wisconsin, in addition to many satellite locations. <sup>14</sup> Despite these benefits and the number of locations, participation in cancer clinical trials remains low. According to the Assessment of Cancer Care and Satisfaction Study (ACCESS), that surveyed 1,839 breast, colorectal and lung cancer

patients, only 8% of respondents reported receiving cancer treatment as part of a clinical trial. 64% of respondents reported they were never told about clinical trials as a treatment option. Additionally, cancer patients from Milwaukee reported a lower participation rate in clinical trials, even though many trials are located there. To increase cancer patient enrollment in clinical trials, it is necessary to increase the number of facilities offering cancer clinical trials and educate the public and providers about the benefits of clinical trials.

Cancer patients have also shown greater satisfaction with care when they participated in shared treatment decisions with medical staff and whose family was included in treatment decision making. <sup>15</sup> However, patients that express low levels of satisfaction mention difficulties with travel, age, lack of insurance, and problems understanding written medical information. <sup>15</sup>

Increasing quality cancer care education, implementing shared decision-making, and increasing the availability of culturally appropriate patient navigation systems can all help to increase patient satisfaction with cancer care.

## **Priority I: Increase access to quality cancer care**

# Strategy A: Increase the number of Wisconsin oncology care providers who follow nationally validated practice guidelines.

## Action steps Organization could take to implement this strategy

Develop collaborative efforts to increase treatment compliance with nationally validated guidelines.

Develop demonstration projects within health systems to increase treatment compliance with nationally validated treatment guidelines in practice.

Encourage health professionals and providers to participate in quality improvement initiatives, such as the American Society of Clinical Oncology's Quality Oncology in Practice Initiative & others.

Educate cancer patients and their caregivers to advocate for treatment that is compliant with nationally validated practice guidelines.

# Strategy B: Increase the number of Wisconsin cancer care facilities that are accredited by the American College of Surgeons (ACoS).

## Action steps Organization could take to implement this strategy

Develop collaborative approaches to promote the ACoS accreditation program.

Encourage mentorship of cancer treatment facilities that are eligible or are seeking accreditation.

Increase patient awareness of ACoS standards & accredited facilities.

Co-sponsor a conference on cancer quality improvement featuring an update on credentialing programs.

# Strategy C: Increase the number of patients that are provided with a synopsis of their coordinated cancer care plan.

## Action steps Organization could take to implement this strategy

Review existing models of cancer care plans.

Develop demonstration projects within American College of Surgeons accredited facilities.

Monitor health care policy related to requirements for cancer treatment plans and communicate those results.

Feature cancer treatment plan at regional or statewide conferences.

## **Priority II: Increase participation in cancer clinical trials**

## Strategy A: Increase the number of facilities offering cancer clinical trials to patients.

Action steps Organization could take to implement this strategy Co-sponsor workshops & mentoring program to assist smaller facilities with Institutional Review Board & Data Safety Monitoring Board processes and other issues related to community based research.

Develop provider & health system educational campaign on the value of cancer clinical trials.

Develop targeted resources to inform providers and patients of WI Act 194-2005 addressing insurance coverage in the context of a cancer clinical trial.

# Strategy B: Develop and promote public education campaigns to promote clinical research, focusing on cancer clinical trials.

## Action steps Organization could take to implement this strategy

Convene representatives of all Wisconsin institutions offering clinical trials to explore effective and consistent messaging to patients & caregivers about cancer clinical trials.

Feature clinical trials education targeted to providers at statewide or regional conferences and events.

Collaborate with other chronic disease partners to review evidence-based patient and public education resources and develop campaign to promote clinical trials to community health workers, caregivers, and the public.

Develop promotional media campaign tool-kit aimed at increasing patient participation in clinical trials to offer in local, targeted media.

## **Priority III: Improve patient satisfaction with their cancer care**

# Strategy A: Increase the number of cancer care facilities that have implemented a standing order referral to a cancer information resource.

Action steps Organization could take to implement this strategy

Assess available cancer information resources.

Encourage health systems and institutions to adopt available cancer information resources and referral systems.

# Strategy B: Increase the number of cancer care facilities that are practicing shared decision making between providers, patients & family.

Action steps Organization could take to implement this strategy Convene partners to identify, review and promote resources available on shared decision making.

Develop educational opportunities to inform providers on the practice of shared decision making.

Evaluate need for a cancer patient's "Bill of Rights" in Wisconsin.

Develop patient and caregiver education resources to address shared decision making.

# Strategy C: Increase the availability of culturally appropriate patient navigation systems within communities and health systems.

Action steps Organization could take to implement this strategy Assess current status of patient navigator programs in Wisconsin, including their impact on patient behavior & satisfaction.

Gain support from health systems & providers on the need for and value of patient navigators.

Support collaborative approaches to promoting patient navigation, such as the WI Community Health Worker initiative.

Work with higher education systems to review model community health worker training programs.

Recruit & train members of communities to be navigators in the community they represent.

#### Strategy D: Improve quality cancer care education for underserved populations.

## Action steps Organization could take to implement this strategy

Develop collaborative efforts to address provider cultural competency.

Review evidence-based strategies to improve health literacy resources and techniques.

Support a project to link the ACCESS and WICaRE data to evaluate factors that may influence patient satisfaction with cancer care.

Work with health systems to improve health literacy resources for provider use with patients.

 $\hbox{Co-sponsor conference on health literacy and cultural competency targeted to health systems, providers, and patient advocates.}$ 

# **Targets for Change**

# INCREASE THE NUMBER OF AMERICAN COLLEGE OF SURGEONS APPROVED CANCER PROGRAMS IN WISCONSIN

CANCER PROGRAMS IN WISCONSIN			
Baseline: 38	2015 Goal: 48		
Commission on Cancer. <i>Approved Cancer Programs</i> . American College of Surgeons (ACoS). Chicago, II. web.facs.org/cpm/default.htm.	The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.		

# INCREASE THE PERCENTAGE OF ADULT CANCER PATIENTS IN CANCER CLINICAL TRIALS

CLINICAL INIALS	
Baseline: 8%	2015 Goal: 10%
Trentham-Dietz A, Walsh MC. ACCESS: Assessment of Cancer Care and Satisfaction. Summary of Results. University of Wisconsin Paul P. Carbone Comprehensive Cancer Center. Madison, WI. 2008.	The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# INCREASE THE PERCENTAGE OF CANCER PATIENTS WITH A WRITTEN SUMMARY OF THE CANCER TREATMENT THEY RECEIVED

THE VAROER THEATMENT THE TRESERVED				
Baseline: Pending	2015 Goal: Pending			
*Note this baseline will not be available until 2011. At that time we will update the online version of the Plan with this Target for Change. Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. Survivorship Module. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2011.	The goal will be developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.			

# **Targets for Change**

# DECREASE THE NUMBER OF PATIENTS WITH DIFFICULTY READING HOSPITAL MATERIAL OR FILLING OUT MEDICAL FORMS

Baseline: 30% 2015 Goal: 15%

Trentham-Dietz A, Walsh MC. ACCESS: Assessment of Cancer Care and Satisfaction. Summary of Results. University of Wisconsin Paul P. Carbone Comprehensive Cancer Center. Madison, WI. 2008.

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# INCREASE THE PERCENTAGE OF PATIENTS WHO WERE ENCOURAGED TO PARTICIPATE IN DECISION MAKING ABOUT THEIR HEALTH CARE

Baseline: 89% 2015 Goal: 95%

Trentham-Dietz A, Walsh MC. ACCESS: Assessment of Cancer Care and Satisfaction. Summary of Results. University of Wisconsin Paul P. Carbone Comprehensive Cancer Center. Madison, Wl. 2008.

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

### INCREASE THE PERCENTAGE OF PATIENTS WHOSE TREATMENT STAFF MADE AN EFFORT TO INCLUDE THEIR FAMILIES DURING IMPORTANT HEALTH CARE DECISION MAKING

Baseline: 82% 2015 Goal: 95%

Trentham-Dietz A, Walsh MC. ACCESS: Assessment of Cancer Care and Satisfaction. Summary of Results. University of Wisconsin Paul P. Carbone Comprehensive Cancer Center. Madison, Wl. 2008.

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# **Chapter 4: SURVIVORSHIP**

# **Chapter 4: Survivorship**

# Goal: Improve the quality of life for cancer survivors

### Parameter for the WI CCC Plan 2010-2015:

The Survivorship Chapter begins when active cancer treatment is completed and continues throughout life or until the primary goal is symptom management.

### **Definitions for this Chapter:**

**Survivor** refers to those people who have been diagnosed with cancer, including people with no evidence of disease and people living with cancer.

**Co-survivors** refer to the persons who support cancer survivors and who are affected by the diagnosis, including family members, friends, and caregivers.

**Survivorship issues** include but are not limited to physical, psychosocial, emotional, sexual, financial, and spiritual support or concerns.

**Providers and trainees** include but are not limited to physicians, RNs, fellows, residents, social workers, and psychologists.

### Introduction:

Over 64% of those diagnosed with cancer today are expected to be five-year cancer survivors. 16 Cancer survivors are faced with difficult medical and life decisions at each stage of living with the disease. From the time of diagnosis and beyond, the quality of life for every cancer survivor and co-survivor is affected in some way. As the population increases and cancer detection and treatment improve, the number of cancer survivors is expected to increase exponentially.16 In order to properly address survivorship issues and improve the quality of life of survivors, it is important to raise awareness of survivors' needs, educate and empower survivors to address their needs, and increase access to quality care and services. As survivorship issues evolve and become a more prominent part of cancer care, it is also important to increase survivorship related data through surveillance and research.

As the number of survivors increase, it is important to raise awareness among providers, policy makers, and the public about the needs of survivors. Increasing the awareness of survivorship issues and needs among providers will improve the care survivors receive throughout their lifetime. Educating policy and decision makers is an effective strategy to increase funding and promote policy changes for survivorship services and research. Lastly, it is important to educate the public about survivorship issues in order to best address the needs of survivors and co-survivors.

Survivors and co-survivors each have personalized issues and needs that arise post-treatment. Providing tools and resources to survivors and co-survivors enables them to advocate for themselves. Increasing the number of survivors that participate

in coordinated care with their medical decision making team, providing community based educational forums on survivor needs and issues, and informing survivors about transitions back to school and work are all effective strategies to educate and empower survivors and those that support them. Collaborative efforts to increase access to survivorship information, the provision of individualized survivor care plans, expansion of professionals trained in survivorship issues, and access to integrative medicine are also strategies that address the availability of quality care and services for survivors.

Limited surveillance and research has been done to study survivorship issues and epidemiological trends. The Behavioral Risk Factor Surveillance Survey has begun to collect preliminary data on survivorship issues, including Wisconsin specific data. Currently, it is difficult to properly monitor declines and improvements in care. It is important to increase survivorship related data through surveillance and research through the creation of a survivorship-focused database and a Wisconsin specific survivorship resources depository. Through the creation of such monitoring systems we hope to gain more insight on the issues survivors and co-survivors experience and the best practices needed to support them.

# **Priority I: Raise awareness of survivors' needs**

### Strategy A: Increase health care provider awareness of survivor needs and available best practices.

### Action steps to implement this strategy

Encourage professional organizations and health systems to offer training and tools to providers on how to address survivorship issues.

Educate providers and trainees about the long-term and latent effects of treatment and specific care needs related to these effects.

Develop a reference resource that outlines survivorship issues and discussion points for providers, including care planning and guidelines for follow-up.

# Strategy B: Promote policy changes and increased funding for survivorship services by educating policy and decision makers.

### Action steps to implement this strategy

Educate leaders by comparing cancer survivorship rehabilitation to other chronic disease rehabilitation models to instill the need for policy reform and funding.

Educate leaders about the importance of health insurance coverage for survivorship issues.

Network with advocacy organizations to support federal and state legislation to improve funding for survivorship services, research, and surveillance.

### Strategy C: Educate the public about the needs of survivors and co-survivors.

# Action steps to implement this strategy

Collaborate with other national and state groups to better understand and promote survivorship best practices to the public.

Develop a media campaign to raise awareness and portray a consistent message about survivorship issues.

Show the human impact of cancer survivorship through a series of case stories from Wisconsin for press and legislative purposes.

# **Priority II: Educate and empower survivors**

# Strategy A: Educate survivors and co-survivors on how to be active partners in their medical decision making team.

# Action steps to implement this strategy

Provide training to cancer survivors to become an active partner with their provider in decision making regarding their care throughout care continuum.

Develop methods to educate co-survivors about advocacy and understanding the survivor experience and beyond.

Disseminate survivorship information and best practices through an annual statewide Cancer Survivorship Conference.

# Strategy B: Provide community based educational forums to address specific and unique needs of cancer survivors.

# Action steps to implement this strategy

Facilitate local survivorship training workshops that promote best practice adoption within local communities.

Encourage medical facilities to adopt survivorship best practice models from national or local organizations.

# Strategy C: Make information on return to work or school transition issues available to survivors and those in their work or school environments.

# Action steps to implement this strategy

Discuss best practices and disseminate survivorship information through an annual statewide cancer survivorship conference.

Develop a training module on transitioning back to work and/or school that is available statewide through websites and provider agencies.

# **Priority III: Increase access to quality care and services**

# Strategy A: Increase access to survivorship information and broaden advocacy opportunities through collaborative partnerships.

# Action steps to implement this strategy

Educate provider organizations on how to assist survivors in addressing survivorship issues.

Establish a state-wide coalition to collaboratively address survivorship issues.

Strengthen partnerships with other state and national organizations to increase opportunities for advocacy on survivorship issues in Wisconsin.

### Strategy B: Ensure cancer survivors have an individualized survivor care plan.

# Action steps to implement this strategy

Provide information about survivorship care plan templates and available models to implement survivor care plans on the WI CCC Program website.

Explore possibility of standardization of key survivorship care plan elements across the state.

# Strategy C: Expand the number of professionals who are trained to address cancer survivorship issues.

# Action steps to implement this strategy

Identify underserved geographic regions in Wisconsin where targeted implementation projects are needed.

Educate cancer treatment provider organizations on how to assist survivors in addressing survivorship issues.

Hold at least one of the statewide Cancer Survivorship Conference in an underserved area.

# Strategy D: Increase communication regarding the use of complementary and alternative medicine.

# Action steps to implement this strategy

Make resources available for providers and survivors that identify evidence-based strategies for safe integration of conventional medicine and complementary and alternative medicine.

Encourage professional organizations and health systems to offer training and tools to providers on evidence-based strategies for safe integration of conventional medicine and complementary and alternative medicine.

# Priority IV: Increase survivorship related data through surveillance and research

### Strategy A: Create a database to capture data on Wisconsin survivors.

### Action steps to implement this strategy

Implement a pilot project to develop a survey to gather survivorship specific data to establish the current baseline.

Coordinate with established data collection processes to implement an ongoing project to gather survivorship specific surveillance data.

### Strategy B: Develop a Wisconsin specific survivorship resources depository.

# Action steps to implement this strategy

Research and gather all currently available resources for survivors.

Provide searchable database that can be accessed by providers and survivors on available resources.

Promote or facilitate the organization within the depository of clinical trials related to survivorship issues.

Prevention. Atlanta, GA. 2011.

# **Targets for Change**

# INCREASE THE PERCENTAGE OF SURVIVORS LIVING FIVE YEARS AFTER THEIR INITIAL CANCER DIAGNOSIS

Baseline: Pending 2015 Goal: Pending

\*Note this baseline will not be available until 2011. At that time we will update the online version of the Plan with this Target for Change. Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. Survivorship Module. U.S. Department

of Health and Human Services, Centers for Disease Control and

The goal will be developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# INCREASE THE PERCENTAGE OF CANCER PATIENTS THAT RECEIVED FOLLOW UP INSTRUCTIONS

Baseline: Pending 2015 Goal: Pending

\*Note this baseline will not be available until 2011. At that time we will update the online version of the Plan with this Target for Change.

Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. Survivorship Module. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2011.

The goal will be developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# INCREASE AVAILABILITY OF STATEWIDE SURVEILLANCE DATA RELATED TO SURVIVORSHIP

Baseline: None 2015 Goal:
Establish Surveillance System

Information from WI CCC Plan 2010-2015 workgroup planning process.

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# **Chapter 5: PALLIATIVE CARE**

# **Chapter 5: Palliative Care**

# **Goal: Reduce suffering from cancer**

### Parameter for the WI CCC Plan 2010-2015:

Palliative Care Chapter focuses on the time when symptom management is the primary goal and continues up to and during the last phase of life.

### **Definitions for this Chapter:**

**Total symptom management** refers to the comprehensive multidisciplinary management of patients' physical, psychological, social, spiritual and existential needs.

Hospice care is a philosophy of care that provides physical, social, emotional and spiritual care to terminally ill patients and their families when they are no longer seeking cure-oriented treatments. The goal of hospice care is to enable patients to improve the quality of a patient's last days by offering comfort and dignity. Hospice care affirms life and neither hastens nor postpones death.

### Introduction:

From 2002 to 2006, there was an average of 10,841 cancer deaths each year in Wisconsin.<sup>12</sup> Access to quality palliative care services and total symptom management reduces patients' suffering from cancer. In order to provide accessible palliative care, it is important to improve advance care planning, access to quality symptom management, and access to quality end of life care.

Despite advances in the prevention, screening and treatment of cancer, there is still no cure for all cancers. Advance care planning aids in the event where cancer no longer responds to curative treatment. Advance care documents give patients, providers, caregivers and family members the opportunity to discuss the patient's goals of care. There are several benefits to having advance directives, yet too few Wisconsinites have advance directives on file. In order to increase the number of completed advanced care documents by cancer patients, it is important to promote the accessibility and completion of the documents as well as the discussion of goals of care between cancer patients, families and providers.

Cancer patients encounter a multitude of physical and emotional symptoms, including pain, during and after treatment. In 2008, Wisconsin was one of five states to receive a grade 'A' for facilitating health care professionals to effectively manage the pain and suffering of patients without legislative or regulatory barriers. Although Wisconsin is a leader in the nation for pain management policies, many cancer patients in the state still experience barriers in receiving total symptom management. Informing providers of standard cancer symptom management

while educating and consulting with patients and their families to inform all parties of its benefit can help improve the total symptom management a patient receives. Identifying indicators and useful sources of data for monitoring quality symptom management may help further improve symptom management for all cancer patients.

When a patient receives a diagnosis of advanced incurable cancer, the focus of their treatment becomes reducing suffering and improving the quality of life during the last phases of life. Patients and their families should be offered services to address physical, psychological, social, spiritual and bereavement issues involved in the dying process. End of life services are available through hospice

in every Wisconsin county and a growing number of hospitals include palliative care services. Yet many cancer patients are not able to access quality symptom management. To increase the utilization of end of life care for patients and their families, providers should be trained to meet the standard of care for cancer symptom management, be educated to understand cultural aspects of end of life care, and make earlier referrals to palliative care services including hospice. Identifying sources of data to monitor quality symptom management is a goal that will move Wisconsin toward ensuring every resident's right to total symptom management and quality of life up to and during the last phases of life.

# **Priority I: Improve advance care planning**

# Strategy A: Promote completion of advanced care documents for all cancer patients near the time of diagnosis or early in their treatment.

# Action steps to implement this strategy

Assess baseline and set goals for number of cancer patients with advanced care documents.

Promote access to and utilization of quality state approved advanced care documents.

Conduct research to increase understanding of cultural barriers to completion of advanced directives.

### Strategy B: Improve accessibility of advanced care documents within a health care system.

# Action steps to implement this strategy

Develop uniform system-wide methods for making quality advanced care documents readily available.

Make patient and their families aware of their advanced care documents and show them how to access those documents.

Educate health care teams on the importance of and the state mandate on documenting advance directives.

# Strategy C: Increase advanced care directives conversations between cancer patients, their families and providers.

# Action steps to implement this strategy

Encourage health care systems to develop provider reminders for advanced care directive conversations.

Educate providers on need for and the reimbursement of advanced directives conversations.

Train providers on how to conduct culturally appropriate advanced directives conversations.

Provide patient and family education on the importance of advanced directive and how to ask for them.

# **Priority II: Increase access to quality symptom management**

# Strategy A: Increase number of providers that meet standard of care for cancer symptom management.

# Action steps to implement this strategy

Promote additional training for physicians in cancer symptom management.

Establish minimum continuing medical education requirements for physicians in pain or palliative care.

Promote additional training & certification for other providers and allied staff (nurses, LPNs, CNAs, etc.) in palliative care & cancer symptom management.

Increase number of palliative care fellows.

# Strategy B: Increase educational opportunities for cancer patients and their families to understand their right to quality symptom management.

Action steps to implement this strategy Create and promote culturally appropriate educational resources on cancer symptom management for cancer patients and their families.

Advise cancer patients that quality symptom management is an expected part of their cancer care.

# Strategy C: Increase consultations for patients with advanced cancer that would benefit from palliative care services.

Action steps to implement this strategy Develop guidelines for which patients could benefit from palliative care consultation.

Develop culturally appropriate tools that make it simpler for patients and families to request palliative care consultations.

# Strategy D: Identify indicators and useful sources of data for monitoring quality symptom management.

Action steps to implement this strategy Encourage health systems to adopt and implement quality symptom management standards.

Encourage health systems to assess and respond to symptom severity.

Promote creation and adherence to standard pain management tools within a health system.

# Priority III: Increase access to quality end of life care

### Strategy A: Increase cancer patient referrals to and utilization of hospice services.

# Action steps to implement this strategy

Create Wisconsin report card by county or region to measure percentage of cancer patient referrals and length of stay in hospice.

Create and promote culturally sensitive education resources on end of life care for providers, cancer patients and their families.

Advise cancer patients that quality end of life care is an expected part of cancer care.

# Strategy B: Decrease number of cancer patients who die in intensive care units (ICU) and emergency rooms (ER).

### Action steps to implement this strategy

Establish baseline data on cancer patient ICU and ER deaths.

Provide training opportunities and guidelines for ICU and ER staff on palliative care services and how to access them.

Establish algorithms that ICU and ER staff can use to quickly identify appropriate cancer patients for palliative care consultation.

# Strategy C: Increase number of systems that provide culturally appropriate bereavement services for cancer patients and families.

# Action steps to implement this strategy

Promote health care systems offerings of bereavement services to non-hospice patients.

# **Targets for Change**

# INCREASE THE NUMBER OF WI RESIDENTS 65 YEARS OR OLDER THAT HAVE AN ADVANCED CARE DOCUMENT

**Baseline:** Pending

\*Note this baseline will not be available until 2011. At that time we will update the online version of the Plan with this Target for Change. Health Plan Employer Data and Information Set (HEDIS) measures 2010, volume 2. National Committee for Quality Assurance. 2010. The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

2015 Goal: Pending

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

### INCREASE THE PERCENTAGE OF CANCER PATIENTS WITH PAIN UNDER CONTROL

Baseline: Pending

\*Note this baseline will not be available until 2011. At that time we will update the online version of the Plan with this Target for Change. Centers for Disease Control and Prevention. BRFSS: Behavioral Risk Factor Surveillance System. Survivorship Module. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Atlanta, GA. 2011.

The goal will be developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

2015 Goal: Pending

### MAINTAIN THE HIGHEST LEVEL STATE GRADE FOR PAIN POLICIES

**Baseline: A grade** 

Pain & Policy Studies Group. Achieving Balance in State Pain Policy: A Progress Report Card (Fourth edition). University of Wisconsin Paul P. Carbone Comprehensive Cancer Center. Madison, Wisconsin, 2008.

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

2015 Goal: A grade

### INCREASE THE NUMBER OF WISCONSIN HOSPITALS WITH A PALLIATIVE CARE PROGRAM

Baseline: B grade

2015 Goal: A grade

Center to Advance Palliative Care. America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals. National Palliative Care Research Center. New York, NY. 2008.

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# DECREASE THE PERCENTAGE OF HOSPICE PATIENTS WITH A LENGTH OF STAY LESS THAN 8 DAYS

Baseline: 30%

2015 Goal: 20%

The 2009 Report on Wisconsin Hospices and Patients. The Hospice Organization and Palliative Experts of Wisconsin. Madison, WI. 2009.

The goal was developed by the WI CCC Program and partners for purposes of the WI CCC Plan 2010-2015.

# Chapter 6: DATA COLLECTION & REPORTING

# **Chapter 6: Data Collection & Reporting**

# Goal: Improve the quality of cancerrelated data

### Parameter for the WI CCC Plan 2010-2015:

The Data Collection and Reporting Chapter focuses on all cancer related data throughout the continuum of cancer – from prevention to end of life.

### Introduction:

Data can influence the continuum of cancer care and offer new insights into how cancer could be prevented and treated in the future. To better understand the impact of cancer in Wisconsin and identify areas of ongoing research and outreach, it is necessary to improve the ongoing, timely, systematic collection and analysis of cancer incidence and mortality data.

State and national organizations have assessed the strengths and weaknesses of the Wisconsin Cancer Reporting System (WCRS), reaching the consensus that the current WCRS staffing levels are inadequate. The Wisconsin Cancer Reporting System has the third highest staff to case ratio in the nation. Wisconsin's caseload is 4,063 cases per staff, almost double that of the national average. Additionally, standards for timely reporting to the WCRS are not met on a consistent basis. Most cancer cases are reported nine to twelve months after diagnosis despite WCRS requirements that all cases be reported within six months of diagnosis and CDC requirements for a 90% complete database 12 months after the close of the reporting cycle.

This information needs to be continually reported, collected and, disseminated. In order to improve the WCRS there must be an increase in staff and funding for the WCRS, improvement in reporting compliance, and an increase in utilization of cancer registry data.

As cancer research evolves and the techniques used to address issues across the cancer care continuum change, it is vital to identify and disseminate emerging research. The collaboration of various research and data collection projects throughout the state can help identify new and existing data sources. Additionally, improving the timeliness of existing data would subsequently increase the utilization and potential impact of the data. Altogether, improving data collection for existing data sources, improving the utilization of existing data, and increasing the linkages with other data systems will collectively improve Wisconsin specific cancer related data sources.

There are new issues that emerge across the cancer care continuum that need to be monitored. One of these emerging issues is environmental factors and the role they may play in cancer prevention and control. Due to preliminary indicators showing that some environmental factors contribute to cancer incidence and mortality, it is important to continue monitoring environmental issues as they pertain to cancer. We will monitor the connection between the environment and cancer and the role it may play in future WI CCC Plans.

# **Priority I: Improve the WI Cancer Reporting System**

### Strategy A: Increase staffing and funding for the WI Cancer Reporting System.

Action steps to implement this strategy

Develop a promotional campaign to increase awareness of career development options for Certified Tumor Registrars.

Support efforts to increase state funding for WI Cancer Reporting System.

### Strategy B: Improve reporting compliance.

Action steps to implement this strategy Increase electronic reporting to the WI Cancer Reporting System.

 $\label{promote timely reporting to the WI Cancer Reporting System. \\$ 

Improve quality and completeness of cancer patient data reported to the WI Cancer Reporting System, particularly regarding race/ethnicity, social security number, stage of disease at diagnosis and treatment.

### Strategy C: Increase use of cancer registry data.

Action steps to implement this strategy Increase access to public data sets.

Review administrative rules and help communicate the policies and procedures to qualified researchers.

# **Priority II: Improve Wisconsin specific cancer related data sources**

# Strategy A: Improve data collection for existing data sources.

# Action steps to implement this strategy

Facilitate a collaboration of cancer data collectors and users to assess emerging cancer issues and how to incorporate them into existing cancer data reporting systems.

Train health care system intake personnel and individuals who gather patient histories about the importance of properly reporting demographic information, specifically related to race and ethnicity.

### Strategy B: Improve utilization and timeliness of existing data.

# Action steps to implement this strategy

Develop a resource to educate end users on utilization of cancer findings.

Educate researchers on tailoring their data findings to different audiences and focus on the impact their findings might have for different organizations.

### Strategy C: Improve linkages with other data systems.

# Action steps to implement this strategy

Inventory and promote existing cancer-related data and relevant reports.

Collaborate with other cancer-related data groups to help guide cancer data collection and reporting.

# **Priority III: Monitor emerging cancer data issues**

# Strategy A: Collect data to measure emerging needs identified within other chapters of the WI CCC Plan.

# Action steps to implement this strategy

Work with the CCC task forces to identify data needs and support collection efforts.

Research existing databases as potential data sources for cancer-related measurements.

Collaborate with other cancer groups to develop new cancer data-related projects.

### Strategy B: Assess possible environmental issues as they relate to cancer.

# Action steps to implement this strategy

Inventory environmental-related cancer risk data & relevant findings with experts on this issue.

Promote the inventory to Wisconsin residents and organizations.

Identify information or data gaps and develop a plan to address those gaps.

# **Targets for Change**

# DECREASE THE NUMBER OF CANCER CASES PER FEDERALLY FUNDED STAFF AT THE WI CANCER REPORTING SYSTEM

WI CANCER REPORTING SYSTEM				
Baseline: 4,063	2015 Goal: 2,000			
State Profiles provided at CDC NPCR Program Manager's Meeting, March 2006, Atlanta, GA. 2006.	The goal was developed by the WI CCC Program, WI Cancer Reporting System and partners for purposes of the WI CCC Plan 2010-2015.			

# INCREASE THE ELECTRONIC REPORTING OF CANCER CASES TO WI CANCER REPORTING SYSTEM

Baseline: 80%	2015 Goal: 90%
The baseline was developed for purposes of the WI CCC Plan 2010-2015 by the WI CCC Program through correspondence with partners from the Wisconsin Cancer Reporting System.	The goal was developed by the WI CCC Program, WI Cancer Reporting System and partners for purposes of the WI CCC Plan 2010-2015.

# INCREASE THE INTEGRATION OF STATEWIDE SURVEILLANCE SYSTEMS FOR CANCER DATA

Baseline: None	2015 Goal: Establish a system to integrate all surveillance systems for cancer data
Information from WI CCC Plan 2010-2015 workgroup planning process.	The goal was developed by the WI CCC Program, WI Cancer Reporting System and partners for purposes of the WI CCC Plan 2010-2015.

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### **Online Information & Resources**

The following Appendices can be viewed and downloaded at www.wicancer.org:

How You Can Use the WI CCC Plan 2010-2015.

Appendix A: Cancer Screening Guidelines

Appendix B: Wisconsin Demographics





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