## The Maine Comprehensive Cancer Control Plan 2006 - 2010

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www.mainecancerconsortium.org

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Maine Cancer Consortium c/o American Cancer Society One Main St., Suite 300 Topsham, ME 04086

207-287-4715

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May 2006

#### Dear Mainers:

Cancer has become the leading cause of death in our state and leaves no family untouched. It is estimated that 7,910 Mainers will be told, "You have cancer" in 2006. They will join the thousands of individuals in the state who are already living with the disease. By the end of the year, family, friends, and co-workers will mourn the loss of over 3,000 people to cancer.

The Maine Cancer Consortium is pleased to present the Maine Cancer Plan 2006 – 2010. Recognizing the need to dramatically impact the cancer burden, the Maine Cancer Consortium, Maine's statewide comprehensive cancer control partnership, has updated the Maine Cancer Plan to reflect emerging needs and new issues in cancer prevention, detection, and care. The plan serves as a blueprint for what can and should be done at the state and local level for cancer prevention, detection, and care efforts in Maine. It identifies activities for coordinated action by government, the private sector, the non-profit sector, and Maine's communities and people.

This cancer plan, created with the assistance of more than 130 organizations, builds upon Maine's existing efforts, programs and services.

Thank you for using the Maine Cancer Plan 2006 – 2010. The Maine Cancer Consortium invites you to learn more about our efforts and to join us in our ongoing efforts to reduce the burden of cancer in Maine.

Sincerely,

Kip DeSerres, MSPH

Chair

Don Magioncalda, MD

Co-Chair

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The Maine Cancer Plan 2006 – 2010 was created by the Maine Cancer Consortium, an extraordinary group of dedicated and passionate individuals who generously volunteered their time and expertise to this effort. The Maine Cancer Plan 2006 – 2010 reflects their knowledge of and experiences with the most important cancer issues facing Maine and its people.

A sincere thank you goes to the Maine Cancer Consortium Board of Directors. They have led Maine's comprehensive cancer control efforts through many opportunities and challenges, and because of their guidance and commitment, Maine has become a leader in comprehensive cancer control.

Kolawole Bankole, MD, MS Public Health Division, City of Portland

Nadine Bullion, LCSW
Eastern Maine Medical Center, CancerCare of Maine

\*Kip DeSerres, MSPH American Cancer Society

Melanie Feinberg, BA Maine Medical Center

Tina Pettingill, MPH, CPC
Public Health Division, City of Portland

Mary Beth Hill, LSW Penobscot Bay Medical Center, Cancer Care Center

Evelyn Kieltyka, MSN, MS, FNP Family Planning Association of Maine

Barbara Leonard, MPH Maine CDC (12/05)

Allen L'Italien, RN, OCN
Eastern Maine Medical Center, CancerCare of Maine

Elisa Madore Houlton Regional Hospital

\*Don Magioncalda, MD MaineGeneral Medical Center

Kandyce Powell, MSN, RN Maine Hospice Council, Inc.

Meredith Tipton, PhD, MPH University of New England

The Maine Cancer Plan 2006 – 2010 could not have been developed without the diligence of the Maine Cancer Consortium Work Groups. Members of the Work Groups are the state's foremost experts in cancer prevention, detection, treatment, rehabilitation and survivorship, palliation, data, and evaluation. They worked tirelessly to identify what should be done to reduce the impact of cancer on Mainers. Their hard work provides the foundation for this Plan, and their dedication to fighting cancer is inspirational. The names of the Work Group members can be found at the beginning of each section.

Additional acknowledgements and thanks are extended to the following for their assistance in providing data analysis and support: Castine Verrill, MS, Maine Cancer Registry, Katie Meyer, ScD, Chronic Disease Epidemiologist, Kip Neale, Maine Behavioral Risk Factor Surveillance System Program, Joni Foster, BS, HIV Education Coordinator, Meredith Anderson, MPH, Epidemiologist, Brenda Joly, PhD, MPH, University of Southern Maine Muskie School of Public Service, and Amy Black, MA, Maine Center for Public Health.

State cancer planning has become a national movement over the past five years, and today, all states and several tribal and territorial organizations have developed a cancer plan. These plans have informed the content and format of the *Maine Cancer Plan* 2006-2010, and for that, we are grateful. Special thanks goes to the Arizona and Maryland comprehensive cancer control program staff for their willingness to share their thorough and well-written state cancer plans, both of which significantly influenced the development of the *Maine Cancer Plan* 2006-2010.

Many thanks to Anita Ruff, MPH, CHES, Centers for Disease Control and Prevention's New England Regional Public Health Advisor for writing the Plan. Lastly, special thanks are extended to Holly Richards, BS and Netta Apedoe, MPH, of the Maine Comprehensive Cancer Control Program for their work on this Plan.

The Maine Cancer Plan 2006 – 2010 is dedicated to those in Maine who have been touched by cancer.

## EXECUTIVE SUMMARY

In 2006, 7,910 Mainers\* will be told, "You have cancer." They will join the thousands of individuals in the state who are already living with the disease. By the end of the year, family, friends, and coworkers will mourn the loss of over 3,000 people to cancer. Unfortunately, there is no one in Maine who has not been touched by cancer.

Cancer takes a huge toll on Maine and its people. For the first time in history, cancer is the leading cause of death in Maine. At the end of each day, twenty-two Mainers will have been diagnosed with cancer, and nine will have died from the disease. It is a significant public health issue in terms of personal suffering, increased medical costs, premature deaths, and loss of productive years of life. However, the good news is that cancer mortality is on the decline so fewer Mainers are dying from cancer than ever before.

Recognizing the need to dramatically impact the cancer burden, the Maine Cancer Consortium (Consortium), Maine's statewide comprehensive cancer control partnership, has updated the Maine Cancer Plan to reflect emerging needs and new issues in cancer prevention, detection, and care. After an extensive review of scientific literature, data, and past accomplishments, the Consortium has developed goals, objectives, and strategies, which if achieved, will have significant bearing on cancer in Maine.

The Maine Cancer Plan 2006 – 2010 seeks to impact Maine's cancer burden in these areas:

Cancer Disparities
Primary Prevention
Early Detection
Treatment
Rehabilitation and Survivorship
Palliation and End of Life Care
Data and Surveillance
Implementation
Evaluation

The purpose of the *Maine Cancer Plan* 2006 - 2010 is to serve as a blueprint for what can and should be done at the state and local level for cancer prevention, detection, and care efforts in Maine. It identifies activities for coordinated action by government, the private sector, the non-profit sector, and Maine's communities and people. This is a living Plan and serves as a guide for Maine individuals and organizations in the fight against cancer.

<sup>\*</sup> The use of the word "Mainers" throughout this Plan refers to everyone who lives in Maine. This includes those who are native to the state, relocated to Maine, immigrants, refugees, migrant workers and anyone who accesses healthcare in Maine.

## INTRODUCTION

In 2006, 7,910 Mainers will be told, "You have cancer." They will join the thousands of individuals in the state who are already living with the disease. By the end of the year, family, friends, and coworkers will mourn the loss of over 3,000 people to cancer. Unfortunately, there is no one in Maine who has not been touched by cancer.

Cancer takes a huge toll on Maine and its people. For the first time in history, cancer is the leading cause of death in Maine.<sup>3,i</sup> At the end of each day, twenty-two Mainers will have been diagnosed with cancer, and nine will have died from the disease. It is a significant public health issue in terms of personal suffering, increased medical costs, premature deaths, and loss of productive years of life. However, the good news is that cancer mortality is on the decline so fewer Mainers are dying from cancer than ever before.

Cancer is a costly disease. In 2004, 7,778 hospitalizations occurred in Maine as a result of cancer with direct and indirect costs of cancer totaling nearly \$700 million. The economic, psychological, and social burden of cancer on individuals, families, and communities is beyond measure. This burden can be dramatically reduced if proven advances in prevention, early detection, and care are made available to all Mainers.

A problem of this scope can only be addressed with a comprehensive, coordinated, and interdependent approach: comprehensive cancer control. Comprehensive cancer control is defined as a collaborative process through which a community and its partners pool resources to promote cancer prevention, improve cancer detection, increase access to health and social services, and reduce the burden of cancer.

Recognizing the need to dramatically impact the cancer burden, the Maine Cancer Consortium (hereafter referred to as the Consortium), the statewide comprehensive cancer control partnership, was established in 1999. After an extensive review of literature, data, and current activities, the Consortium has developed goals, objectives, and strategies that, if achieved, will have significant bearing on cancer in Maine. The Consortium has put forth these goals, objectives and strategies in this document, *The Maine Cancer Plan* 2006 – 2010 (hereafter referred to as the Plan).

Specifically, the implementation of the Plan will:

- Increase state and local coordination of and access to high quality prevention, detection, treatment, rehabilitation/survivorship, palliative, and end of life care services in Maine;
- Increase the proportion of Maine residents who appropriately utilize screening, follow-up, treatment, rehabilitation, survivorship, hospice and palliative care services;
- Improve the quality of cancer surveillance and other data systems, and
- Increase support from policy and grant makers for comprehensive cancer control in Maine.

The purpose of the Plan is to serve as a blueprint for what can and should be done at the state and local level for cancer prevention, detection, and care efforts in Maine. It identifies activities for coordinated action by government, the private sector, the non-profit sector, and Maine's communities and people. This is a living Plan and serves as a guide for Maine individuals and organizations in the fight against cancer.

<sup>&</sup>lt;sup>1</sup> Both heart disease and cancer are experiencing a decline in mortality, although heart disease has gone down at a faster rate. This may be due largely to a reduction in tobacco use.

### THE MAINE CANCER CONSORTIUM

The Maine Cancer Consortium was created in 1999 to develop and implement Maine's comprehensive cancer control plan. The mission of the Consortium is to reduce the burden of cancer in Maine by working collaboratively to optimize quality of life by improving access to care, prevention, early detection, treatment, rehabilitation, survivorship, palliation and end of life care.

Membership to the Consortium is free and open to anyone committed to furthering the mission. Representatives include those from public and private organizations involved in all aspects of cancer prevention, control, and care. Currently, there are over 130 organizations involved in the Consortium. A list of organizations is located on the back cover.

The Consortium is comprised of an elected Board of Directors, Work Groups and Task Forces. An organizational chart is located in Appendix B.

Since the release of Maine's first cancer plan, there has been significant progress in the fight against cancer, including those activities initiated by the Consortium, as well as related factors.

#### Examples include:

- Obtaining funding for several initiatives, including skin cancer prevention, colorectal cancer detection, rehabilitation and survivorship, and end of life issues.
- Developing a consensus statement on colorectal cancer screening guidelines.
- Collecting Maine's first ever data on the needs of cancer survivors.
- Identifying the quality of life for those at the end of life in Maine's long-term care institutions and Veterans Homes.
- Achieving progress for approximately 68% of the strategies assessed in the prior version of the Maine Cancer Plan.
- Developing an educational series on cancer-related topics for Consortium members.
- Implementation of skin cancer prevention activities in classrooms, state and municipal parks and recreation departments, school athletics, and other community organizations.
- Development and implementation of the *No Sun for Baby Program*, a hospital-based education for new parents.
- Administration of grants to eight hospitals on colorectal cancer awareness and screening.
- Increased professional awareness on skin cancer prevention and detection, colorectal cancer screening, and cancer genetics.
- Increased representation and involvement of community organizations in implementing Cancer Plan activities.
- Creation of the Maine Comprehensive Cancer Control Program at the Maine Center for Disease Control and Prevention, including two full time staff members and federal funding.

In addition to the progress made by the Maine Cancer Consortium, there have been other correlating activities that have impacted Maine's cancer prevention, control and care efforts. These include the Master Settlement Agreement with tobacco companies, the creation of the Maine Center for End of Life Care, and the passage and implementation of the Breast Cancer Treatment Act.

## THE BURDEN OF CANCER IN MAINE

For the first time in history, cancer has become the leading cause of death in Maine with one in four deaths due to cancer. There is good news, though. Improvements in prevention, detection, and treatment of many types of cancer have led to a decline in the overall cancer death rate in Maine and the nation. Despite these declines, cancer continues to demand significant focus and resources. The population in Maine is aging and becoming demographically more diverse. Because the risk of having cancer increases with age, it is anticipated that the number of cancer cases will double by 2050. This increase will place a significant demand on the health care system.

#### Cancer Incidence

Cancer incidence is the number of newly-diagnosed cases of cancer occurring in a population in a given period of time. In 2002, Maine's overall cancer incidence rate was 500.8 per 100,000 population, which was higher than the United States overall cancer incidence rate of 479 per 100,000 white population (Figure 1).

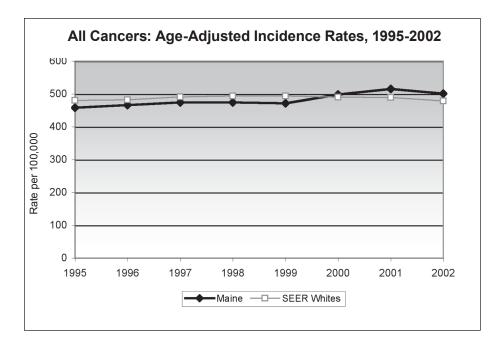


Figure 1: Total Cancer Incidence Rates, 1995 – 2002 Source: The Surveillance, Epidemiology and End Results Program (white population) and the Maine Cancer Registry

The four leading cancer diagnoses in Maine are lung, breast, prostate and colorectal cancers accounting for over half of all the cancer diagnoses in Maine. Mirroring national trends, Maine men have higher overall cancer incidence rates than females (589.9 per 100,000 vs. 439.2 per 100,000 respectively in 2002).

Within Maine, there are differences between the 16 counties. For instance, according to the most recent data from 2000-2002, Cumberland and Lincoln Counties have a significantly lower overall

<sup>&</sup>quot; This may be attributed to advancements in the prevention and treatment of cardiovascular disease, the long time leading cause of death in Maine and the United States.

cancer incidence rates than other Maine counties. Conversely, Washington and Somerset Counties have significantly higher overall cancer incidence rates.

See Appendix J for additional cancer incidence statistics.

#### Cancer Mortality

Cancer mortality is the number of deaths due to cancer. For the first time in history, cancer is the leading cause of death in Maine. In 2002, Maine's cancer mortality rate was 213.9 per 100,000 population, higher than that of the United States (191.6 per 100,000) (Figure 2). Additionally, Maine has the highest cancer mortality rate in New England.

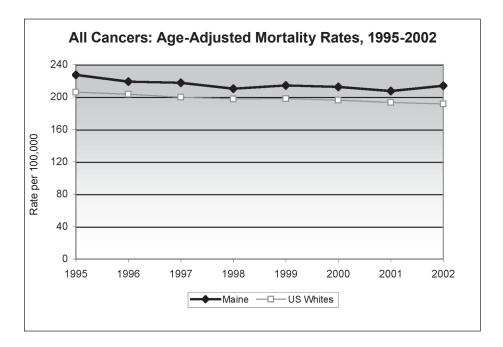


Figure 2: Total Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics.

The leading causes of cancer deaths in Maine are lung, breast, colorectal, prostate, ovarian, and pancreatic cancers. Data from 2000-2002 indicates that Washington County has a significantly higher overall cancer mortality rate than other Maine counties. Similar to cancer incidence rates, more Maine men die of cancer than women.

See Appendix I for additional cancer mortality statistics.

#### Cost

According to the National Institutes of Health, in 2005 cancer will cost this country an estimated \$210 billion which includes nearly \$136 billion for lost productivity and over \$70 billion for direct medical costs.<sup>6</sup>

Each year,

- Colorectal cancer treatment costs about \$6.5 billion.
- Breast cancer treatment costs nearly \$7 billion.

• Cervical cancer treatment costs about \$2 billion.<sup>7</sup>

In Maine, chronic diseases, including cancer, are the leading causes of disability. The estimated cost of cancer for Maine is \$700 million for all related costs. This includes \$234 million for direct medical costs, \$61 million for indirect morbidity (lost productivity due to illness), and \$356.1 million for mortality (lost productivity due to premature death).<sup>iii</sup>

iii Adapted from national rates and the estimated number of cases that were detected in Maine in 2000, ACS Facts & Figures, 2000

## **CANCER DISPARITIES**



## **CANCER DISPARITIES**

The face of Maine is changing. Maine is becoming an older and more diverse state. There is a need to adapt cancer prevention, detection, and care system to better meet the needs of all Mainers.\* Disparities in health care access, utilization, and delivery are well established.8 Access to, and delivery of, quality health care and differences in cancer screening and follow-up, as well as disparities in cancer treatment,9 palliative care, and pain management<sup>10</sup> are all factors related to racial/ethnic and geographic disparities in cancer rates and outcomes.

#### What are Health Disparities?

Cancer affects all people. However, it may not affect all Mainers equally. A National Institutes of Health working group defined health disparities as differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the United States. These population groups may be characterized by gender, age, ethnicity, education, income, social class, disability, geographic location, and sexual orientation.<sup>11</sup>

#### Age

The risk of having and dying from cancer increases dramatically with age, and the majority of cancers occur in people aged 65 and older (Figures 3 & 4).<sup>12</sup> Today, Maine ranks fourth in the nation for the percentage of adults over the age of 65. With the growth in this population expected to accelerate rapidly, there is an expected increase from 14% in 2000 to 26.5% in 2030, which will make Maine the second oldest state in the United States after Florida.<sup>13</sup> This statistic underscores the increasing importance of high quality and accessible cancer detection, treatment, survivorship and end of life services.

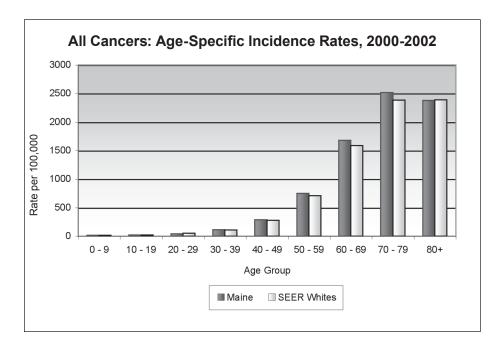


Figure 3: Age-Specific Incidence Rates, 2000-2002 Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program.

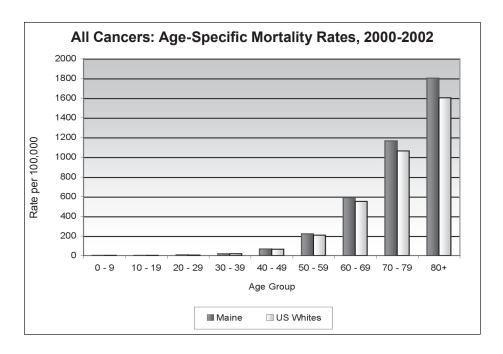


Figure 4: Age-Specific Mortality Rates, 2000-2002 Source: National Center for Health Statistics.

#### Race and Ethnicity

While almost 97% of Maine's population is white, people of different races and ethnicities are living throughout the State. For example, racial and ethnic minorities account for 7.8% of Portland's population. Washington Country has the highest percentage of racial minorities in Maine (6.5%) with 4.4% of its population identifying themselves as Native American. Since 1999, several thousand refugees have settled primarily in the southern part of the state, the health and social needs must be understood and addressed.

Nationally, it has been well documented that disparities exist in the cancer incidence and mortality among different racial and ethnic groups. For instance, from 1997 to 2001, African Americans were at a higher risk of developing and dying from cancer than any other racial or ethnic group. These disparities are due, in part, to social and economic inequities, although higher rates of some cancer in racial minorities cannot be explained only by socio-economic factors. Members of racial and ethnic minority populations are more likely to be poor and lack health insurance coverage. This often leads to delayed treatment and decreased survival.<sup>14</sup>

Percentage of Mainers by Race and Ethnicity, 2004 <sup>15</sup>
Caucasian – 96.3%
Black or African-American – 0.6%
American Indian – 0.4%
Asian – 0.7%
Other – 0.6%
Two or more races – 1.4%
Hispanic or Latino (of any race) 0.9%

#### Socioeconomic Status

Socioeconomic status (SES) refers to a combination of income and other social measures. Inequalities in SES, primarily measured by income and education, underlie many health disparities in Maine, including decreased access to medical care, poor housing, and fewer opportunities to choose healthy behaviors, such as good nutrition.<sup>16</sup>

Many of the differences in cancer incidence and mortality rates among racial and ethnic groups may be due to factors associated with social class rather than ethnicity. Socioeconomic status, in particular, appears to play a major role in the differences in cancer incidence and mortality rates, risk factors, and screening prevalence among racial and ethnic minorities. Moreover, studies have found that SES, more than race, predicts the likelihood of a groups' access to education, certain occupations, and health insurance, all of which are associated with a person's chance of developing and surviving cancer.<sup>17</sup>

In Maine, 140,902 (11%) people are living in poverty with a huge range between poverty and income distribution among Mainers. For example, the poverty rate in York County is 7.9%, while in Washington County, 17.6% of its residents live in poverty. This disparity is alarming and must be addressed when discussing equitable access to cancer prevention, detection, and care resources.

#### **Insurance Status**

Approximately one in eight non-elderly Mainers does not have health insurance, which is equal to the combined populations of Oxford, Lincoln, Washington, Franklin and Piscataquis Counties. Maine people pay a higher percentage of their income for health care than 90% of other states in the United States, making access unaffordable to many. Additionally, many Mainers who have health insurance do not have sufficient coverage to protect themselves from major financial hardship due to illness. Finally, the uninsured are three times more likely to delay care when ill.<sup>19</sup>

### Language and Place of Birth

Although Maine has a small racial and ethnic minority population, language is still a significant barrier to many. Almost eight percent of Maine residents speak a language other than English at home.<sup>20</sup> French is the most common non-English language spoken in Maine. Lewiston, in particular, has the high percentage of a language other than English spoken at home (28%).<sup>21</sup> Additionally, one percent of Mainers are linguistically isolated, meaning that all members 14 years old and over have at least some difficulty with English. It is imperative that cancer information and resources be available in a variety of languages and readability levels to ensure that all Mainers have information that is linguistically appropriate and easy to understand.

Primary Languages Spoken in Maine <sup>22</sup>				
Arabic*	Passamaquoddy			
Chinese	Russian			
French	Somali*			
German	Spanish			
Italian	Tagalog			
Mon-Khmer, Cambodian	Vietnamese			

According to the U.S. Census, there were 36,691 foreign-born residents in Maine in 2000. While the foreign-born represent 3.0% of Maine's overall population, there are significant differences throughout Maine. For example, 7.8% of Portland's population is foreign-born, over twice as many as the state as a whole. Those who are foreign-born are more likely to live in poverty, which impacts health behaviors.<sup>23</sup> This creates unique opportunities and challenges for Maine's public health, medical and social services communities to assure that linguistically and culturally appropriate information and services are available and utilized.

#### Geography

Maine is New England's largest state and is almost equal in land area to the five other New England states combined. The only state east of the Mississippi River with areas of frontier land, Maine is one of the least densely populated states in the United States. Maine is a geographically diverse state, comprised of sixteen counties with a total land area of 30,862 square miles. Over 1.3 million people reside in Maine. Portland is Maine's largest city, and the population in the greater Portland area is over 150,000. Only six other municipalities have populations over 20,000; all but one are located in the southern part of the state.

In 2005, over 60% of Maine's 1.3 million residents live in a rural area, as compared to 21% in the United States as a whole. Rural residents tend to be older, poorer, less educated, and are more likely to be uninsured than their urban counterparts.<sup>24</sup>

These rural communities have higher rates of chronic illness and disability and report poorer overall health status then their urban neighbors. Residents of rural areas generally have less contact and fewer visits with physicians and, in general, lower levels of preventive care.

#### Sexual Orientation

The burden of cancer may vary according to sexual orientation. *The Healthy People* 2010 *Companion Document for Lesbians, Gay, Bisexual, and Transgender (LGBT) Health* is the first comprehensive document of the status of LGBT.<sup>25</sup> According to the report, evidence suggests that LGBT may be at higher risk for some types of cancer, such as breast cancer, cancers related to AIDS, lung cancer, and cancers caused by human papillomavirus. Research is hampered by the lack of data collection on sexual orientation in national surveys and cancer registries. The report highlights the need for better data collection and more research to better identify cancer-related disparities among the LGBT population.<sup>26</sup>

<sup>\*</sup>Two languages not in the top rank of languages spoken in Maine, but spoken by the largest ethnic groups in Cumberland, York and Androscoggin counties.

There are a few key factors that may increase risk for various cancers. Survey research and clinical experience suggest that these risk factors may be more common among lesbians and women who partner with women than among heterosexual women. In general, lesbians may be more likely to smoke, drink more alcohol, and be overweight. All of these behavioral factors increase the risk of cancer. Additionally, lesbians are often less likely to use oral contraceptives, bear children or breast feed, receive routine mammography, or go to the doctor regularly, all of which have been shown to decrease cancer risk.

#### Barriers to Cancer Prevention, Detection and Care

Growing evidence indicates that most people in America receive neither adequate cancer prevention and detection services nor the most appropriate care when faced with a cancer diagnosis. Factors contributing to this failing are many and complex, but the clear and central issue is the failure of our health care system to deliver, in an equitable and timely manner, the cancer care known to be most effective, regardless of a person's insurance status or ability to pay.<sup>27</sup>

The President's Cancer Panel identified several barriers that impact one's ability to receive appropriate cancer-related services. These include:

- Barriers limiting or preventing access to cancer care, including those related to the organization and operation of the health care system.
- Systems barriers, including fragmentation of care, gatekeepers who control access to screening and specialists, and limitations or exclusions on specific drugs and services, including clinical trials.
- Financial barriers.
- Physical barriers, including living in rural or frontier areas.
- Barriers related to lack of information or education, including a lack of accurate cancer-related information that is readily available, understandable, clear, and delivered in a sensitive and culturally acceptable manner.<sup>28</sup>

Certainly, many Mainers face these barriers, and it is imperative to eliminate these obstacles to ensure that all Mainers receive optimal cancer services that does not jeopardize their financial and emotional well being.

## Goal: To reduce cancer disparities in Maine.

Objective 1: Create a Health Disparities Work Group to research and identify barriers to cancer care as well as to develop an action plan to reduce disparities in cancer care by 2010.

- 1. Identify and recruit representatives from disparate populations.
- 2. Identify strategies for addressing cancer disparities.

- 3. Convene a meeting with community members and researchers to identify key research questions related to health disparities in Maine.
- 4. Seek funding for resources to address identified barriers.

# Objective 2: Increase public and professional awareness about cancer health disparities in Maine by 2010.

#### Strategies

- 1. Identify and disseminate a set of core competencies for health care professionals to increase knowledge and understanding of the contributing factors to health disparities.
- 2. Provide at least two educational sessions on core competencies annually to health care professionals.
- 3. Collaborate with government agencies, academic health centers, community and faith-based organizations and private foundations to educate the public about cancer disparities.
- 4. Convene a meeting with health care professionals, cancer survivorship experts and other stakeholders to develop strategies to educate policy makers about unmet needs for cancer treatment of the uninsured and underinsured.
- 5. Identify and advocate the use of existing resources, such as language services in health care facilities.

# Objective 3: Improve capacity to collect cancer data on disparate populations by 2010.

#### Strategies

- 1. Collaborate with the Maine Hospital Association and Office of Minority Health to improve valid recording of race and ethnicity on hospital admission records.
- 2. Analyze cancer data to ascertain disparities in age, gender, race/ethnicity, socio-economic status, sexual orientation and geographic location in Maine.
- 3. Advocate for the Office of Data, Research and Vital Records to improve valid recording of race and ethnicity on death certificates.
- 4. Systematically over-sample disparate populations to increase understanding of cancer prevention and detection knowledge and behaviors.

# Objective 4: Increase awareness of and access to cancer resources among disparate populations by 2010.

- 1. Link disparate populations to available cancer resources via the Maine Cancer Consortium Website.
- 2. Create and distribute resource guides for disparate populations in Maine.
- 3. Research and develop linguistically and culturally appropriate cancer resources for disparate populations.
- 4. Coordinate community outreach meetings with disparate populations to increase awareness of and access to cancer resources.

## PRIMARY PREVENTION



#### Prevention Work Group Members and Contributors

Netta Apedoe, MPH

Maine Comprehensive Cancer Control Program

Kolawole Bankole, MD, MS

Public Health Division, City of Portland

Bonnie Bickford

American Cancer Society

Tina Chapman, BA

Healthy Maine Partnership of Greater Waterville

Deborah Deatrick, MPH

Maine Health

Denise Delorie, BS Town of Fairfield

Kip DeSerres, MSPH American Cancer Society

Judith Feinstein, MSPH Maine Oral Health Program

Andrew Finch, LCSW Healthy Maine Partnerships

Jim Fortunato, BS

Redington-Fairview General Hospital

Dean Girvois

The Power of Prevention, A Health Maine Partnership

Judith Graber, MS

Environmental Public Health Tracking Program

Chriss Hayden, LPN, BS

Public Health Division, City of Portland

Lori Kaley, MS, MSB

University of Southern Maine, Muskie School of

Public Service

Allen L'Italien, RN, OCN

Eastern Maine Medical Center, Cancer Care of Maine

Dorean Maines

Partnership for a Tobacco Free Maine

Kathleen Martin

Public Health Division, City of Portland

Doug Michaels

Healthy Acadia, A Healthy Maine Partnership

Nancy Oden CLEAN: Maine

\*Tina Pettingill, MPH, CPC

Public Health Division, City of Portland

Holly Richards, BS

Maine Comprehensive Cancer Control Program

Anita Ruff, MPH, CHES

Centers for Disease Control and Prevention

Bethany Sanborn, MPH, CHES

Greater Portland Partners for Health, A Healthy

Maine Partnership

Amanda Sears

Environmental Health Strategy Center

Kathianne Shorey Fryeburg Academy

Andrew Smith, S.M., Sc.D.

Environmental and Occupational Health Program

Ken Smith, MS
Genentech BioOncology

**Bob Stillwell** 

Maine Radiation Control Program

Sharon Tisher, JD

University of Maine at Orono

Castine Verrill, MS
Maine Cancer Registry

Angela Westoff
Healthy Androscoggin

\*Work Group Chair

## PRIMARY PREVENTION

Studies over the past decade have demonstrated that over half of all cancers are preventable and that lifestyle factors impact cancer risk. Cancer prevention can be defined as those actions taken by individuals and communities to promote healthy lifestyles through behavior changes, policies and environments. Current recommendations include reducing tobacco use, increasing physical activity, controlling weight, improving diet, limiting alcohol, utilizing safer sex practices, and avoiding excessive sun exposure (Figure 5). Many of these cancer prevention strategies not only reduce the risk of multiple cancers but also significantly reduce the risk of other chronic diseases.<sup>29</sup>

#### Cancer Risk Reduction Benefits

Prevention Strategy	Bladder	Breast	Cervical	Colorectal	Lung	Oral	Pancreatic	Prostate	Skin	Stomach	Uterus
Avoid tobacco	•		•	•	•	•	•			•	
Be physically active		•		•							
Maintain a healthy weight		•		•							•
Eat a healthy diet	•	•		•	•	•	•	•		•	
Limit alcohol		•		•		•					
Limit sexual partners & use condoms			•								
Get appropriate screening tests		•	•	•				•			
Avoid excessive sun exposure						•			•		

Figure 5: Cancer Risk Reduction Benefits Source: Modifiable Risk Factors of Cancer.<sup>30</sup>

#### TOBACCO USE

In November 1998, Maine and 45 other states across the country successfully sued the tobacco industry for the recovery of Medicaid health care costs attributed to tobacco use. As a result, it is estimated that Maine has received approximately \$50 million per year through the Master Settlement Agreement.

Over the past four years, Maine has ranked number one in the nation for its exemplary use of tobacco settlement funding on tobacco prevention, cessation and treatment programs.<sup>31</sup> Through the Partnership For A Tobacco-Free Maine (PTM), the state tobacco prevention and control program, and its many collaborative partners, Maine has made significant strides in reducing tobacco use.

#### Highlights include:

- Increasing taxes on cigarettes to two dollars a pack.
- Decreasing overall consumption of cigarettes by 28% in six years.
- Decreasing youth smoking rates.
- Increasing the number of work places with smoke-free policies.<sup>32</sup>

Tobacco use is the biggest risk factor for lung cancer, Maine's leading cancer killer, and is directly related to almost 30% of all cancer deaths. In the United States, adult smokers lose an average of 13 years of life because of the negative consequences of smoking.<sup>33</sup> In Maine, lung cancer incidence and mortality rates are higher than the rest of the United States (Figures 6 & 7). It is estimated that 1,030 Mainers will be diagnosed with lung cancer in 2006, and 960 will die of this disease.<sup>34</sup>

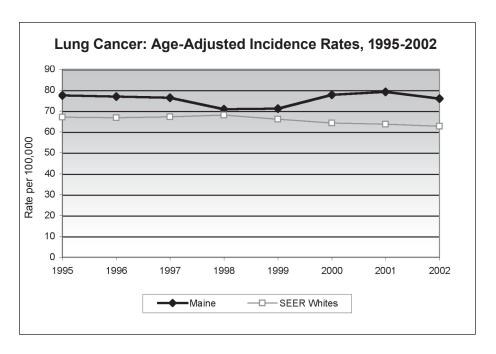


Figure 6. Maine Lung Cancer Incidence Rates, 1995-2002 Source: Maine Cancer Registry Program and Surveillance Epidemiology and End Results Program

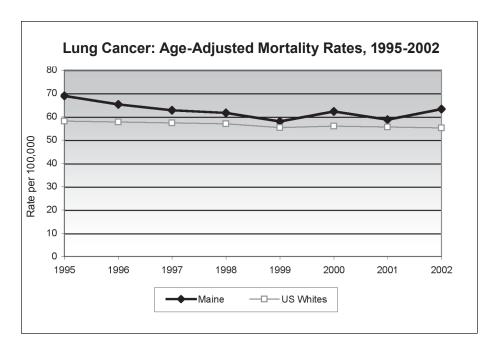


Figure 7. Age-Adjusted Lung Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics

#### Adult Tobacco Use

For lung cancer incidence to decline, efforts must continue to reduce tobacco initiation rates and increase cessation rates in Maine. In 2004, almost a quarter of Maine adults smoked. There are several groups of adults that are more likely to smoke than others, including 18-24 year olds, MaineCare recipients, and adults without insurance.<sup>35</sup> Additionally, men are more likely to smoke than women.

#### Youth Tobacco Use

It is estimated that every day, over 3,800 Maine youth under 18 try smoking cigarettes for the first time. There is evidence that few people initiate their smoking behavior after their teenage years, and that in the United States, nearly 90% of adult smokers began smoking before the age of nineteen.<sup>36</sup> With children and adolescents being the only groups in the United States and in Maine continuing to initiate smoking in large numbers, it is clear that youth prevention and cessation efforts should continue to be strengthened.

The good news is that Maine's youth smoking rates are decreasing (Figures 8 & 9). Highlights include:

- A statistically significant decline in the percentage of middle school and high school students that have ever tried smoking.
- A decrease in the percentage of high school students who are current smokers (2001 26.9%; 2004 22.6%).<sup>37</sup>

The bottom line, though, is that one in five Maine high school students are current smokers; therefore, it is imperative that future activities and resources focus on preventing Maine's youth from smoking.

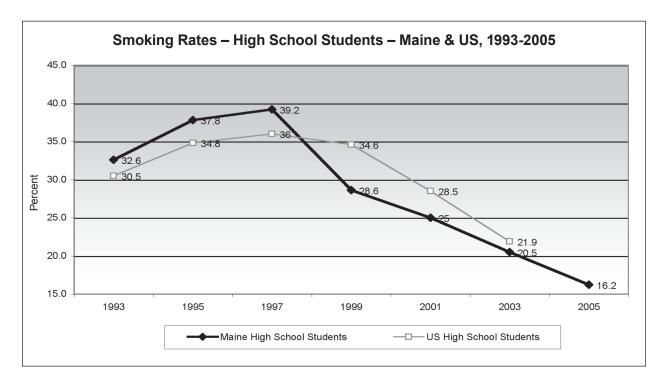


Figure 8. Smoking Rates — High School Students, Maine & U.S., 1993-2005 Source: Maine Department of Education, Youth Risk Behavior Survey

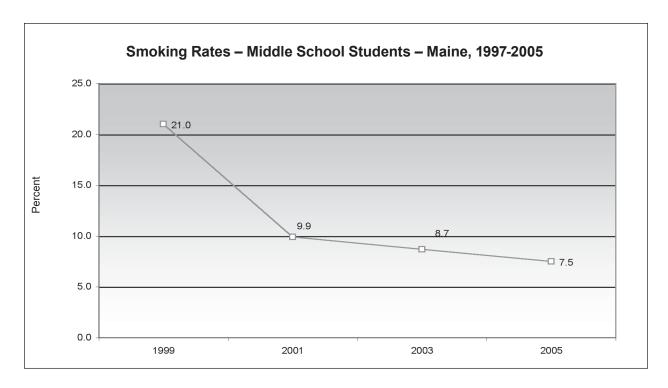


Figure 9. Smoking Rates — Middle School Students, Maine, 1997-2005 Source: Maine Department of Education, Youth Risk Behavior Survey

Goal: To reduce the initiation of tobacco use, to increase the number of people who successfully quit using tobacco, and to reduce exposure to secondhand smoke.

# Objective 1: Reduce the proportions of Maine adults aged 18 and older who use tobacco products to 18% by 2010.

Baseline: 21% of adults are current smokers [have smoked 100 cigarettes in their lifetime and smoke now], BRFSS, 2004.

- 1. Implement and maintain community-based tobacco prevention and control initiatives throughout Maine.
- 2. Advocate for maximum funding to address tobacco and tobacco-related chronic disease through the Fund for Healthy Maine and other sources.
- 3. Promote voluntary policies that reduce exposure to secondhand smoke at home.
- 4. Determine and promote effective messages and culturally appropriate communication methods regarding smoking and cessation for disparate populations.
- 5. Increase the availability of cessation resources for disparate populations.
- 6. Increase the number of college campuses with 24/7 tobacco-free policies (See Appendix A for definition).

# Objective 2: Reduce cigarette smoking among pregnant and postpartum women to 15% by 2010.

Baseline: 6% of women smoke during the last three months of pregnancy and 21% smoke after pregnancy, PRAMS data, 2003.

#### Strategies

- 1. Increase implementation of health care professional-based education and patient counseling resources for pregnant women.
- 2. Advocate for accessible, affordable, and proven cessation resources statewide for pregnant and postpartum women.

# Objective 3: To reduce to bacco use of $9 - 12^{th}$ graders to 15% and 6-8<sup>th</sup> graders to 5.5% by 2010.

Baseline: 16.2% for 9-12th graders and 7.5% for 6-8th graders, MYRBS, 2005.

- 1. Implement evidence-based community programs statewide that include teacher training and parental involvement.
- 2. Engage youth in developing and implementing tobacco control interventions.
- 3. Increase to 100% the number of Maine schools who have implemented Comprehensive School Health Education and have a Coordinated School Health Program.
- 4. Increase to 100% the number of school districts in Maine who have adopted 24/7 tobacco-free policies (See Appendix A for definition).
- 5. Provide accessible, affordable and proven cessation programs for youth in and out of school.
- 6. Seek funding for the development of a statewide, age appropriate, web-based interactive tobacco treatment resource.
- 7. Continue to implement a statewide media campaign to counter pro-tobacco influences, increase pro-health messages and deglamorize use.
- 8. Advocate for enforcement of laws that restrict minors' access to tobacco products.
- 9. Develop and promote parental education for racial and ethnic minorities, such as school parent advisory committees and local community meetings.
- 10. Increase the number of policies adopted and enforced to make outdoor recreation areas tobacco-free environments.

# Objective 4: To increase the proportion of adults who receive advice to quit smoking annually from a health care professional by 2010.

Baseline: 80.6%, BRFSS, 2002.

#### Strategies

- Continue to work with health care professionals to develop systems to increase the number of patients who receive brief advice, counseling, and pharmacotherapy from medical professionals.
- 2. Continue to provide training and resources for health care and social service professionals on tobacco cessation.
- 3. Advocate for and promote insurance coverage for adult tobacco treatment, including coverage of individual and group counseling and proven medications.
- 4. Increase the number of worksites that provide employee tobacco treatment services onsite or through other means.
- 5. Increase the number of hospitals that assess and refer patients for cessation therapy at point of contact.

# Objective 5: Reduce involuntary exposure to secondhand smoke (SHS) for all Maine residents by 2010.

Baseline: 87% of workplaces do not allow smoking in any work areas, BRFSS, 2002; 67% of adults do not allow smoking in their home, BRFSS, 2000.

- 1. Advocate for the closing of loopholes in state and local policies, including voluntary policies that restrict smoking in public places in Maine.
- 2. Promote voluntary policies that reduce the involuntary exposure to secondhand smoke at home
- 3. Increase parental awareness of the harmful effects of SHS on children.
- 4. Increase enforcement of and monitor compliance with existing clean indoor air laws.
- 5. Increase the number of worksites that exceed the state worksite tobacco laws and completely prohibit smoking on buildings or on grounds.

#### OVERWEIGHT/OBESITY, PHYSICAL ACTIVITY & NUTRITION

Obesity is best measured by the body mass index (BMI), which is a formula that takes into account one's weight and height. An adult is defined as overweight if his/her body mass index falls between 25-30 and is defined as obese if it is 30 or above. A body mass index over 25 is closely associated with increased morbidity and mortality.

While tobacco addiction is the leading underlying cause of cancer, recent studies indicate that obesity has become a major risk factor. it. Unfortunately, obesity is the leading risk factor for non-smokers. It is estimated that obesity, which is related to physical inactivity and poor nutrition, kills about six Maine people every day.<sup>38</sup> Obesity costs \$0.5-1.0 billion in health care dollars every year, or roughly \$400-\$800 per capita per year.<sup>39, 40</sup>

A 2003 study from the *New England Journal of Medicine* showed that being overweight or obese is associated with increased risk of death from all cancers, as well as many specific cancers. It is estimated that 90,000 deaths due to cancer could be prevented each year in the United States if men and women maintained normal weight. Overweight and obesity were found to account for an estimated 14% of all deaths from cancer in men and 20% of those in women.<sup>41</sup>

#### Overweight and Obesity in Adults

Obesity rates have risen 75% from about one in ten Mainers in 1990 to more than one in five in 2002. Today, 59% of Maine adults are either overweight or obese. Moreover, available adult data in Maine are self-reported, and according to national, directly measured surveys, the proportion of overweight and obese adults in Maine and in the United States is probably closer to 61%. Further, although Maine's rates of overweight and obese adults are comparable to national rates, Maine has the highest rate of adult obesity in New England.

## Overweight and At Risk for Overweight in Youth

The trends among youth are equally alarming. Overweight among children is defined as being at or above the 95<sup>th</sup> percentile BMI for age and gender, and at risk for overweight is defined as being between the 85<sup>th</sup> and 94<sup>th</sup> percentile BMI for age and gender. About one-third of Maine youth are either overweight or at risk of becoming overweight. Even more alarming, a 2004 survey found that 33% of entering Maine kindergarteners were overweight or at risk for becoming overweight.

Like adult rates, youth rates have increased to epidemic proportions. For instance, in just 20 years, the national rate of overweight children has doubled, while the rate of overweight teens has tripled.<sup>44</sup> The most currently available comparable data suggest this is true in Maine as well (Figure 10).

Child and Youth Overweight and Risk for Overweight, Maine

	At Risk for Overweight	Overweight
High School	15%	13%
Middle School	18%	13%
Kindergarten	18%	15%

Figure 10: Child and Youth Overweight and Risk for Overweight, Maine

Source: High School and Middle School data from 2003 Maine YRBS and Kindergarten data from 2004 Maine Child Health Survey.

#### Adult Physical Activity

One of the major factors to obesity/overweight prevention is physical activity. National recommendations for adults include 30 minutes or more of moderate activity for five or more days per week or 20 minutes or more of vigorous activity for three or more days per week. In Maine, however, only three-quarters of adults engage in physical activity at the recommended levels.

Increasingly, workers today are employed in jobs that require very little physical labor. Additionally, many people cite lack of time as a barrier for being physically active. The societal trends of working many hours, commuting long distances, and working multiple jobs restrict the amount of leisure time available.

The rural nature of Maine has a significant impact on the capacity to improve physical activity. Limited sidewalks, walking trails, bicycle paths, and other resources for physical activity in rural areas are important environmental barriers. Access to facilities for physical activity is a major hurdle for many Mainers. Additionally, climate and limited daylight also impact the opportunity to be active outdoors year round.

#### Youth Physical Activity

Today's society has become very sedentary, and this has impacted the well-being of our youth. Increased rates of overweight in children have coincided with a nationwide declining trend in walking and biking. Most children in Maine are bused or driven to school. Additionally, physical activity continues to be displaced with television, electronic games, and computers.

According to a 1999 Kaiser Family Foundation study, American children ages 2-18 spend an average of four hours per day watching television or videotapes, playing video games, or using a computer.<sup>45</sup> Maine data also confirm this proliferation of screen use. For instance, on an average school day, one in four (26.8%) Maine high school students watch three or more hours of television, and one in five (21%) use a computer for fun or play video games for at least one hour per day.<sup>46</sup>

School budget cuts to physical education programs have also contributed to the decrease in youth physical activity rates (Figure 11). The Maine Youth Risk Behavior Surveillance System indicates that 36% of Maine high school students participated in an insufficient amount of physical activity.

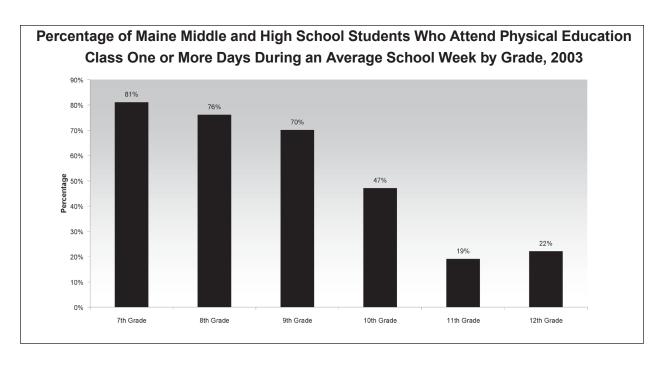


Figure 11: Percentage of Maine Middle and High School Students Who Attended Physical Education Class One Or More Days During An Average School Week By Grade, 2003

Source: Maine Youth Risk Behavior Surveillance System, Maine Department of Education

#### Nutrition

Mainers are consuming too many calories. In just 13 years (1984-1997), calories consumed in the United States increased 15% on a per capita per day basis, with a concurrent decrease in physical activity. <sup>47</sup> In Maine, data indicates that almost three-quarters of adults and high school students do not eat the recommended five servings of fruits and vegetables each day.

Soda consumption is another factor that has been studied and appears to be a contributing factor to poor nutrition, especially among youth. In the United States, the largest source of added sugars is non-diet soda.<sup>52</sup> According to the U.S. Department of Agriculture, 69% of American boys between ages 12-19 consume soda on a given day. Among those who drink soda, an average of 868 cans per year is consumed, 95% of which is non-diet. Among the 62% of girls in this age group who drink soft drinks, an average of 627 cans per year is consumed, 90% of which is non-diet. <sup>48</sup>

# Goal: To reduce and prevent adult risk of colorectal and other cancers through healthful eating habits and physical activity.

Objective 1 : Increase to 30% the proportion of adults who consume five or more servings of fruits and vegetables every day by 2010.

Baseline: 27% of adults, BRFSS, 2003, Maine CDC/PTM Outcome Survey, 2005.

Objective 2: Reduce the proportion of adults that are overweight to 35% or obese to 20% by 2010.

Baseline: 38% overweight; 23% obese, BRFSS, 2004.

Objective 3: Increase to 80% the proportion of adults who participate in any physical activities in the past month.

Baseline: 78.4%, BRFSS, 2004.

Objective 4: Increase to 55% the proportion of adults who participate in 30 minutes of moderate physical activity five or more days per week OR vigorous physical activity three or more days per week.

Baseline: 53.1%, BRFSS, 2003.

- 1. Encourage restaurants to display nutrition information at point of contact.
- 2. Encourage at least three Maine insurers to reimburse preventive nutrition services for adults.
- 3. Promote adequate nutrition intake for adults through culturally and linguistically appropriate education.
- 4. Advocate for ongoing implementation of the Physical Activity & Nutrition Plan.
- 5. Increase the number of communities with walk/bike paths or trails.
- 6. Encourage at least three Maine insurers to provide financial incentives for member's participation in fitness programs.
- 7. Increase the number of employers with environments and policies that support physical activity and improved nutrition for their employees.

# Goal: To reduce risk of colorectal and other cancers through healthful eating habits and physical activity beginning as a child.

Objective 1: Increase to 35% the proportion of youth who consume five or more servings of fruits and vegetables per day by 2010.

Baseline: 23% of high school students, MYRBS, 2003.

Objective 2: Reduce the proportion of youth who are overweight to 5% or at risk for being overweight to 10% by 2010.

Baseline: High school: 13% overweight/15% at risk for overweight and Middle school: 13% overweight and 18% at risk for overweight, MYRBS, 2003.

Objective 3: Reduce the proportion of kindergarten students who are overweight to 5% or at risk for being overweight to 10% by 2010.

Baseline: 15% overweight and 18% at risk for overweight, Maine Child Health Survey, 2004.

Objective 4: Increase to 80% the proportion of youth who engage in vigorous physical activity three or more days per week for 20 minutes or more each time by 2010.

Baseline: 61% high school, 72% middle school, MYRBS 2003.

- 1. Encourage restaurants to display nutrition information at point of decision.
- 2. Encourage at least three Maine insurers to reimburse nutrition services for youth.
- 3. Promote adequate nutrition intake for youth through culturally and linguistically appropriate education.
- 4. Provide advocacy for ongoing implementation of the Physical Activity and Nutrition Plan.
- 5. Advocate for all school districts to comply with USDA PL-108-265 Wellness Policy implementation.
- 6. Increase the number of community opportunities for youth to be physically active.
- 7. Increase the number of schools offering scheduled and supervised physical activity during the school day.
- 8. Increase to 100% the number of Maine schools who have implemented Comprehensive School Health Education and have a Coordinated School Health Program.

#### **ORAL HEALTH**

Nationally, more than 30,000 new cases of cancer of the oral cavity and pharynx are diagnosed annually and result in over 8,000 deaths. These cancers include the mouth, tongue, lips, throat, parts of the nose, and larynx. Oral cancers represent only 2 - 4% of all cancers diagnosed annually in the United States, but their relative survival rates are among the lowest of major cancers. In 2002, Maine's oral cancer incidence and mortality rates were higher than for the United States (Figures 13 & 14).

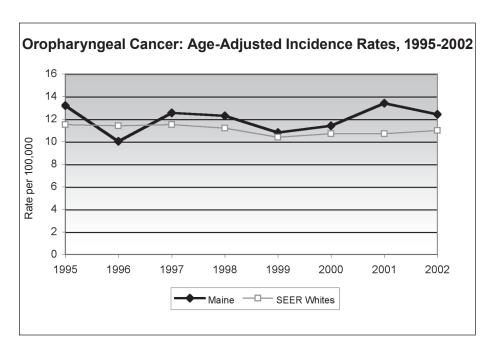


Figure 12: Age-Adjusted Oropharygeal Cancer Incidence Rates, 1995-2002 Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program

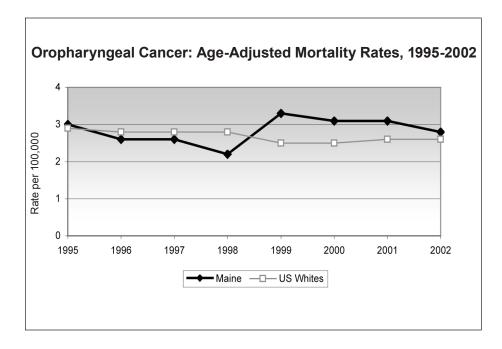


Figure 13: Age-Adjusted Oropharygeal Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics

Reduction of high-risk behaviors, including tobacco use and excessive use of alcohol are significant in preventing oral cancers. The combination of tobacco and alcohol is believed to represent a substantially greater risk than either substance used alone. Among the other factors that can place a person at risk for these cancers are viral infections, immunodeficiencies, poor nutrition, exposure to ultraviolet light, and certain occupational exposures.

In Maine, where there is limited access to oral health services, combining activities to address risk factors within other education, prevention, and early detection initiatives will be key in further reducing the incidence of oral cancers.

# Goal: To reduce the risk of oral and pharyngeal cancers in Maine.

Objective 1: Advocate and support the creation of an evidence-based state oral health improvement plan to reduce the incidence of oral cancer by 2010.

#### Strategies

- 1. Advocate for and participate in the continuation of coordinated efforts between the Maine Oral Health Program and other public, private, governmental and non-profit stakeholders to create and implement the state oral health improvement plan.
- 2. Advocate for the development and implementation of statewide oral health data and surveillance system to collect and disseminate oral health data.

Objective 2: Provide educational opportunities for the public, health professionals and decision makers about the relationship between oral health and systemic health.

- 1. Advocate for and participate in the development and implementation of comprehensive statewide oral health education and awareness programs inclusive of media campaigns that target at- risk populations.
- 2. Increase to 100% the number of Maine schools who have implemented Comprehensive School Health Education and have a Coordinated School Health Program.
- 3. Advocate for and support activities to educate physicians about the link between oral health and overall health.

#### **SUN SAFETY**

#### Skin Cancer Task Force

Netta Apedoe, MPH

Maine Comprehensive Cancer Control Program

Peggy Belanger, RN, BSN Southern Maine Medical Center

Bonnie Bickford

American Cancer Society

Tammy English, MS, RN, OCN

Central Maine Medical Center

Deborah Halbach,

Maine Academy of Family Physicians

Chriss Hayden, LPN, BS

Public Health Division, City of Portland

Eric Kostelnik, MD

Dermatology Associates

\* Task Force Chair

Raya Kouletsis, MS

Maine School Administration District #3

Kent Main

Shering Plough

\*Diane Peterson, CTR, MSB

Mercy Hospital

Holly Richards, BS

Maine Comprehensive Cancer Control Program

Anita Ruff, MPH, CHES

Centers for Disease Control and Prevention

\*Ken Smith, MS

Genentech BioOncology

Stephanie Swan, MEd, CHES

Maine Department of Education

Donna Walsh, RD

Inland Hospital

Research has clearly demonstrated that excessive sun exposure increases the risk for basal and squamous cell carcinomas, as well as malignant melanomas. The melanoma incidence and mortality rates for both the United States and Maine have steadily increased (Figures 14 & 15).\*

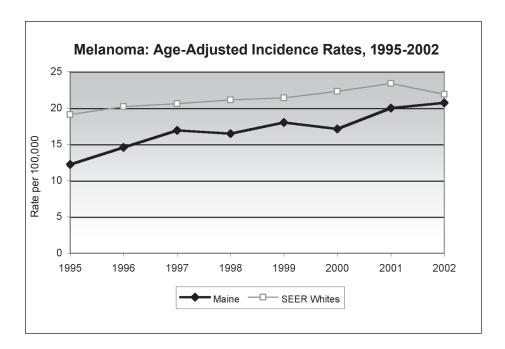


Figure 14: Age-Adjusted Melanoma Incidence Rates, 1995-2002 Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program

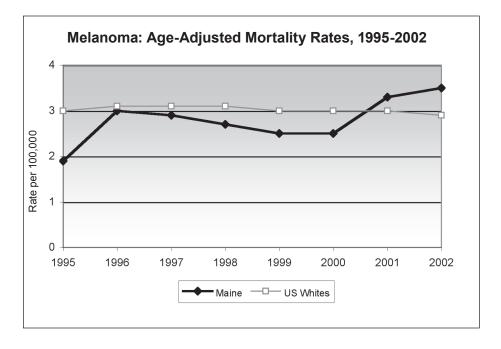


Figure 15: Age-Adjusted Melanoma Mortality Rates, 1995-2002 Source: National Center for Health Statistics

<sup>\*</sup>A portion of the increase in Maine can be attributed to increased reporting of melanoma from physicians.

Excessive exposure to the sun causes most skin cancers, and numerous studies have shown that sunburns during the first 20 years of life are linked to melanoma, the most fatal form of skin cancers. Sun safety practices, such as using sunscreen with a Sun Protection Factor (SPF) of 15 or greater, wearing protective clothing, hats and sunglasses, and seeking shade during peak sun exposure times, can prevent many sunburns. Among Maine adults, nearly one-third report that they always or nearly always use sunscreen. However, only one in five Maine high school students use sunscreen when outdoors.

# Goal: To reduce the risk of skin cancer in Maine.

Objective 1: Increase awareness of skin cancer prevention and detection through at least five annual education opportunities for Maine primary care physicians by 2010.

### Strategies

- 1. Survey hospitals to determine existing skin cancer education efforts.
- 2. Develop and implement medical education for primary care providers in Maine.
- 3. Develop and implement a pilot medical education distance learning activity for rural and island primary care physicians.
- 4. Implement at least two skin cancer education presentations at primary care professional trade association meetings and/or grand rounds.
- 5. Seek funding to develop and expand educational efforts

# Objective 2: Increase to 50% the number of municipal parks and recreation departments with a sun protection policy or guidelines developed by 2010.

- 1. Survey and monitor municipal parks and recreation departments to determine the existence of sun protection policies and guidelines.
- 2. Provide sample policy/guidelines.
- 3. Present or display sun safety education to at least 20 municipal parks and recreation departments.

# Objective 3: Increase to 90% the number of hospitals with birthing units that provide sun safety education to parents of newborns.

Baseline: 66% of hospitals, MCCCP No Sun for Baby Program, 2006.

### Strategies

- 1. Provide mini-grants to implement the No Sun for Babies Program.
- 2. Provide technical assistance, as needed.
- 3. Review the No Sun for Babies Program manual annually.
- 4. Follow-up with the hospitals annually to assess their sun safety activities.
- 5. Seek funding to support and expand efforts.

# Objective 4: Increase to 15% the proportion of Maine youth who use a sunscreen with an SPF of 15 or higher when outside for more than one hour.

Baseline: 12.4%, MYRBS, 2005.

### Strategies

- 1. Develop and disseminate sun safety kits to public and private elementary schools.
- 2. Work with elementary school teachers to identify creative ways to use the kits.
- 3. Increase the utilization of middle and high school sun safety kits.
- 4. Provide sun safety mini-grants to at least 30 elementary schools.
- 5. Develop at least two community-based sun safety education programs.
- 6. Increase to 50% the number of schools/SADs that have sun protection policies or guidelines.
- 7. Seek funding to support and expand efforts.

# Objective 5: Increase awareness and compliance of state law in regards to tanning regulations.

Baseline: 386 facilities in active compliance, Radiation Control Program, 2005.

- 1. Survey tanning bed facilities to assess awareness and compliance of tanning regulations.
- 2. Include education on tanning regulations in at least five existing communication outlets.
- 3. Enhance awareness of tanning regulations and the dangers of tanning in middle and high schools through sun safety kits.
- 4. Evaluate legislation.

### SEXUAL HEALTH

Certain sexually transmitted diseases, including human papillomavirus (HPV), hepatitis B (HBV), and human immunodeficiency virus (HIV), are associated with cancer. Certain types of HPV, specifically HPV-16 and HPV-18, are the major causes of cervical cancer and may also play a role in cancers of the anus, vulva, vagina, and penis. Hepatitis viruses, particularly HBV, have been linked to liver cancers, and HIV has been linked with lymphoma, anal cancer, and Kaposi's sarcoma. Risk factors for sexually transmitted diseases (STDs) include unprotected sexual contact and multiple partners.

Currently, early detection of certain HPV types, such as HPV-16 and -18 is the standard for prevention of cervical cancer. However, with new technologies emerging for HPV-testing, the development of effective HPV vaccines, and increased awareness of HPV among the general public, there may be more emphasis on primary prevention of cervical cancer. Additionally, methods used to prevent other STDs will have some impact on reducing the incidence of HPV infection and, indirectly, the incidence of cervical cancer.

Goal: To reduce the risk of cervical and other cancers associated with sexually transmitted disease in Maine.

Objective 1: Reduce by 10% the incidence of sexually transmitted diseases associated with the development of cancer in Maine by 2010.

Baseline: 12 cases of Acute HBV incidence in Maine, Maine CDC STD Program, 2004; National HPV incidence estimate: 6.2 million.

- 1. Provide health care/social service professionals with at least five opportunities for HPV education.
- 2. Promote public knowledge about HPV by developing and disseminating at least 500 fact sheets for females and health care professionals through collaboration between the Maine Breast and Cervical Health Program, the Maine Comprehensive Cancer Program and the Maine HIV, STD and Viral Hepatitis Program.
- 3. Increase the number of HIV and STD prevention interventions that target individuals at high risk for HPV, HBV and HIV infection.
- 4. Conduct at least two public education campaigns to promote safer sex and/or vaccines by 2010.
- 5. Seek funding for HPV vaccination.

# Objective 2: Promote Hepatitis B vaccine for Maine children 19-35 months of age.

Baseline: 92% received 3 or more doses of hepatitis B vaccine, CDC National Immunization Survey, 2004.

# Objective 3: Promote Hepatitis B vaccines for at-risk adults accessing STD clinics.

### Strategies

- 1. Implement at least two interventions annually to increase the number of children who receive Hepatitis B vaccine by the time they enter kindergarten.
- 2. Provide at least two opportunities annually for people working with middle school children to learn more about viral hepatitis prevention and resources.
- 3. Increase the proportion of sexually active adults who receive free Hepatitis B vaccine by 2010.

# Objective 4: Increase abstinence to 60% among sexually active 9 – 12<sup>th</sup> graders by 2010

Baseline: 55%, MYRBS, 2005.

# Objective 5: Increase condom use at last intercourse to 63% among sexually active 9 - 12<sup>th</sup> graders by 2010.

Baseline: 59%, MYRBS, 2005.

### Strategies

- 1. Implement Comprehensive School Health Education and a Coordinated School Health Program that includes an age appropriate comprehensive sex education curriculum.
- 2. Provide sexuality counseling and education.
- 3. Provide condoms and full family planning services through high school health center grantees.
- 4. Conduct public education to promote condom use as a social/community norm.
- 5. Seek funding to support and expand efforts.

#### **ENVIRONMENTAL HEALTH**

About 20 chemicals found in the environment, including arsenic, asbestos, benzene, cadmium, chromium, radon, and vinyl chloride, have been identified as known human carcinogens by national and international agencies. Many additional chemicals have been identified as being potential human carcinogens. The cancer burden posed by specific environmental carcinogens (aside from occupational exposure) has not been well defined. Despite the fact that the contribution of environmental carcinogens to the cancer burden is not as well understood as some of the other major causes of cancer, such as tobacco use, preventive measures should be initiated. Such measures are largely based on what is known at the present and include the reduction of exposure to hazardous chemicals in the workplace and the reduction of environmental pollution.

### Radon

Radon is a naturally occurring radioactive gas that enters homes primarily through soil, gas, and well water. Radon is the second leading cause of lung cancer after tobacco use.<sup>49</sup> Most of the cancers attributed to radon exposure are expected to occur among Mainers who have used tobacco, a consequence of a synergistic effect of the two exposures together. The National Research Council has estimated that one-third of the radon attributed lung cancer cases could be avoided if all homes had radon levels below the Environmental Protection Agency's action guidelines of 4 picocuries of radon per liter (pCi/L).

One survey estimated that 30% of Maine homes have indoor air radon levels exceeding 4 pCi/L, and a study of 650 schools across the state found 32% had at least one classroom with a radon concentration above 4 pCi/L.<sup>50</sup> Radon from domestic well water may also constitute a significant indoor air radon problem in Maine. Results of a survey of over 3,000 homes found that one in six homes with domestic wells had high levels of radon in the water that could result in high indoor air levels.<sup>51</sup> Of those homes found with high radon concentration, roughly 33% were mitigated in 2000-2001 (Figure 16).

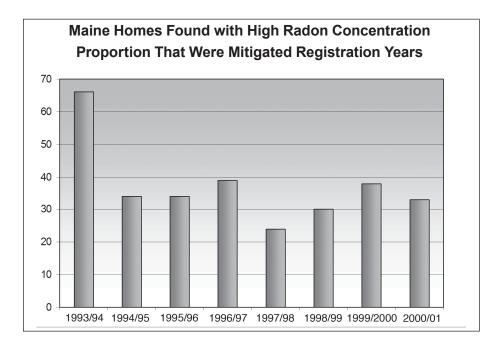


Figure 16: Maine Homes Found with High Radon Concentration, 1993-2001 Source: Maine Department of Human Services, Maine CDC, Program Files, 1993-2001

See Appendix G for Environmental Protection Agency map of radon zones in Maine.

#### Arsenic

Arsenic is a naturally occurring element found in ground and surface water, as well as in many foods. Arsenic-containing pesticides were commonly used in many agricultural settings in Maine in the early to mid-1900s. The effect this has had on ground water is unknown. In a recent report on

arsenic in drinking water, the National Research Council concluded that there is a causal relationship between chronic ingestion of inorganic arsenic and skin, bladder, and lung cancer. <sup>52</sup> Current data indicate that somewhere between 2 - 14% of Maine homes with domestic wells have water with arsenic levels exceeding the national guidelines. Data from 1998 - 2002 indicate that Maine has the highest bladder cancer mortality rate for males and the sixth highest for females in the country. Bladder cancer incidence is also higher in Maine than for the United States but to a lesser degree (Figures 17 & 18). See Appendix H for a map of arsenic distribution in Maine.

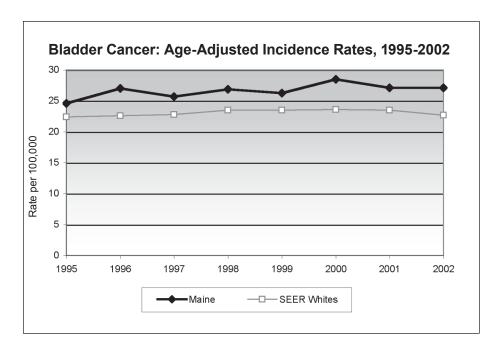


Figure 17: Age-Adjusted Bladder Cancer Incidence Rates. 1995-2002 Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program

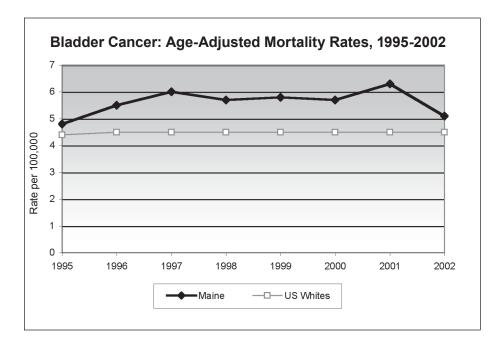


Figure 18: Age-Adjusted Bladder Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics

# Goal: Reduce the risk of cancer from carcinogens in Maine's environment.

# Objective 1: Decrease to 20% the proportion of homes that have indoor air radon levels in excess of the U.S. EPA action guideline of 4 pCi/L by 2010.

Baseline: 33% of homes have indoor radon levels in exceed 4 pCi/L, 1989-1991, EPA State Radon Survey-Maine Chapter.

### Strategies

- 1. Test 5,000 homes annually for indoor radon air levels.
- 2. At least 450 homes known to have radon levels above 4 pCi/L were mitigated annually by 2010.

# Objective 2: Increase annually the number of homes with private wells that are tested for radon in water.

Baseline: Approximately 2,800/year, Maine CDC Radiation Control Program.

#### Strategies

- 1. Annually promote radon and well water testing through public education and awareness activities.
- 2. Reduce maximum exposure levels for radon in well water downward from current value of 20,000 pCi/L (in conjunction with a downward revision in the radon in air standard).
- 3. Seek funding to support and expand efforts.

# Objective 3: Decrease the proportion of homes that have drinking water with arsenic levels above the federal drinking water standard and Maine Maximum Exposure Guideline for arsenic of 10 micrograms per liter(ug/L).

Baseline: 11% of homes have drinking water with arsenic levels above federal standards, Maine CDC, Program Files, Random Sample Survey 2000/2001.

- 1. Promote arsenic and well water testing through public education and awareness activities.
- 2. Increase the number of private testing laboratories that include arsenic to standard water potability tests.
- 3. Ensure that at least 75% of Maine homes with private wells are tested for arsenic.
- 4. Complete and disseminate research on the effectiveness of point-of-use treatment systems in reducing arsenic exposure from drinking water.
- 5. Seek funding to support and expand efforts
- 6. Seek funding and corresponding personnel to dedicate time to private well arsenic issues.

# Objective 4: Increase public awareness of and protection from carcinogens in the environment by 2010.

### Strategies

- 1. Increase awareness of fish advisories and consumption guidelines.
- 2. Generate at least one news story in at least three major Maine media outlets regarding fish consumption guidelines annually.
- 3. Increase the number of policies that reduce carcinogens in the environment by at least one through coordination with specific projects of the Alliance for a Clean and Healthy Maine.
- 4. Advocate for the legislative reauthorization and strengthening of Maine's Toxics Use Reduction/Pollution Prevention Program.
- 5. Assist in the development of effective regulatory strategies to reduce exposure to high-ranking carcinogens through the Maine Air Toxics Initiative.
- 6. Evaluate and disseminate the results of the New England Study of Environment and Health on bladder cancer incidence and risks in the New England states.

# Objective 5: Improve the completeness and usability of data available to inform public policy on the connections between environmental exposure and cancer incidence.

- 1. Develop the capacity of the Maine Cancer Registry for rapid reporting of childhood cancer and the geocoding of all cancers.
- 2. Assess the feasibility of using risk factor data from the Maine Cancer Registry to assess cancer incidence and toxic exposure.
- 3. Develop a state Environmental Public Health Tracking Program that links health data with environmental data for the purpose of investigating the role environmental exposures play in chronic disease.

# **EARLY DETECTION**



# Early Detection Work Group Members and Contributors

Netta Apedoe, MPH Allen L'Italien, RN, OCN

Maine Comprehensive Cancer Control Program

Eastern Maine Medical Center, CancerCare of Maine

Ruth Calderwood, RN Joe Mando

CancerCare Center American Cancer Society

Kip DeSerres, MSPH Patricia Manning, RN, BSN, OCN

American Cancer Society Eastern Maine Medical Center, CancerCare of Maine

Andrew Dionne, MD

MaineGeneral Medical Center

Don Magioncalda, MD

MaineGeneral Medical Center

James Ervin Dan Meyer, PhD

Maine Coalition to Fight Prostate Cancer

Maine-Dartmouth Family Practice Residency

Gregory Feero, MD, PhD Katie Meyer, ScD, MPH

Maine-Dartmouth Family Practice Residency Maine CDC

Sherry Gilberti Diane Mulkhey, RTT
St. Mary's Regional Medical Center Central Maine Medical Center

**,** 

Chriss Hayden, LPN, BS

Holly Richards, BS

Public Health Division, City of Portland

Maine Comprehensive Cancer Control Program

Sharon Jerome, BA Anita Ruff, MPH, CHES

Maine Breast & Cervical Health Program Centers for Disease Control and Prevention

\*Evelyn Kieltyka, MSN, MS, FNP Heather Sylvester, MS

Family Planning Association of Maine Maine Center for Cancer Medicine and Blood Disorders

Nelson Leavitt Marvann Zaremba

Maine Coalition to Fight Prostate Cancer Maine Breast & Cervical Health Program

\*Work Group Chair

# **EARLY DETECTION**

Cancer screening refers to the early detection of cancer or pre-cancerous changes in individuals who do not exhibit signs or symptoms suggestive of the disease. Detection of cancer before symptoms develop leads to the diagnosis of cancer at an earlier stage when treatment may improve health outcomes. Scientific evidence supports the use of screening for the early detection of some cancers, including breast, cervical and colorectal cancer.<sup>53</sup> For other cancers, the evidence is less certain. For example, it is not clear yet whether screening for prostate cancer reduces mortality.<sup>54</sup>

An effective early detection program has six components that must be present for a program to have an impact on cancer morbidity and mortality: public and patient education, professional referral, availability of services, access to services, quality assurance, and surveillance and evaluation of early detection activities and outcomes. Several national organizations, including the U.S. Preventive Services Task Force and the American Cancer Society, have developed screening guidelines for several types of cancer (Appendix D). These guidelines set the standard for cancer screening and represent the best in scientific knowledge and clinical practice to date. In utilizing these guidelines, it is essential that healthcare professionals employ a holistic approach to detection.

In addition to identifying cancer in its earliest stages, and therefore reducing mortality, early detection could substantially reduce the billions of dollars spent on cancer treatment each year. Not only does cancer screening save lives by detecting breast, cervical and colorectal cancer early; it is also the first step in preventing many cases of colorectal and cervical cancers from ever developing. 55, 56, 57

### **BREAST CANCER**

In 2006, it is estimated that 1,040 Maine women will be diagnosed with breast cancer. Maine's breast cancer incidence rates have remained relatively stable over the past decade and are slightly lower than for the United States as a whole (Figure 19).

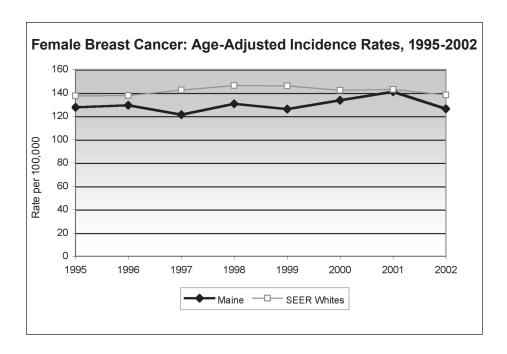


Figure 19: Age-Adjusted Breast Cancer Incidence Rates, 1995-2002 Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program.

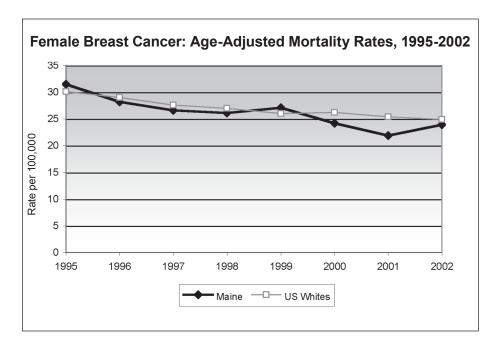


Figure 20: Age-Adjusted Breast Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics

Age is the biggest risk factor for breast cancer with 77% of diagnoses among women over 50.<sup>58</sup> Other risk factors that impact a woman's risk of getting breast cancer include a personal or family history of breast cancer, nulliparity, and being overweight. Although white women develop breast cancer at higher rates than African American women do, it is important to realize that African American women have a higher likelihood of dying from the disease.

Over the past twenty years, with the increase in mammography use and improved treatment, the death rate from breast cancer has subsequently decreased (Figure 20). Despite this decrease, breast cancer is still the second leading cancer killer for women in Maine with an estimated 200 breast cancer deaths in 2006.

Studies have shown repeatedly over the past 20 years that mammography is the best way to detect breast cancer in its earliest stages. Several national organizations recommend breast cancer screening annually for women 40 and older (Appendix D). Getting a mammogram annually, can reduce the risk of dying of breast cancer by approximately 20%-25% over 10 years for women aged 40 or older.<sup>59</sup>

Maine has one of the highest rates of mammography use in the United States (Figure 21). This is due in part to the successful implementation of the Maine Breast and Cervical Health Program, which offers free mammography and Pap tests to income eligible women ages 40 and over. Advocacy and education efforts have also played an important role. Additionally, all Maine insurers are required to pay for breast cancer screening, which helps to reduce the financial barrier of screening costs.

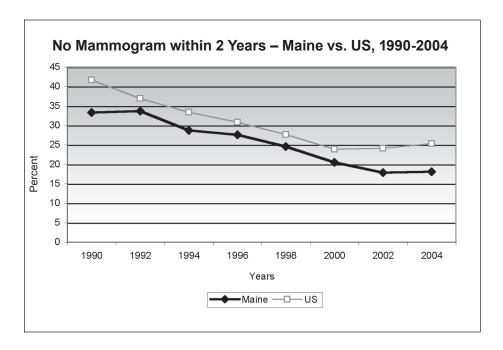


Figure 21: Mammography Use 1990-2004. Source: Behavioral Risk Factor Surveillance System.

# Goal: To promote, increase, and optimize the utilization of high quality breast cancer screening and follow-up services.

Objective 1: Increase the proportion of Maine women aged 40-49 who have received both a mammogram and a clinical breast exam within the past two years to 80% by 2010.

Baseline: 72.7% have received both, Maine BRFSS, 2004.

#### Strategies

- 1. Provide advocacy for ongoing implementation and expansion of Maine Breast and Cervical Health Program.
- 2. Provide continuing education programs on current mammography technique and clinical breast exam technique inclusive of sensitivity training on cultural, elderly and physical needs.
- 3. Work with health professional training programs to teach students state-of-the-art techniques for breast cancer screening exams and tests.
- 4. Develop culturally and linguistically appropriate screening messages for disparate populations.
- 5. Seek funding to pay for screening services for women 40-49 in the Maine Breast and Cervical Health Program and other community—based programs.

Objective 2: Increase the proportion of Maine women aged 50 and older who have received both a mammogram and a clinical breast exam within the preceding year to 70% by 2010.

Baseline: 62% have received both, Maine BRFSS, 2004.

#### Strategies

- 1. Provide advocacy for ongoing implementation and expansion of Maine Breast and Cervical Health Program.
- 2. Provide continuing education programs on mammography and clinical breast exam technique inclusive of sensitivity training on cultural, elderly and physical needs.
- 3. Work with health professional training programs to teach students state-of-the-art techniques for breast cancer screening exams and tests.
- 4. Develop culturally and linguistically appropriate screening messages for disparate populations.
- 5. Seek funding to pay for screening services for women 50 and older in the MBCHP and other community—based programs.

Objective 3: Maintain the proportion of Maine Breast and Cervical Health Program participants with a diagnosis of breast cancer who receive appropriate follow-up.

Baseline: 100% Maine Breast and Cervical Health Program/ October 2005 MDE Submission Data Quality.

#### Strategy

1. Develop a relationship with cancer treating hospitals to explore the collection of data on timely results.

# **CERVICAL CANCER**

Cervical cancer screening is important to detect significant abnormal cell changes that may arise before cancer develops. Since the introduction of the Papanicolaou (Pap) test, cervical cancer incidence and mortality rates have significantly declined in the United States and in Maine (Figures 22 & 23). Less than fifty women in Maine were diagnosed with cervical cancer in 2005. While the number of women affected by cervical cancer is relatively small compared to other cancers, it is one of the most preventable and treatable cancers.<sup>60</sup>

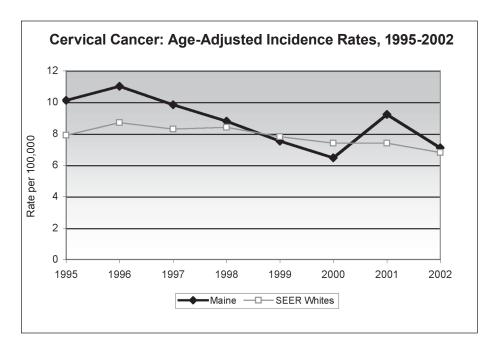


Figure 22: Age-Adjusted Cervical Cancer Incidence Rates, 1995-2002 Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program.

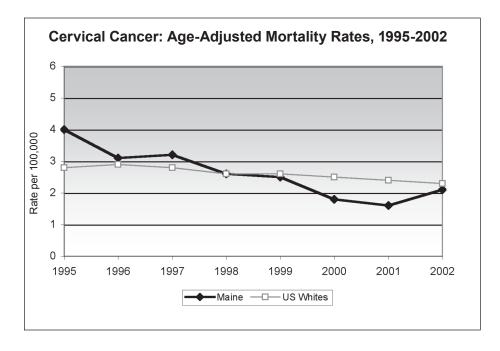


Figure 23: Age-Adjusted Cervical Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics

The primary risk factor for cervical cancer is certain types of human papillomavirus (HPV). Other risk factors include smoking, poor nutrition, and immunosuppression.<sup>61</sup> Southeast Asian women have the highest invasive cervical cancer incidence rates. For example, cervical cancer incidence rates are five times higher among Vietnamese American women than white women.<sup>62</sup>

Additionally, after the age of 25, the incidence and mortality of invasive cancer in African American women increases rapidly with age, while in white women, it rises more slowly.

Studies have shown repeatedly that early detection is effective in reducing the number of women dying of cervical cancer. With routine screening, women significantly improve their odds of finding cervical cancer at its earliest and most treatable stages. Several national organizations have developed screening guidelines (Appendix D).

In 2004, almost 89% of Maine women had a Pap test within three years. This is one of the highest screening rates for cervical cancer in United States. This is due in part to the successful implementation of the Maine Breast and Cervical Health Program, which offers free mammography and Pap tests to income eligible women ages 40 and over. Advocacy and education efforts have also played an important role. Additionally, all Maine insurers are required to pay for cervical cancer screening, which helps to reduce the financial barrier to getting screened.

# Goal: To reduce by 30% the rate of cervical cancer deaths by 2010.

Baseline: 2.1 per 100,000 deaths, Maine Cancer Registry, 2002.

# Objective 1: Increase the proportion of Maine women with a uterine cervix who have ever received a Pap test to 98% by 2010.

Baseline: 96% of women aged 18 and older with a uterine cervix have ever received a Pap test, BRFSS, 2004.

- Provide advocacy for ongoing implementation of Maine Breast and Cervical Health Program.
- 2. Provide advocacy for ongoing funding of Title X (Family Planning) activities.
- 3. Provide continuing education programs about cervical cancer screening inclusive of HPV and vaccine education to health care professionals.
- 4. Collaborate with organizations that represent women with a higher prevalence of cervical cancer to develop and disseminate culturally and linguistically appropriate messages.

# Objective 2: Increase the proportion of Maine women with a uterine cervix that received a Pap test within the preceding 1 to 3 years to 92% by 2010.

Baseline: 89% of women aged 18 and older with a uterine cervix have received a Pap test within the previous 3 years, BRFSS, 2004.

#### Strategies

- 1. Provide advocacy for ongoing implementation of Maine Breast and Cervical Health Program
- 2. Provide advocacy for ongoing funding of Title X (Family Planning) activities.
- 3. Provide continuing education programs about cervical cancer screening inclusive of HPV and vaccine education to health care professionals.
- 4. Collaborate with organizations that represent women with a higher prevalence of cervical cancer to develop and disseminate culturally and linguistically appropriate messages.

# Objective 3: Maintain the proportion of patients diagnosed with invasive cervical cancer who receive or have access to appropriate treatment (within 60 days to treatment starting) by 2010.

Baseline: 100% Maine Breast and Cervical Health Program/April 2005 MDE Submission Data Quality.

### Strategies

1. Develop a relationship with cancer treating hospitals to explore the collection of data on timely results.

# Objective 4: Reduce the number of women who are diagnosed with regional or distant stage cervical cancer by 2010.

Baseline: 30% Regional and 6% Distant, Maine Cancer Registry, DHHS, 1995-2002.

- 1. Conduct case studies of current cancer deaths.
- 2. Develop interventions based on the analysis of case studies.

## **COLORECTAL CANCER**

Colon Cancer Task Force

Netta Apedoe, MPH

Maine Comprehensive Cancer Control Program

Peggy Belanger, RN, BSN Southern Maine Medical Center

Shelly Bodkin, RN Calias Regional Hospital

\*John Bosco, MD

Brunswick Gastroenterology Associates, P.A.

Nadine Bullion, LCSW

Eastern Maine Medical Center, CancerCare of Maine

Steve Coleman, MD Maine General Medical Center

Kip DeSerres, MSPH American Cancer Society

Doug Dieckmann, BA American Cancer Society

Andrew Dionne, MD MaineGeneral Medical Center

Gregory Feero, MD, PhD

Maine-Dartmouth Family Practice Residency

Melanie Feinberg, BA Maine Medical Center

Andrew Harmon American Cancer Society

Chriss Hayden, LPN, BS

Public Health Division, City of Portland

Sharon Jerome, BA

Maine Breast & Cervical Health Program

Michael Jones, MD Maine Medical Center Virginia Lewis

Maine Primary Care Association

Don Magioncalda, MD MaineGeneral Medical Center

Joe Mando

American Cancer Society

Dan Meyer, PhD

Maine-Dartmouth Family Practice Residency

Katie Meyer, ScD, MPH

Maine CDC

Susan Miesfeldt, MD

Maine Center for Cancer Medicine and Maine Medical Center

Peter Millard, MD

Eastern Maine Medical Center

Natalie Morse

MaineGeneral Medical Center

Holly Richards, BS

Maine Comprehensive Cancer Control Program

Susan Rowan, BS Maine Cancer Foundation

Michael Roy, MD Maine Medical Center

Anita Ruff, MPH, CHES

Centers for Disease Control and Prevention

Molly Schwenn, MD Maine Cancer Registry

Rob Werner, MBA American Cancer Society

Sherri Woodward

MaineGeneral Medical Center

<sup>\*</sup>Task Force Chair

Colorectal cancer is the second leading cause of both new cancer cases and cancer deaths in Maine.<sup>63</sup> Maine has the 10<sup>th</sup> highest colorectal cancer mortality rate in the country, which is slightly higher than the United States. Despite the availability of proven screening methods, Maine's colorectal cancer incidence and mortality rates have remained relatively stable over the past 10 years (Figures 24 & 25).

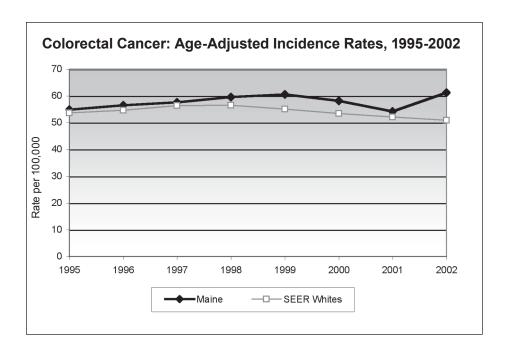


Figure 24: Age-Adjusted Colorectal Cancer Incidence Rates, 1995-2002 Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program

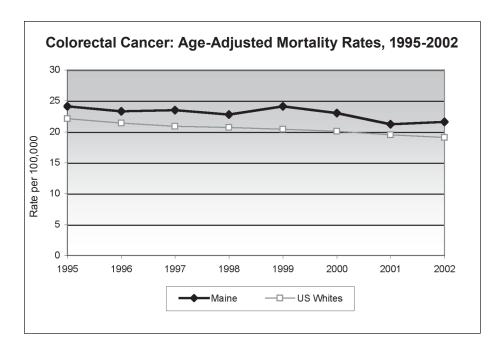


Figure 25: Age-Adjusted Colorectal Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics

The primary risk factor for colorectal cancer is age, with more than 90% of cases diagnosed in individuals older than 50. Risk is also increased by a personal or family history of colorectal cancer and/or polyps, as well as smoking, alcohol consumption, physical inactivity, poor nutrition, and being overweight. Both men and women are at increased risk for colorectal cancer. Additionally, the death rate for colorectal cancer among African Americans is almost 30% higher than among whites and more than two times higher than for Hispanics, Native Americans, Asian Americans, and Pacific Islanders.<sup>64</sup>

Routine screening can reduce the number of people who die of colorectal cancer by as much as 60% or more. <sup>65</sup> Several national organizations recommend colorectal screening for average risk adults age 50 and over (Appendix D). There are several approved screening methods, including fecal occult blood test, flexible sigmoidoscopy, and colonoscopy. In 2002, a Medical Advisory Committee of the Maine Cancer Consortium's Colorectal Cancer Task Force developed a consensus statement on colorectal screening, which stated that any form of colorectal cancer screening is preferable to no screening (Appendix D).

While colorectal screening has been proven to be effective in preventing and detecting cancer early, only half of Maine adults over 50 are getting screened regularly. Compared with other cancer detection tests, colorectal cancer screening rates in Maine are significantly lower. Reasons for this could include the lack of a statewide, free screening program (similar to the Maine Breast and Cervical Health Program), lack of a mandated insurance benefit, confusion over the screening options, lack of understanding about risk, and discomfort with the screening tests and preparation.

Goal: To promote, increase, and optimize the utilization of high-quality colorectal cancer screening and follow-up services.

Objective 1: Increase the proportion of adults aged 50 and older who have ever received a screening colonoscopy or sigmoidoscopy to 75% by 2010.

Baseline: 59.1% colonoscopy/sigmoidoscopy, BRFSS, 2004.

- 1. Inventory the number of professionals regionally who perform colonoscopies.
- 2. Sustain the Maine Comprehensive Cancer Control Program's colorectal cancer social marketing campaign.
- 3. Provide at least four continuing education programs about colorectal screening guidelines and procedures annually for health care professionals.
- 4. Work with health professional training programs to teach students state-of-the-art techniques for colorectal cancer screening exams.

# Objective 2: Increase access to colorectal cancer screening by reducing financial barriers by 2010.

### Strategies

- 1. Work with health insurers to provide coverage for colorectal cancer screening, specifically colonoscopy, as a benefit.
- 2. Identify and seek grant funding opportunities for colorectal screening for under and uninsured Maine residents.

# PROSTATE CANCER

Prostate cancer is the third most common cancer diagnoses for Maine men. In 2006, it is estimated that 1,470 men will be diagnosed with prostate cancer, and 170 men will die. In Maine, the incidence of prostate cancer is increasing while the mortality rate is decreasing (Figures 26 & 27).

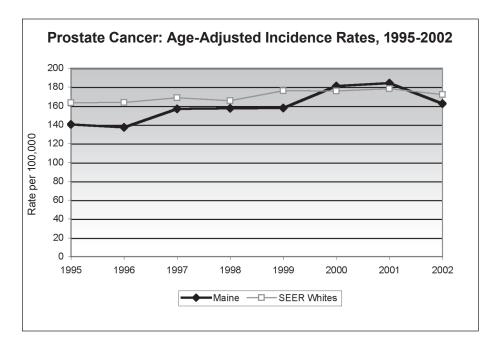


Figure 26: Age-Adjusted Prostate Cancer Incidence Rates, 1995-2002

Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program

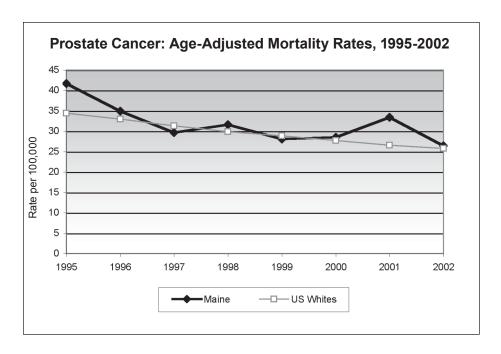


Figure 27: Age-Adjusted Prostate Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics

Whether to recommend screening for prostate cancer among asymptomatic men is a difficult public health issue. There is currently no consensus among major medical and health organizations in the United States about recommendations for screening. Several national organizations, including the American Cancer Society and the American Urological Association, recommend that health care professionals offer the prostate specific antigen (PSA) test. Other organizations, including the United States Preventive Services Task Force, do not advocate for routine prostate cancer screening.

While there is inconclusive evidence to promote widespread prostate cancer screening, several national organizations endorse shared decision making between men and their health care professionals (Appendix D). This includes men and their health care professionals discussing the potential benefits and uncertainties regarding prostate cancer screening and subsequent treatment, consider patient preferences, and individualize the decision to screen or not.

Among racial groups, African American men have the highest risk of dying from prostate cancer, and their increased risk begins at earlier ages. In addition to age and race/ethnicity, the only other known risk factor for developing prostate cancer is family history. Risk of developing prostate cancer in men who have a father, brother, or son with prostate cancer is two to three times the risk than for other men.

# Goal: To reduce prostate cancer mortality in Maine by 2010.

Objective 1: Increase primary care physicians' awareness of the risks and benefits of early detection prostate cancer screening by providing four educational sessions annually by 2010.

#### Strategies

- 1. Provide advocacy for ongoing implementation of Prostate Cancer Coalition initiatives.
- 2. Survey hospitals to determine existing prostate cancer education efforts.
- 3. Seek funding to support and expand efforts.
- 4. Monitor new and ongoing national studies of prostate cancer screening.

# SKIN CANCER

Skin cancer is the most commonly occurring cancer in Maine and the United States. Melanoma, the most serious form of skin cancer, accounts for only 5% of all skin cancers but is responsible for 75% of all skin cancer deaths.<sup>66</sup> Almost 400 Mainers will be diagnosed with melanoma in 2006.

According to the United States Preventive Services Task Force (USPSTF), the evidence is lacking that skin examination by health care professionals is effective in reducing mortality or morbidity from skin cancer. Additionally, the USPSTF found that benefits from screening are unproven, even in high risk populations. However, health care professionals should be aware that fair-skinned men and women over age 65, patients with atypical moles and those with more than 50 moles are known groups at substantially increased risk for melanoma. Also, health care professionals should remain alert for skin lesions with malignant features noted in the context of physical examinations performed for other purposes.<sup>67</sup>

# Goal: To promote and support early detection of skin cancer in Maine by 2010.

Objective 1: Increase awareness of skin cancer prevention and detection through at least five annual education opportunities for Maine primary care physicians by 2010.

- 1. Survey hospitals to determine existing skin cancer education efforts.
- 2. Develop and implement medical education for primary care providers in Maine.
- 3. Develop and implement a pilot medical education distance learning activity for rural and island primary care physicians.
- 4. Implement at least 2 skin cancer education presentations at primary care professional trade association meetings and/or grand rounds.
- 5. Seek funding to develop and expand educational efforts.

# **GENETICS**

Knowledge about cancer genetics is rapidly expanding, with implications for all aspects of cancer management, including prevention, screening, and treatment. Even though all cancer is genetic, just a small portion, perhaps 5 - 10%, is inherited. Genetic information, including information from family history and from DNA-based testing, provides a means to identify people who have an increased risk of cancer. Family history often identifies people with a moderately increased risk of cancer. Less often, family history indicates the presence of an inherited cancer predisposition resulting in a relatively high lifetime risk of cancer.

Genetic assessment is likely to aid clinical decision-making only when management is based on genetic information (e.g., when the clinical interventions being considered would be offered to genetically susceptible people but not to those of average risk, or when interventions that are effective in people of average risk are ineffective in those with genetic susceptibility). Intrinsic benefits of genetic information, such as improvement in quality of life as a result of knowledge about genetic susceptibility, may be accompanied by potential personal and social risks as well. Genetic information may sometimes provide a direct health benefit by demonstrating the lack of a known inherited cancer susceptibility.

Gene tests for some cancers are also available. Specific genetic mutations have been identified as linked to several types of cancer, and, for certain types of cancer, this information has been converted into clinical tests. For example, scientists identified gene mutations that are linked to an inherited tendency to develop colon or breast cancer, and tests for an inherited susceptibility to these cancers are commercially available.

Genetic counseling has been defined by the American Society of Human Genetics as a communication process that deals with the human problems associated with the occurrence or risk of occurrence of a genetic disorder in a family. Genetic counseling generally involves some combination of rapport building and information gathering, establishing or verifying diagnoses, risk assessment and calculation of quantitative occurrence/recurrence risks, education and informed consent processes, psychosocial assessment, support, and counseling appropriate to a family's culture and ethnicity.

Goal: Improve public and health care professional awareness of developments in cancer genetics.

# Objective 1: Increase the number of referrals by 100% for cancer genetic services by 2010.

Baseline: 284 referrals and 138 consultations to cancer genetic services, Maine Center for Cancer Medicine, Maine Medical's Cancer Risk and Prevention Clinic Program and Eastern Maine Medical Center, 2005.

- 1. Develop health care professional educational material on available cancer risk assessment services, and what the professionals can expect to receive with cancer risk assessment (genetic) services.
- 2. Develop and disseminate public education materials regarding cancer genetics.
- 3. Provide educational resources to Maine hospital staff by a cancer genetic professional.





# **Section Contributors**

Netta Apedoe, MPH
Maine Comprehensive Cancer Control Program

Kip DeSerres, MSPH American Cancer Society

Melanie Feinberg, BA Maine Medical Center

Allen L'Italien, RN, OCN Eastern Maine Medical Center, CancerCare of Maine

Don Magioncalda, MD MaineGeneral Medical Center

Anita Ruff, MPH, CHES Centers for Disease Control and Prevention

Molly Schwenn, MD Maine Cancer Registry

# **TREATMENT**

The goal of cancer treatment is to cure the person with cancer or control the progression of the disease while maintaining the highest quality of life possible. Treatment for many types of cancer has improved over the past 10 years. New chemotherapy drugs, better surgical techniques, improved radiation therapy, and increased use of multi-modality therapy have combined to increase survival rates.<sup>69</sup>

## High Quality Cancer Care

One indicator of high quality care is accreditation through the American College of Surgeons (ACoS) Commission on Cancer. Accredited hospitals ensure quality care through various cancer-related programs, including prevention, detection, pretreatment evaluation, staging, optimal treatment, rehabilitation, surveillance for recurrent disease, support services, and end-or-life care. Currently, there are 37 hospitals in Maine that diagnose and treat cancer patients (Appendix F). Of those, there are 11 ACoS approved hospital cancer treatment centers throughout Maine (Appendix E).

Another indicator of high quality care is the use of nationally recognized treatment guidelines. These guidelines provide guidance to health care professionals on standardized cancer treatment, leading to quality of care. Consistent use of national guidelines by health care professionals will assure that all Mainers with cancer are receiving treatment equitably.

#### Clinical Trials

Access to clinical trials is an indicator of quality care because it provides access to innovative therapies and treatment modalities. Before a new treatment method is made available to the public, it must undergo a clinical trial. These strictly monitored and carefully evaluated trials test the therapy's safety and efficacy. Any new treatment must successfully complete three phases of trials before the federal Food and Drug Administration approves it for general use.

Despite efforts by the National Cancer Institute and other organizations, participation in clinical trials remains low with only 2-3% of eligible adult patients enrolling in clinical trials. Barriers to participation include lack of infrastructure that supports physicians to enroll patients, refusal of eligible patients to participate, misunderstanding of the nature and purpose of the trials, and social, cultural and economic issues.

In Maine, private insurers are required to pay for routine patient care costs associated with clinical trial. Also, Medicare offers reimbursement for the routine costs associated with a trial, such as office visits and tests.

# Geographic Access to Treatment

In the past, there has been an assumption that people in Maine do not have adequate access to cancer treatment and specialty services. To identify whether those diagnosed with cancer in Maine have access to high quality cancer treatment and specialty services, the Maine Cancer Registry surveyed hospitals regarding select cancer-related services, including American College of Surgeon

Commission on Cancer certification, the availability of specialist physicians, the existence of imaging modalities, and the provision of cancer treatment.

According to the results, a smaller percentage of Mainers are close to ACoS-certified hospitals than the other services. For example, 38.4% of Mainers are less than 10 miles from an ACoS-certified hospital, while 58.6% are within this range of an oncologist. Additionally, radiotherapy facilities are the least widely distributed of cancer treatment modalities. The survey indicated that in some circumstances, significant portions of Maine residents may be at risk for inadequate cancer care, based on distance to services.<sup>70</sup>

Although some of the distance effect on health care utilization may be system-related, it has been shown that when facing travel barriers, patients are consciously willing to assume more risk in order to receive local care.<sup>71</sup> This indicates the need for and importance of the availability of skilled health care professionals and high quality cancer treatment services in all of Maine's communities.

In Maine, every county has a medically underserved area. This could be a whole county or a group of contiguous counties, a group of county or civil divisions or a group of urban census tracts in which residents have a shortage of personal health services. Additionally, there are over 117,000 Mainers considered to be medically underserved, meaning they face economic, cultural or linguistic barriers to health care.

#### Financial Access to Treatment

Cancer is a costly disease, both for the society and the individual. In addition to the direct cost of medical care and wages lost due to illness, the financial burden on cancer patients is exacerbated due to the increased out-of-pocket expenses. Even those with insurance can be devastated by elevated expenses associated with high deductibles and co-payments, transportation, child and elder care, home care expenses, special foods or equipment, and compounded by lost wages.<sup>72,73,74</sup> Disparate groups, including racial and ethnic minorities and those with lower socioeconomic status, often have reduced access to treatment because of lack of insurance or due to cultural barriers. In addition to the financial burden of medical care and associated out-of-pocket expenses, cancer survivors may experience long-term financial and legal difficulties stemming from disability and other problems associated with returning to work.

#### Access to Information

In order for patients and their families to make sound decisions about cancer treatment, there is a need for timely, reliable, and understandable information. Unfortunately, many in Maine do not have access to such information. Patients with low literacy levels or who may not speak English face significant barriers to obtaining understandable information on cancer treatment options.

Unmet needs for information and assistance in understanding one's own medical situation often lead to non-compliance with the recommended treatment and follow-up. In addition, a lack of information and understanding contributes negatively to patients' quality of life and increases anxiety about their condition.<sup>75</sup>

### Cancer in Children

In 2005, approximately 9,510 children in the United States under the age of 15 were diagnosed with cancer, and about 1,585 children died from the disease. An estimated 61 children are diagnosed each year in Maine (Figure 28). While cancer is the second leading cause of death among Maine children 1 to 14 years of age, it is still relatively rare (Figure 29). The three most common types of childhood cancer in Maine are leukemia (23%), central nervous system (20%) and lymphomas (14%).

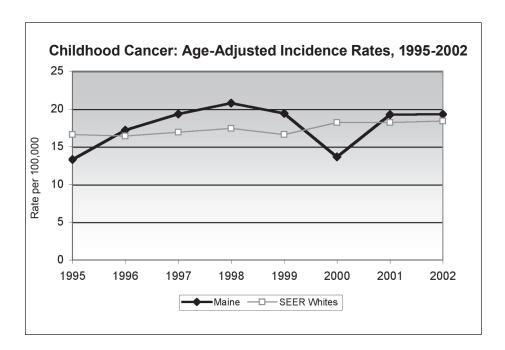


Figure 28: Age-Adjusted Childhood Cancer Incidence Rates1995-2002 Source: Surveillance, Epidemiology and End Results Program and the Maine Cancer Registry Program

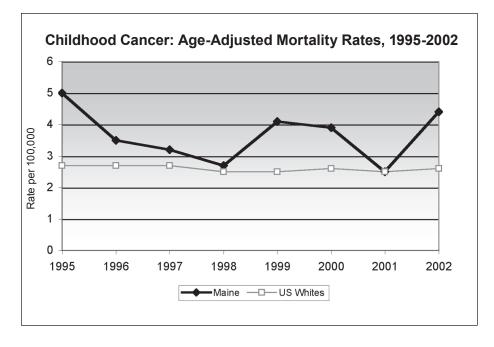


Figure 29: Age-Adjusted Childhood Cancer Mortality Rates, 1995-2002 Source: National Center for Health Statistics

Currently there are two pediatric cancer centers in the state, Eastern Maine Medical Center in Bangor and Maine Children's Cancer Program in Portland. Although there have been significant advances in the treatment of childhood cancer, many children in Maine can only access these services by long and frequent journeys.<sup>78</sup> Research indicates that because of the medical complexities and psychosocial needs of children with cancer, they need a comprehensive team of highly trained pediatric cancer experts.<sup>79</sup> With only two pediatric facilities in Maine, obtaining high quality, accessible treatment can be a challenge.

Additionally, treatment of children's cancers is extremely traumatic for both children and their families and should be treated as a family disease. Quality of life concerns that must be addressed include the significant emotional, physical and financial costs that are related to treatment, as well as identified any quality of life or long term supportive or palliative care. Long-term survivors of childhood cancers are also at high risk for second malignancies.<sup>80</sup>

### Integrated Medicine

In addition to the traditional medical treatments for cancer, there are other forms of treatment that are used in addition to (complementary) or instead of (alternative) standard treatments. These practices generally are not considered standard medical approaches, which go through a long and careful research process to prove they are safe and effective.

Moreover, there is integrative medicine, which is a total approach to care that involves the patient's mind, body, and spirit. It combines standard medicine with the complementary and alternative medicine (CAM) practices that have shown the most promise, such as using relaxation as a way to reduce stress during chemotherapy.<sup>81</sup> CAM may include dietary supplements, megadose vitamins, herbal preparations, special teas, acupuncture, massage therapy, magnet therapy, spiritual healing, and meditation. Research on the effectiveness of CAM is ongoing and should be reviewed and evaluated annually.

Goal: To assure that all Maine residents have access to high-quality cancer treatment information and services.

Objective 1: Increase the use of national treatment guidelines among professionals in Maine by 2010.

- 1. Assess the utilization of national treatment guidelines among professionals.
- 2. Work with professional organizations in Maine to promote the use of national guidelines.

# Objective 2: Increase by 15% oncology certification of health care professionals by 2010.

### Strategies

- 1. Survey hospitals to assess level of oncology certification among staff.
- 2. Advocate for and promote certification.

# Objective 3: Increase patient utilization of cancer treatment education resources by 2010.

### Strategies

- 1. Survey and assess the availability and utilization of hospital-based, culturally and linguistically appropriate patient education resources.
- 2. Encourage the use of cancer treatment education resources by health care professionals.
- 3. Include information and links to treatment-related resources on the Maine Cancer Consortium website.
- 4. Implement web-based resources for integrative therapies within medical and community organizations.
- 5. Promote recruitment and enrollment of Mainers in state and national level clinical trials.

# Objective 4: Increase by three the number of hospitals in Maine accredited by the American College of Surgeons Commission on Cancer by 2010.

Baseline: 11 hospitals.

#### Strategies

- 1. Survey ACoS and non-ACoS-approved hospitals to assess current linkages and interest in developing affiliate programs.
- 2. Survey non-ACoS-approved hospitals to assess barriers to pursuing affiliation or accreditation.
- 3. Partner with ACoS to promote the benefits of ACoS approval to hospital administrators.
- 4. Provide assistance to non-ACoS-approved hospitals on the accreditation process.

# Objective 5: Provide culturally appropriate pain and symptom management and supportive services that enhance quality of life by 2010.

- 1. Assess and promote use of best practices for pain and symptom management and supportive services.
- 2. Provide patient and professional education on pain and symptom management and supportive services.
- 3. Identify cancer treatment barriers for disparate populations.

# REHABILITATION AND SURVIVORSHIP



### Rehabilitation and Survivorship Work Group Members and Contributors

Netta Apedoe, MPH

Maureen Higgins, LCSW

Maine Comprehensive Cancer Control Program The Leukemia & Lymphoma Society

Jane Brissette Brenda Joly, MPH, PhD

American Cancer Society

University of Southern Maine, Muskie School of

Public Service

\*Nadine Bullion, LCSW

Eastern Maine Medical Center, CancerCare of Maine

Deanna McClure, RN, OCN

Franklin Memorial Hospital

Paulette Burbank

New England Rehabilitation Hospital of Portland Michael Reisman

Beth C. Wright Center Jessica Colamaria, MSW

Cancer Community Center Holly Richards, BS

Maine Comprehensive Cancer Control Program

Doug Dieckmann, BA
American Cancer Society
Anita Ruff, MPH, CHES

Centers for Disease Control and Prevention

Melanie Feinberg, BA

Maine Medical Center

Judy Sweeney, PT

New England Rehabilitation Hospital of Portland
Michele Garrity

University of Maine at Orono \*Cheryl Tucker

American Cancer Society

Donna Green, RN

Maine Medical Center

Trisha Van Horne, LCSW

Central Maine Medical Center

\*Work Group Chair

### REHABILITATION AND SURVIVORSHIP

Cancer survivors are those people who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends, and caregivers.<sup>82</sup> According to the National Cancer Institute, there are over 9.8 million Americans who have been diagnosed with cancer, living proof that having cancer is no longer a death sentence.

According to the American Cancer Society, the five-year survival rate for all cancers has increased as a result of improvements in cancer screening and treatment.<sup>83</sup> Sixty-four percent of adults diagnosed with cancer today were alive five years after their diagnosis, and nearly 79% of those who had childhood cancer were alive after 10 years.<sup>84</sup>

While this is remarkable progress, increased survivorship has introduced a number of challenges to cancer survivors and their families. Survivors face many physical, psychological, social, spiritual, and financial issues throughout their diagnosis and treatment and for the rest of their lives. <sup>85</sup> In addition, there is a growing need to promote health, prevent secondary disease, and ensure the well-being of long-term cancer survivors and their families.

Because survival rates for all childhood cancers have dramatically improved over the past 30 years, there are unique issues facing childhood cancer survivors. These include fertility, heart failure, cognitive functioning, and secondary cancers, as well other psychosocial and financial issues.

To identify the specific needs of cancer survivors in Maine, an assessment was conducted in 2004 to answer the following questions:

- What are the cancer treatment and follow-up needs of cancer patients seeking rehabilitation and survivorship services in Maine?
- What rehabilitation and survivorship services do cancer patients use? Are these services useful, affordable, and helpful?
- How did those living with cancer learn about these services?

The results of the survey indicated that almost half of the respondents did not use any of the 15 identified services. When asked why they did not use a service, the majority responded that they did not have a need for the service. This could indicate two things: 1) the rehabilitation and survivorship services currently offered are not the services cancer survivors want; or 2) those living with cancer in Maine receive support and assistance from informal networks of family, friends or co-workers.

For those who did use rehabilitation and survivorship services, there was a wide range of usage. For example, 15.1% of respondents used nutrition counseling, while 9.5% used transportation resources, and only 2.2% used speech therapy. Among those who had used services, at least 75% of respondents found each of the services helpful with lodging services identified as the most helpful service for families. A majority of respondents said that they were able to use most of the services within 30 miles of this home, a positive indicator for accessibility. Not surprisingly, physicians were the most common referral source for almost all rehabilitation and survivorship services.

As a follow-up to the 2004 study, a series of focus groups were conducted to assess utilization of rehabilitation and survivorship services by cancer survivors in Maine. The focus groups were conducted with cancer survivors, providers and cancer survivor advocates/family members.

Among the major findings from cancer survivors and advocate/family members are:

- 75% of participants learned about rehabilitation/survivorship services from hospitals/ treatment centers and medical professions;
- 50% identified support groups and services for caregivers as lacking in their communities;
- 63% identified lack of knowledge of available rehabilitation and survivorship services as a major barrier;
- 88% stated that a booklet on services available in the area would have improved their access to services; and
- 38% cited problems with insurance and or no coverage for alternative care a barrier to accessing services.

Some major finds from providers are:

- 67% of providers identified pain management as a service that is not available in their area;
- 100% indicated that family concern and ability to handle and want services was the criteria they used for making referrals; and
- 100% cited personal discomfort with discussing the topic or not being ready as the major barrier to discussing survivor issues.

Combining the knowledge gained from the Maine cancer survivors' assessment and focus groups with the guidance from A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies, there are great opportunities for systematic changes that will impact quality of life for cancer survivors in Maine.

Goal: Increase awareness and utilization of rehabilitation/survivorship services throughout Maine by 2010.

# Objective 1: Improve communication between providers and patients about rehabilitation/survivorship services in Maine by 2010.

- 1. Support the development of materials to promote regular communication between health care professionals and patients.
- 2. Host a list-serve addressing rehabilitation/survivorship issues to connect organizations.
- 3. Develop and disseminate consistent message regarding rehabilitation/survivorship to be used by Consortium members.

# Objective 2: Collaborate with partners to provide a minimum of five educational opportunities for health care professionals to increase understanding of rehabilitation/survivorship issues by 2010.

#### Strategies

- 1. Develop a web-based and hospital-based continuing education training on rehabilitation/survivorship issues for healthcare professionals.
- 2. Promote continuing education training to all primary care and oncology professionals across the state.
- 3. Seek funding to implement training.

# Objective 3: Increase public awareness of rehabilitation/survivorship issues and services by 2010.

#### Strategies

- 1. Assess availability of existing rehabilitation/survivorship resources.
- 2. Develop communication tools to promote existing resources.
- 3. Develop and promote regional rehabilitation/survivorship forums for cancer survivors.
- 3. Advocate for Consortium members to support and participate in at least one forum in each hospital service area.
- 4. Sponsor and promote statewide celebration of National Cancer Survivors Day.
- 5. Seek funding to sponsor an Annual Cancer Survivors Day at the State House.

# Objective 4: Advocate for policies that enhance access to survivor services by 2010.

#### Strategies

- 1. Collaborate with Consortium member organizations to develop a database of survivorship/rehabilitation legislative issues.
- 2. Monitor new and ongoing national studies regarding rehabilitation/survivorship issues.
- 3. Support and sponsor legislation to address rehabilitation/survivorship issues.

# Objective 5: Increase survivors' access to and utilization of rehabilitation/survivorship services by 2010.

- 1. Promote awareness of rehabilitation/survivorship issues and services.
- 2. Develop a plan to address barriers to service access and utilization.
- 3. Support development and expansion of the patient navigation programs.
- 4. Identify and implement initiatives to increase health care professional referrals for rehabilitation/survivorship services.

# PALLIATIVE AND END-OF-LIFE CARE



### Palliation Work Group Members and Contributors

Enoch Albert, RNC, CHPN

Togus Veterans Administration Medical Center

Netta Apedoe, MPH

Maine Comprehensive Cancer Control Program

Jill Bixby, NP, MA, BSN MaineGeneral Medical Center

Becky Colwell

Health Reach Network

Doug Dieckmann, BA

American Cancer Society

Maureen Higgins, LCSW

The Leukemia & Lymphoma Society

Melinda Hutchinson, RN, CHPN

Kennebec Pharmacy and Home Care

Sue Laliberte, RN

Goodall Hospital

Donna Martin, RN
Department of Veterans Affairs

Katie Meyer, ScD, MPH

Maine CDC

Jan Pilotte, RN, MSN, ARNP

Eastern Maine Medical Center

\*Kandyce Powell, MSN, RN

Maine Hospice Council, Inc.

Janice Reynolds, RN, BSN, OCN

Mid Coast Hospital

Holly Richards, BS

Maine Comprehensive Cancer Control Program

Pamela Sirois, RN, BSN, ANP-BC

St. Mary's Regional Medical Center

\*Work Group Chair

### PALLIATIVE AND END-OF-LIFE CARE

Pain control is a significant problem for many with cancer. Thirty percent of people with cancer have pain at the time of diagnosis and 65-85% have pain when their disease is advanced.<sup>86</sup> Cancer pain can be effectively treated in 85-95% of patients using an integrated program of therapies.<sup>87</sup> Despite the existence of effective treatment options, the World Health Organization estimates that up to 70% of patients with cancer pain do not receive adequate relief.<sup>88</sup> Unnecessary suffering, disability, and reduced quality of life are consequences of unrelieved cancer pain, which can lead to longer hospitals stays, increased outpatient visits, and decreased function that may result in loss of income and insurance coverage.<sup>89</sup>

Reasons for ineffective pain management include lack of knowledge for patients and health care professionals, negative attitudes towards the use of medication, fear of drug addiction, drug regulations, concerns about cost, and reimbursement barriers. Additionally, cultural, ethnic, and religious factors have an influence on cancer pain management, including the cause and interpretation of pain.

Certain groups face higher risks of unrelieved pain. Minorities, females, children, the elderly, and the underserved face significant risk for under-treatment of cancer pain. Factors that may be responsible for this disparity include lack of access to pain specialists, lower rates of insurance coverage, cultural differences between patients and professionals, language barriers, and time spent with professionals.<sup>90</sup>

In 2005, the American Pain Society released updated guidelines for the management of cancer pain in adults and children. There were over twenty recommendations, including regular assessment of pain, prepared health care professionals on pain management, and improved communications. <sup>91</sup> Integration of these guidelines into medical practice will improve cancer pain management for those living with cancer in Maine.

#### End-of-Life Care

Despite improvements in prevention, detection, and treatment, cancer is a terminal illness for many people. About half of all people with cancer died from their illness within a few years of presentation. <sup>92</sup> In Maine, cancer is the leading cause of death. With so many dying from cancer, the need for high quality services becomes even more critical.

In American culture there is a recognizable lack of acceptance of death, leading to reluctance in seeking end of life care. Western culture often tries to deny death as a natural process. This may create an atmosphere where some people are unprepared for their own death or the death of a loved one. They may also be unaware of the services and support that are available or they may be reluctant to seek out those services and support.

Additionally, clinical barriers to achieving high quality end of life care must be overcome. These include inappropriate attitudes of health care professionals and patients towards death, ineffective communication, fragmentation of care, and lack of availability and/or insurance coverage for high quality end of life care.<sup>93</sup>

The principles that govern cancer care at the end of life are well accepted. They include responsiveness to the patients' wishes; truthful, sensitive, empathic communication; and meticulous attention to the physical, spiritual, and psychosocial needs of patients and families.

In 2002, Last Acts, a national coalition to improve care and caring near the end of life, published a report assessing the state of end of life care in the United States. Examining issues such as availability of services and trained health care professionals, adequate pain management, and public policies that support end of life care, the report gave Maine an average grade or lower for many of the assessed areas.

Recently, an assessment was conducted to learn more about Mainers' attitudes of hospice and end of life care. Overall, Mainers have an extremely positive view of hospice. However, there is confusion about reimbursement of hospice services with many not knowing that Medicare, Medicaid, and private insurers pay for these services. Given that two-thirds of respondents said they would be more likely to use hospice if they knew the costs were covered, there is an opportunity to work with payers and the public to increase awareness of financial resources for hospice services.

### End-of-Life Care for Children

Certain issues in palliative and end-of-life care are unique to or particularly evident with children. For example, some drugs used to treat pain, nausea, and other symptoms in adults have yet to be tested or labeled for use in infants, children, or adolescents. Pediatricians thus may have inadequate information to guide their choices of drugs and minimize dangerous side effects.<sup>95</sup>

A more comprehensive approach to care is needed. Regardless of the decisions made about curative or life-prolonging treatments, children with life-threatening medical problems and their families should have access to accurate information and excellent supportive care that offers physical, emotional, and spiritual comfort from the time of diagnosis through death and into bereavement, if death is the outcome. Good palliative care should benefit children who survive a life-threatening medical problem as well as those who do not and should support the families of children in both groups.<sup>96</sup>

# Goal: Increase access to high quality hospice and palliative care services for all people.

Objective 1: Increase to 5% the proportion of nurses and physicians caring for cancer patients who have additional certification in hospice and palliative care by 2010.

#### Strategies

- 1. Gather baseline data for the number of nurses and physicians certified in hospice and palliative care.
- 2. Support education curriculum and conferences covering hospice and palliative care.
- 3. Advocate for an increase in the number of nursing schools with End-of-Life Nursing Education Consortium (ELNEC) trained faculty.
- 4. Advocate for an increase in Education in Palliative and End-of-Life Care (EPEC) trained faculty in the medical school.
- 5. Develop continuing education in palliative and end-of-life-care for health care professionals.
- 6. Develop training that incorporates effective messages and culturally appropriate communication methods regarding palliative and end-of-life services for disparate populations.
- 7. Continue to encourage the board of licensure (nursing, medicine, osteopathy) to require continuing education.
- 8. Continue to develop and support certificate programs in hospice and palliative care.

# Objective 2: Develop a mentor program of palliative care and end-of-life health care professional by 2010.

#### Strategies

- 1. Develop mentoring programs for all aspects of end-of-life care.
- 2. Identify and recruit interdisciplinary team members who have expertise in palliative and end-of-life care.

# Objective 3: Integrate Hospice and Palliative Care Services into the health care continuum and make these services available and accessible to all Mainers by 2010.

- 1. Partner with Maine health care organizations to develop strategic plans that reflect an interdisciplinary approach to palliative care.
- 2. Encourage the development of residential/in-patient hospice facilities, as needed.
- 3. Educate health care professionals about the technical amendment to the Medicare Hospice Benefit.
- 4. Encourage collaboration between acute, skilled, long term care and community-based hospice programs.

# Objective 4: Increase to 100% those settings that receive reimbursement for palliative services across the health care continuum.

#### Strategies

- 1. Conduct a survey to gather baseline data regarding how many settings currently receive reimbursement for palliative services.
- 2. Convene at least one meeting per year to clarify issues around reimbursement for end-of -life care.
- 3. Offer at least one education program for third-party payers regarding evidence-based benefits of hospice and palliative care.
- 4. Continue to encourage contracting between the Veterans Administration, Maine Veterans Homes and community-based hospice programs.
- 5. Create and publish a comparison report on hospice and palliative care benefits for all licensed insurers in Maine.
- 6. Continue to advocate for improvements in Medicare hospice reimbursement.
- 7. Increase the utilization of the Medicare hospice benefit.

# Objective 5: Increase the number of settings in the health care continuum that adopt the National Consensus document standards for Palliative Care by 2010.

#### Strategies

- 1. Continue to collect baseline data on the utilization of the standards for the benchmarking process.
- 2. Advocate for the inclusion of palliative care indicators in Quality Improvement Programs within all health care institutions and agencies.
- 3. Evaluate data from Joint Commission surveys on pain management.
- 4. Complete a market research study every five years about end-of-life care for consumers.
- 5. Develop and publish a Maine-specific palliative and end-of-life care report card.
- 6. Offer at least one conference that addresses palliative care disparities for acute care settings.
- 7. Increase the number of palliative care committees in acute care hospitals.

### Objective 6: Increase to 46% public awareness of hospice by 2010.

Baseline: Market research data 36%, 2005 Maine Hospice Council (MHC).

- 1. Continue to develop and sponsor adult education for end-of-life care.
- 2. Create an online resource guide and link with appropriate organizations.
- 3. Develop a web-based hospice and palliative care speaker's bureau and link to appropriate organizations.
- 4. Work with the Maine Hospital Association to increase awareness of hospice and palliative care referrals.
- 5. Offer a series of workshops on expanding hospice access.
- 6. Develop and promote public service announcements, printed materials and other educational efforts at least five times a year.

# DATA AND CANCER SURVEILLANCE



### Data Work Group Members and Contributors

Netta Apedoe, MPH

Maine Comprehensive Cancer Control Program

Amy Black, MA

Maine Center for Public Health

Judith Graber, MS

Environmental and Public Health Tracking Program

Marty Henson, BS

Office of Date, Research, and Vital Statistics

Brenda Joly, MPH, PhD

University of Southern Maine, Muskie School of Public Service

Terri Kelley

Maine Cancer Registry

Dan Meyer, PhD

Maine Dartmouth-Family Practice Residency Program

\*Katie Meyer, ScD, MPH

Maine CDC

Kip Neale

Behavioral Risk Factor Surveillance System Program

Holly Richards, BS

Maine Comprehensive Cancer Control Program

Anita Ruff, MPH, CHES

Centers for Disease Control and Prevention

Castine Verrill, MS

Maine Cancer Registry

Maryann Zaremba

Maine Breast & Cervical Health Program

\*Work Group Chair

### DATA AND CANCER SURVEILLANCE

Timely, complete, and high quality cancer data are necessary in order to provide a solid foundation for developing goals and objectives that focus on areas of greatest need and have the greatest likelihood of succeeding. More specifically, cancer surveillance data are crucial for identifying areas where greater prevention efforts are needed, for identifying potential causes of cancer, and for monitoring progress toward reducing cancer mortality.

In Maine, the Maine Cancer Registry (MCR), a statewide population-based cancer surveillance system, is responsible for collecting information about all newly diagnosed and treated cancers in Maine residents (except basal and squamous cell carcinoma of the skin). This information is used to monitor and evaluate cancer incidence patterns in Maine, as well as to better understand cancer, identify areas in need of public health interventions, and improve cancer prevention, treatment and control.

Since 2004, MCR has achieved and maintained the gold standard for cancer data timeliness, completeness, and quality from the North American Association of Central Cancer Registries. This marked the first time since the inception of the Maine Cancer Registry that Maine cancer data could be compared to other states.

Race and ethnicity are under-reported to the Maine Cancer Registry and other surveillance systems. Because Maine has a small, non-white population, data analysis by race and ethnicity is difficult. Because of this, there is no reliable data on cancer incidence, treatment, and risk factors for racial and ethnic groups in Maine. This makes it difficult to adequately assess the cancer burden for these groups, as well as to develop appropriate interventions for cancer prevention, detection and treatment.

# Goal: Improve data collection and cancer surveillance in Maine.

Objective 1: The Data Work Group will produce a surveillance document to facilitate an evidence-based approach to cancer prevention and control by 2010.

- 1. Identify existing data sources.
- 2. Collaborate to secure analysis for the data source.
- 3. Develop analysis and dissemination plans.
- 4. Seek funding to support data analysis, document creation, and dissemination as needed.
- 5. Ensure analysis of cancer data addresses disparities in age, gender, race/ethnicity, socio-economic status and geographic location in Maine.

# Objective 2: The Data Work Group will continue to provide technical assistance on cancer data and surveillance-related issues to the Maine Cancer Consortium.

### Strategies

- 1. Provide consultation on analysis and interpretation of data to Work Groups.
- 2. Review Maine Cancer Consortium five-year evaluation plan.
- 3. Members of the Data Work Group will serve as liaisons to other Work Groups on datarelated issues.

# Objective 3: The Data Work Group will support maintenance of the Maine Cancer Registry's North American Association of Certified Cancer Registries' certification for data quality, timeliness, and completeness.

### Strategies

- 1. Provide advocacy for ongoing implementation of the Maine Cancer Registry.
- 2. Advocate for continued funding for the Maine Cancer Registry.

# Objective 4: Strengthen data and surveillance efforts as they relate to diverse populations by 2010.

- 1. Collaborate with the Maine Hospital Association and Office of Minority Health to improve valid recording of race and ethnicity on hospital admission records.
- 2. Advocate for the Office of Data, Research and Vital Records to improve valid recording of race and ethnicity on death certificates.
- 3. Support efforts to systematically over-sample disparate populations to increase understanding of cancer prevention and detection knowledge and behaviors.

## **IMPLEMENTATION**



### Communication Work Group Members and Contributors

Netta Apedoe, MPH
Maine Comprehensive Cancer Control Program

Denise Delorie, BS Town of Fairfield

Mary Beth Hill, LSW Penobscot Bay Medical Center, CancerCare Center

Brenda Joly, MPH, PhD University of Southern Maine, Muskie School of Public Service

Elisa Madore Houlton Regional Hospital

Selina McGlauflin Maine Breast & Cervical Health Program

Holly Richards, BS

Maine Comprehensive Cancer Control Program

Anita Ruff, MPH, CHES Centers for Disease Control and Prevention

Tom Saladino, MPS

Maine School Administration District #27

### **IMPLEMENTATION**

One of the hallmarks of a successful comprehensive cancer control initiative is a strong and active partnership. Since 2004, the Consortium evaluated its synergy through the *Partnership Self-Assessment Tool.*<sup>97</sup> Findings from the 2005 survey indicate that the Consortium scored within the first and second zone for all of the six domains identified (Chart 1). The results suggest that more effort is needed in all areas in order to maximize the Consortium's collaborative potential and in order to achieve scores within zone four (optimal performance or target zone).

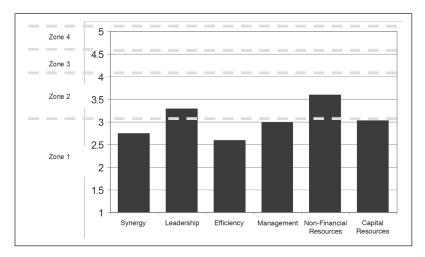


Chart 1. Maine Cancer Consortium Self-Assessment: Overall Results, 2005 Source: Maine Comprehensive Cancer Control Program Evaluation Report 2005

In 2001, the Consortium released the *Maine Cancer Plan* 2001 – 2005 (*Plan* 2001 – 2005), Maine's first-ever comprehensive cancer control plan. Using the Activity Monitoring Tool, Consortium Work Groups have annually assessed the implementation of each section of the Plan, as well as identifying facilitators and barriers to doing so. During the years covered by the *Plan* 2001 – 2005, 68% of all activities were implemented, either partially or fully (Figure 30). While it is too soon for reductions in cancer incidence and mortality to be evident as result of this effort, preliminary data on risk factor and screening behavior demonstrate improvements.<sup>98</sup>

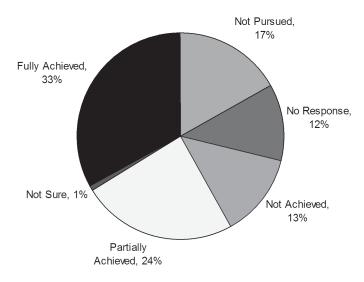


Figure 30: Overall Combined Strategy Status of All Active Workgroups, 2005

# Goal: To enhance the comprehensive cancer control initiative in Maine.

# Objective 1: To implement at least 80% (fully or partially achieve) of the strategies in the Maine Cancer Plan by 2010.

#### Strategies

- 1. Annually identify priority activities.
- 2. Annually develop a plan and timeline for achieving priority activities.
- 3. Identify and secure funding for priority activities, as needed.
- 4. Annually review progress by tracking activities and measuring results.

### Objective 2: To increase the synergy of the Maine Cancer Consortium to 4.0.

Baseline: Maine Cancer Consortium synergy is at 2.8, Maine Comprehensive Cancer Control Evaluation Report, 2005.

- 1. Annually conduct a member satisfaction survey.
- 2. Seek at least two funding opportunities to support the Consortium.
- 3. Annually review interest in and need for the Consortium to seek 501(c) 3 status.
- 4. Review and update the Consortium website monthly.
- 5. Develop and distribute quarterly Consortium newsletters.
- 6. Annually review membership to assess gaps.
- 7. Convene an annual meeting to review progress.
- 8. Bi-annually, assess the structure of the Consortium and make changes, if necessary.

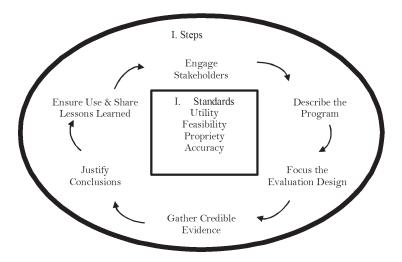




### **EVALUATION**

Evaluation is a critical and central component of Maine's comprehensive cancer control initiatives. It is through the evaluation process that activities can be monitored, Consortium membership satisfaction can be assessed, and progress towards reducing the burden of cancer in Maine can be established. The evaluation of the Maine Cancer Plan and the Consortium is based on the Centers for Disease Control and Prevention's evaluation framework.<sup>99</sup> The figure below depicts the essential components of this framework.

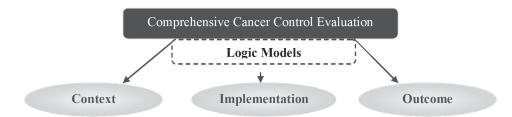
Figure 31: Framework for Program Evaluation in Public Health



Three areas have been identified as the focus for the evaluation design.<sup>100</sup> They include context, implementation, and outcomes (Figure 32). Experts agree that if used together, these three components can improve the program's effectiveness and promote future sustainability.<sup>101</sup>

Figure 32. Comprehensive Cancer Control Evaluation Desin

Source: Maine Comprehensive Cancer Control Evaluation Report 2005.



# Goal: Enhance the Maine Comprehensive Cancer Control initiative through evaluation.

Objective 1: Develop a five-year written evaluation plan to annually assess the partnership and measure progress related to the Maine Cancer Plan (2006-2010) by June 30, 2007.

### Strategies

- 1. The Maine Cancer Consortium in conjunction with the Maine Comprehensive Cancer Control Program will identify an evaluation team to spearhead the development of the evaluation plan.
- 2. Members of the Maine Cancer Consortium will participate in three planning meetings regarding the development of the evaluation plan.
- 3. The Maine Cancer Consortium will review the evaluation plan and provide recommendations for modifying the plan, if needed.

Objective 2: The Maine Cancer Consortium, in conjunction with the lead agency and evaluation team, will participate in the implementation of the evaluation plan (as specified in the plan) through December 31, 2011.

### Strategies

- 1. Fifty percent of Maine Cancer Consortium individual and organizational members will complete an annual partnership survey.
- 2. The Maine Cancer Consortium will annually document progress related to the strategies in the Cancer Plan using tools developed by the evaluation team.

Objective 3: The lead agency and evaluation team will develop and disseminate the annual evaluation report beginning June 30, 2007.

- 1. Members of the Maine Cancer Consortium will review the draft annual report and provide feedback to the evaluation team.
- 2. The lead agency and the evaluation team will disseminate the annual evaluation report.

# **APPENDICES**



### Appendix A

### Terms and Acronyms

ACS: American Cancer Society. The American Cancer Society (ACS) in Maine has been a partner in efforts to reduce the impact of cancer in Maine for many years. The ACS is a community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer, and diminishing suffering from cancer through research, education, advocacy and service. ACS has played a key role in developing this Plan and has agreed to provide both monetary and human resources to the support and implementation of this Plan.

BRFSS: The Behavior Risk Factor Surveillance System, the world's largest telephone survey, tracks health risks in the United States. Information from the survey is used to improve the health of the American people. For more information go to: http://www.cdc.gov/brfss/index.htm

**Cancer**: A population of abnormal cells showing a growth preference over their normal cellular counterparts.

Cancer Incidence: The number of newly-diagnosed cases of cancer occurring in a population in a given period of time.

Cancer Mortality Rate: The death rate specific to cancer or a particular type of cancer.

**CSHE**: Comprehensive School Health Education

CSHP: Coordinated School Health Program, statewide, K-12.

CDC: Centers for Disease Control and Prevention, a part of the US Department of Health and Human Services.

Maine BRFSS: The Maine Behavior Health Risk Factor Surveillance System, tracks health risks in Maine.

MBCHP: The MBCHP is a statewide program which provides breast and cervical cancer screening and diagnostic services to underserved women, provides public and professional education, and supports community partnerships to enhance statewide cancer control activities.

MCR: The Maine Cancer Registry (Registry) is a statewide population-based cancer surveillance system. The Registry has been in existence since 1983. The MCR collects information about all newly diagnosed cancers in Maine residents (except basal and squamous cell carcinoma of the skin). This information is used to monitor and evaluate cancer incidence patterns in Maine. This information is also used to better understand cancer, identify areas in need of public health interventions, and improve cancer prevention, treatment and control. The Registry staff responds to public inquiries including concerns about apparent cancer clusters.

Medicare Hospice Benefit: Hospice care is a special way of caring for people who are terminally ill. It is available as a benefit under Medicare Hospital Insurance (Part A). Medicare beneficiaries who choose hospice care receive non-curative medical and support services for their terminal illness. More information is available at http://www.medicare.gov/Publications/Pubs/pdf/02154.pdf

Melanoma: The most serious type of skin cancer.

Pap test: A screening test for cervical cancer developed by Dr. Papanicolaou.

**PRAMS**: Pregnancy Risk Assessment Monitoring System used to monitor health behavior among pregnant women.

PTM: Partnership For A Tobacco-Free Maine. Legislation passed in June 1997 doubled the cigarette tax and created the state-funded comprehensive tobacco prevention, control and treatment program. In 1999 the Maine Legislature created the Fund for a Healthy Maine (FHM), appropriating all of Maine's tobacco settlement funds to health programs. Approximately \$14 million per year of FHM dollars are allocated to the PTM. PTM also receives over \$1 million a year from the Federal CDC. The PTM leads and administers Maine's tobacco prevention and control program and is responsible for achieving four primary objectives: 1) prevent youth and young adults from using tobacco; 2) motivate and assist tobacco users to stop; 3) eliminate exposure to secondhand; and 4) identify and eliminate tobacco-related disparities among populations.

**PSA**: Prostate-specific antigen blood test used to screen for prostate cancer.

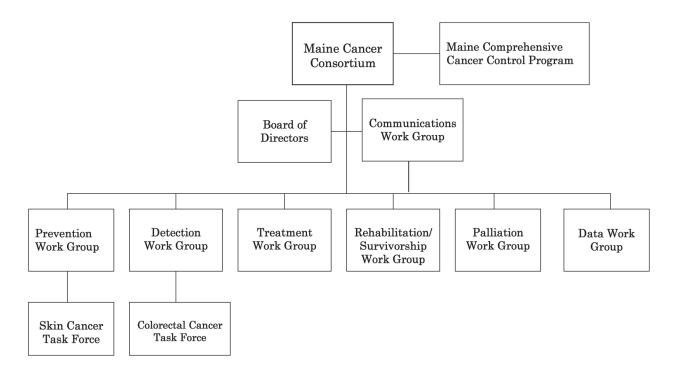
**SEER:** Surveillance, Epidemiology, and End Results Program is a National Cancer Institute network of population-based cancer registries that collects ongoing data on new cancer cases and patient survival rates. SEER rates are used as a national estimate.

**Title X**: A program that provides funding for low income women to receive cervical and other health screenings.

**24**/**7 tobacco**–**free policies**: Refers to policies that prohibit smoking 24 hours a day, 7 days a week within all school/university affiliated buildings and at all university/school sponsored events- both indoor and outdoor.

## Appendix B

### Maine Cancer Consortium Organizational Chart



## Appendix C

### Mandated Health Insurance Benefits Related to Cancer

Year Enacted	Benefit	Type of Contract Affected
1990, 1997	Benefits must be made available for screening mammography	All Contracts
1995	Must provide coverage for reconstruction of both breasts to  All Contracts  produce symmetrical appearance according to patient and  physician wishes.	
1996	Benefits must be provided for screening Pap tests. Effective 1/97	Group, HMOs
1996	Benefits must be provided for annual gynecological exam without prior approval of primary care physician. Effective 1/97.	Groups managed care including HMO
1997	Benefits provided for breast cancer treatment for a medically appropriate time determined by the physician in consultation with the patient. Effective 1/98.	All contracts including HMOs
1998	Coverage required for prostate cancer screening: Digital rectal examinations and prostate-specific antigen tests covered if recommended by a physician, at least once a year for me 50 years of age or older until age 72. Effective 1/2000.	All contracts including HMOs

Source: State of Maine, Department of Professional and Financial Regulations, Bureau of Insurance, Mandated Benefits, 2000. URL: http://www.state.me.us/pfr/ins/mndtsum.htm

### Appendix D

### Cancer Prevention and Screening Recommendations

	Who	When	What	How Often
Breast	Women	40 and over	Mammography and clinical breast exam	Every year
	Women	20 and over	Clinical breast examination ***	At least every three years
	Women	20 and over	Breast self-examination (BSE) is an option for women starting in their 20s. Women who choose to do BSE should receive instruction and have their technique reviewed	On the occasion of a periodic health exam
Cervical	Women	Approximately three years after beginning vaginal intercourse, but no later than 21	Pap test	Every year with conventional Pap test or every two years using liquid-based Pap tests
	Women	30 and over	Pap test	Every two to three years for women 30 and over with three consecutive normal Pap tests
	Women if high risk	35 and over if at high risk ∞	Endometrial tissue sampling	Every year
Prostate	Men	50 and over or 45 and over for high risk	Digital rectal exam (DRE) and prostate-specific antigen (PSA) test <sup>x</sup>	Every year
Colorectal	Women and Men	50 and over*i	Fecal occult blood test	(FOBT) and flexible sigmoidocoppy every five years
			or flexible sigmoidoscopy	Every five years
			or fecal occult blood test	Annually
			or colonoscopy	Every ten years
			or double-contrast barium enema	Every five years
Other	Women and Men	20 and over	Cancer checkup x11	On the occasion of a periodic health examination

Screening mammagraphy should begin at age 40. Women with a family history or other risk factors may benefit from earlier initiation of screening, shorter internals, or the addition of ultrasound or MRI Imaging.

High risk is defined as known HNPCC—associated genetic mutation carrier status, or presence of mutation in a family member, or suspected autosomal dominant predisposition to colon cancer in family member in the absence of genetic testing results.

PSA and DRE should be offered annually, beginning at age 50 for men who have at least a 50-year life expectancy. Men who ask their doctors to make the decision on their behalf should be tested. Men who are at high risk [Black men or men with a history of prostate cancer in close family members] should begin tests at age 65.

People with a personal history of colorectal cancer, admonatous polyps, hereditary colorectal cancer syndromes or chronic inflammatory howel disease should discuss screening schedules with their doctors. Flexible sigmoidescopy and FOBT is preferred compared with either FOBT or flexible sigmoidescopy alone.

### Appendix E

### American College of Surgeons (ACOS) Approved Hospitals

- Central Maine Medical Center Lewiston
- Eastern Maine Medical Center Bangor
- Henrietta D. Goodall Hospital Sanford
- Maine Medical Center Portland
- MaineGeneral Medical Center Augusta and Waterville
- Penobscot Bay Medical Center Rockport
- Redington-Fairview General Hospital Skowhegan
- Southern Maine Medical Center Biddeford
- St. Mary's Regional Medical Center Lewiston
- Stephens Memorial Hospital Norway
- Togus Veterans Administration Medical Center Augusta

# Appendix F

## Cancer Treating Hospitals in Maine

Hospital	County
Central Maine Medical Center – Lewiston	Androscoggin
St. Mary's Regional Med Center – Lewiston	Androscoggin
Aroostook Med Center - Presque Isle	Aroostook
Cary Medical Center - Caribou	Aroostook
Houlton Regional Hospital – Houlton	Aroostook
Northern Maine Medical Center - Fort Kent	Aroostook
Bridgton Hospital - Bridgton	Cumberland
Maine Medical Center - Portland	Cumberland
Mercy Hospital - Portland	Cumberland
Mid Coast Hospital - Brunswick	Cumberland
Parkview Adventist Medical Center - Brunswick	Cumberland
Franklin Memorial Hospital – Farmington	Franklin
Blue Hill Memorial Hospital - Blue Hill	Hancock
Maine Coast Memorial Hospital – Ellsworth	Hancook
Mount Desert Island Hospital - Bar Harbor	Hancock
Inland Hospital - Waterville	Kennebec
MaineGeneral Medical Center - Augusta/Waterville	Kennebec
Togus Regional Veterans Admin Med Center - Togus	Kennebec
Penobscot Bay Medical Center - Rockport	Knox
Miles Memorial Hospital – Damariscotta	Lincoln
St. Andrews Hospital – Boothbay Harbor	Lincoln
Rumford Hospital – Rumford	Oxford
Stephens Memorial Hospital - Norway	Oxford
Eastern Maine Medical Center – Bangor	Penobscot
Millinocket Regional Hospital – Millinocket	Penobscot
Penobscot Indian Health Center - Old Town	Penobscot
Penobscot Valley Hospital – Lincoln	Penobscot
St. Joseph's Hospital - Bangor	Penobscot
Mayo Regional Hospital – Dover-Foxcroft	Piscataquis
Redington-Fairview - Skowhegan	Somerset
Sebasticook Valley Hospital – Pittsfield	Somerset
Waldo County General Hospital – Belfast	Waldo
Calais Regional Hospital - Calais	Washington
Down East Community Hospital - Machias	Washington
Henrietta Goodall Hospital - Sanford	York
Southern Maine Medical Center - Biddeford	York
York Hospital - York	York

## Appendix G

### EPA Map of Radon Zones in Maine



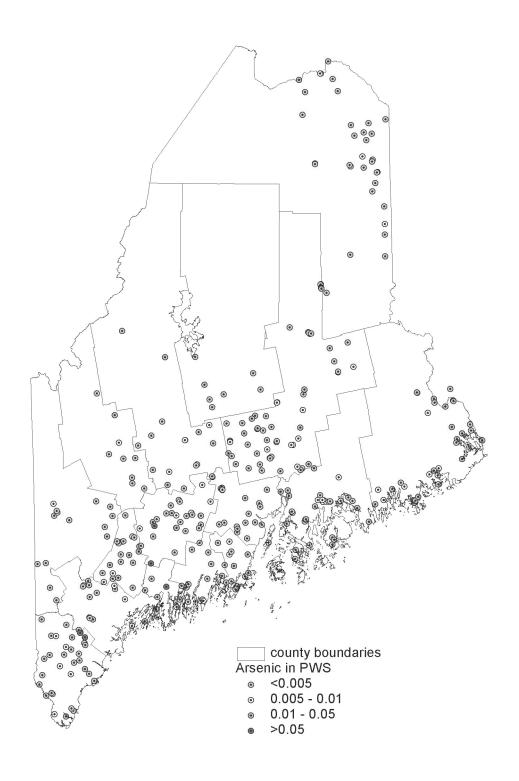
Zone 1: Highest Potential (greater than 4 pCi/L)

Zone 2: Moderate Potential (from 2 to 4 pCi/L)\*

<sup>\*</sup> The "Zone 2" areas are just as likely to have very high radon (10 times the current action level for radon) levels as "Zone 1" areas.

## Appendix H

Maine DHHS, Environmental Health Program Map of Arsenic Distribution by County



### Appendix I

### Cancer Incidence and Mortality Technical Notes

### **Data Sources**

Maine Incidence Data: Maine cancer incidence data is provided by the Maine Cancer Registry, a program within the Maine Center for Disease Control and Prevention (formerly the Bureau of Health). All hospitals and health care facilities that diagnose or treat cancer are required by law to report their cancer cases to the Maine Cancer Registry (Title 22, Chapter 255).

National Incidence Data: The national cancer incidence estimates are provided by the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. The SEER data is collected in specific metropolitan regions and states, representing approximately 26% of the U.S. population. Due to the predominately White population in Maine, SEER incidence rates for Whites only are often used as a more accurate comparison.

Mortality Data: Mortality data for both Maine and the U.S. is provided by the National Center for Health Statistics (NCHS). National rates for Whites only are often used as a more accurate comparison to Maine's population. Data from NCHS was calculated using a statistical software program called SEERStat.

#### **Data Presented**

Age-Adjusted Rates: All cancer incidence and mortality rates are calculated per 100,000 people and age-adjusted to the United States 2000 population. Age-adjustment allows for accurate comparisons between two or more populations that differ in age composition. For example, since cancer is a disease of older populations, states with a larger percentage of people over age 65 would tend to have higher rates of cancer. The process of age-adjustment removes the effect of age, allowing for direct comparisons of rates between communities with differing age distributions.

Age-Specific Rates: The age-specific incidence and mortality rates are calculated for the most recent three-year time period, 2000 to 2002. A combined 3-year period is used to increase the reliability of the results.

**Trend Data**: In order to show recent trends in cancer rates over time, this document includes yearly data from 1995 to 2002. The changes in cancer incidence and mortality rates have not been assessed for statistical significance and should only be used as a general indication of progress.

Stage at Diagnosis Data: Stage at diagnosis describes the extent to which the cancer has progressed at the time of diagnosis. In order to improve the reliability of the data, multiple years

were combined. Maine data is based on years 1995 to 2002 and the SEER data is based on years 1995 to 2001.

### Data Variability and Small Numbers

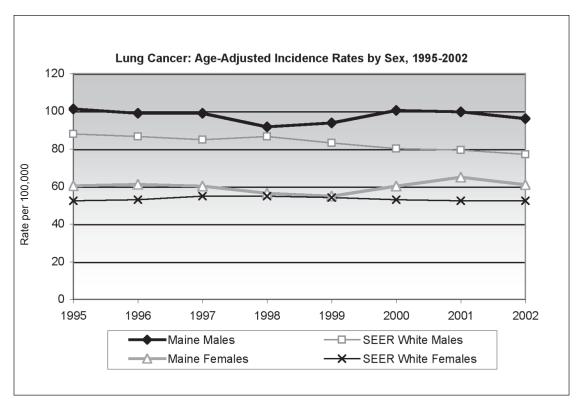
Cancer Rates by County: The number of new cancer cases reported in a county varies from year to year. Cancer rates, therefore, also vary from year to year. Counties with a smaller population tend to have a greater degree of variation from year to year. In general, when there are less than 30 cases a year, it can be difficult to distinguish between normal variation and meaningful changes in the cancer rates. In this report, multiple years of data are combined when producing the county rates. Although combining years makes the rates more stable, caution must still be used when interpreting county rates. Counties with high rates during one time-period could be low during a different time-period.

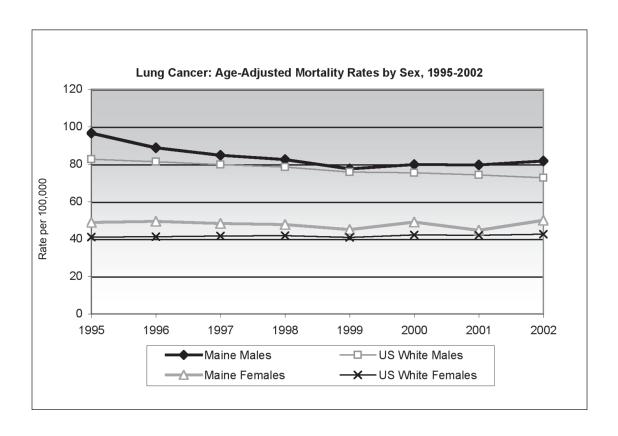
Cancer Rate Trends for Specific Sites: Cancer rate trends for specific cancer sites (body locations) are presented in this report. Cancer rates for less common cancers, such as cervical cancer, are based on a small number of cases. Rates based on a smaller number of cases tend to be less reliable and should be interpreted with caution.

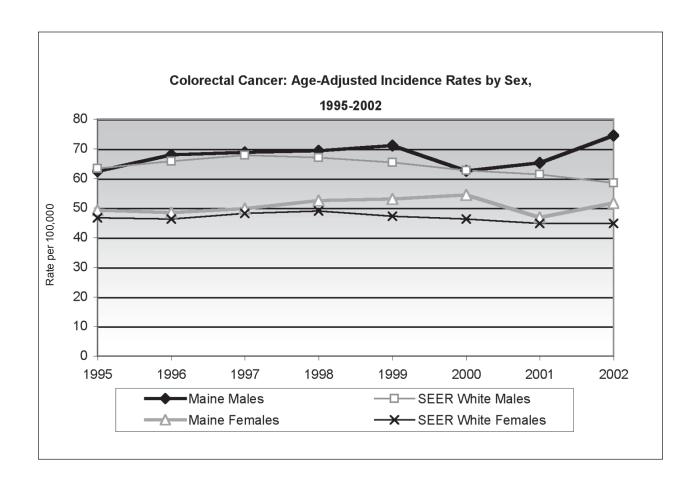
Stage at Diagnosis Data: Stage at diagnosis describes the extent to which the cancer has progressed at the time of diagnosis. Maine staging data is presented from 1995 to 2002. Stage at diagnosis trend data is provided as a way to assess the effects of screening and early detection measures. For cancers that have recommended screening measures, one would hope to see an increase in the percent of local stage diagnoses and a decrease in the percent of regional or distant stage diagnoses over time.

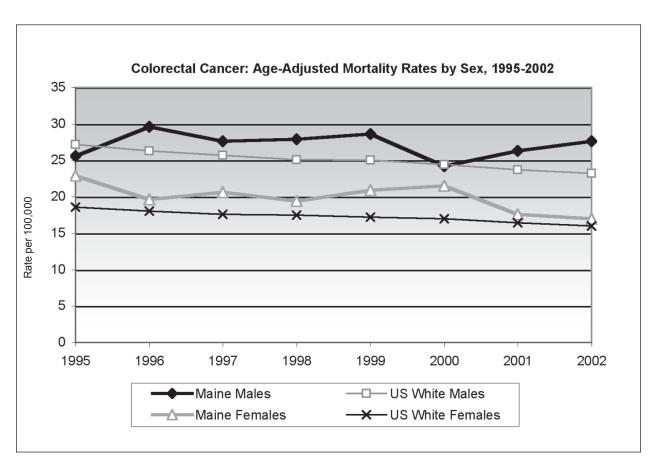
## Appendix J

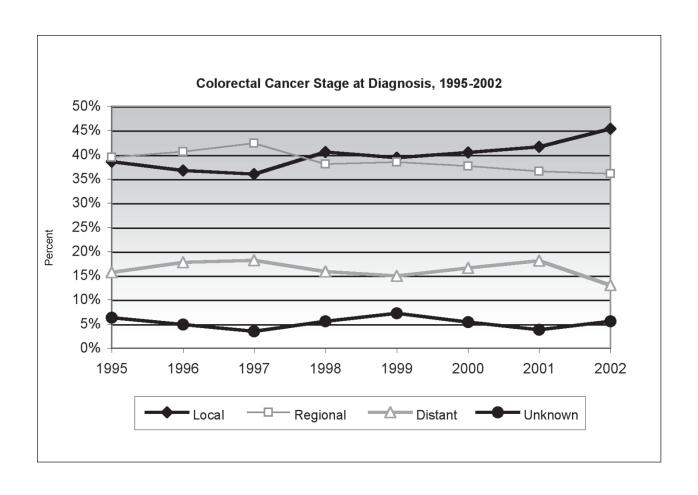
## Additional Cancer Data

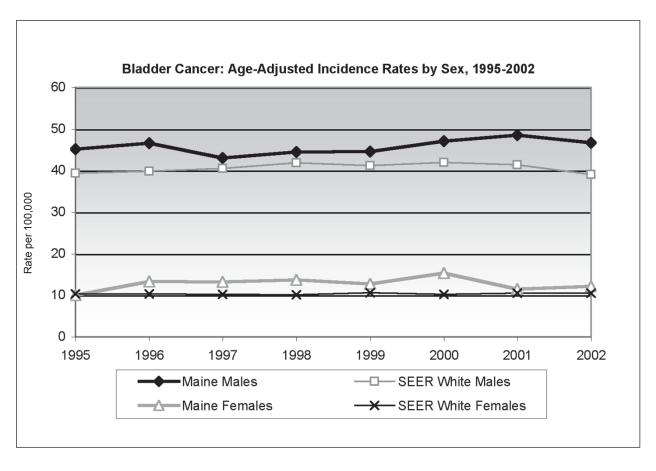


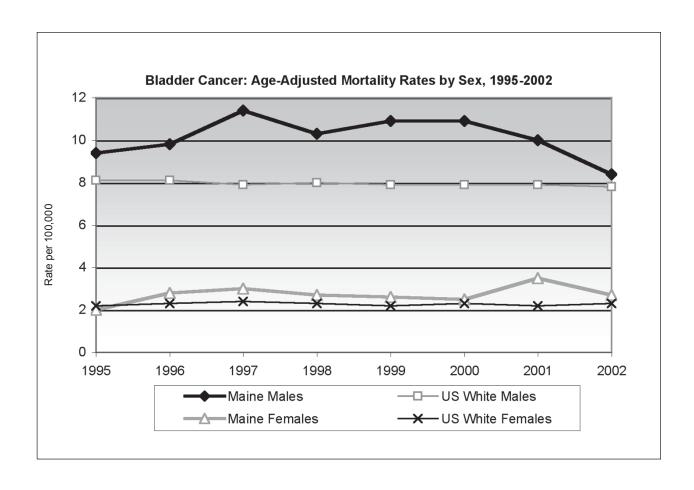


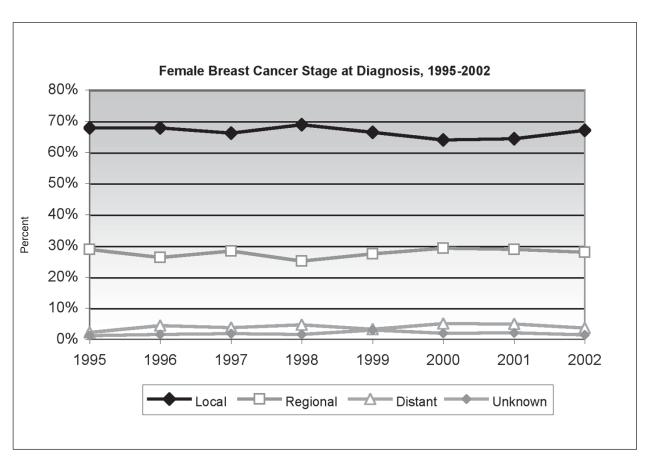


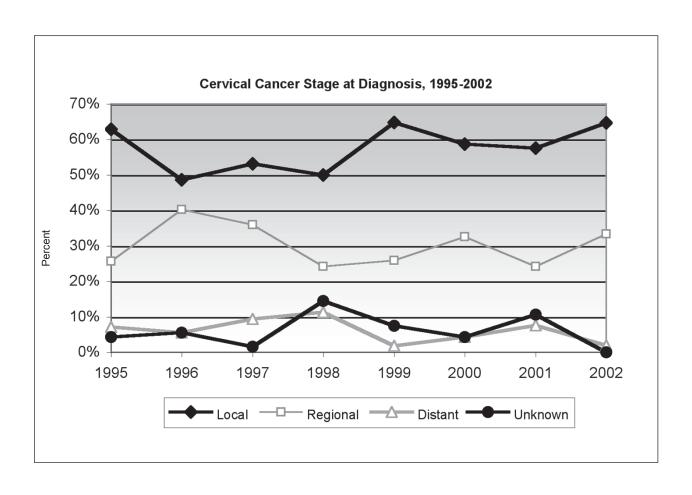


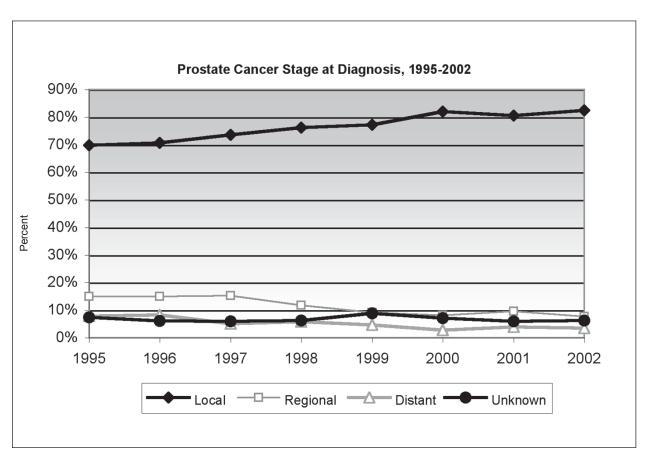












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