# Massachusetts Statewide Plan to Reduce and Eliminate Death and Suffering Caused by Cancer

## 2006 - 2011

massachusetts
comprehensive
cancer control
COALITION

massachusetts comprehensive cancer control COALITION

*Reducing and eliminating suffering and death due to cancer*

250 Washington Street • Suite 4 • Boston, Massachusetts • 02108

7-15-05

Dear Residents of the Commonwealth of Massachusetts;

All of us, I am sure, have been touched by cancer and experienced its effects on our own health or the health of family and friends. Before the end of this decade, cancer will kill more people than any other disease. In Massachusetts and across the nation, many organizations have begun to band together to stop cancer's increasing toll on our lives. The National Cancer Institute and the American Cancer Society have set a common goal, to "eliminate suffering and death due to cancer by 2015." Is this possible?

Many cancers can be prevented and several others can be detected early enough to reduce suffering and save lives. The many recent advances in cancer treatment and palliative care can extend and improve the quality of life for cancer survivors. Continuing these advances in cancer prevention and treatment and making them available to all Massachusetts residents are the challenges and the opportunities that bring us together.

The Massachusetts Comprehensive Cancer Control Coalition is pleased to present this statewide plan to reduce the burden of cancer in our state. The Coalition consists of many different organizations throughout the state and recognizes that the cancer problems are too large for any one group. We are committed to an integrated, collaborative, cooperative team approach. We welcome and encourage new members whose mission is congruent with the overarching goal of reducing and eliminate suffering and death due to cancer.

If you wish to participate or desire more information please contact us at 617 624-5480. Working together we can reduce the deaths and suffering in our state due to cancer.

Sincerely,

Marianne Prout, MD, MPH,
CHAIR, Executive Committee of Massachusetts Cancer Coalition
Boston University School of Public Health, Department of Epidemiology
Boston University School of Medicine, Cancer Prevention and Control

# Massachusetts Statewide Plan to Reduce and Eliminate Suffering and Death Caused by Cancer

**Massachusetts Comprehensive Cancer Control Coalition**

**2006–2011**

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# ACKNOWLEDGMENTS

The Massachusetts Statewide Cancer Plan is a product of the hard work and dedication of the Massachusetts Comprehensive Cancer Control Coalition, a partnership of more than 100 individuals and organizations from across the cancer continuum.

## Massachusetts Comprehensive Cancer Control Coalition Membership

Following is a list of the Coalition membership:

American Association of Retired Persons
American Cancer Society
American Cancer Society NE Pain Initiative
American College of Surgeons—Commission on Cancer
American Lung Association
Ashland Board of Health
Arms Around Arlington
Barnstable County Department of Health and Environment
Baystate Health Systems
Berkshire Endoscopy Center
Berkshire Medical Center
Beth Israel Deaconess Medical Center
Blue Cross/Blue Shield
Boston CARE Community Network
Boston Medical Center
Boston Public Health Commission
Boston University School of Medicine
Boston University School of Public Health
Brandeis University, Heller Graduate School for Social Policy and Management
Brigham and Women's Hospital
Campaign for Tobacco Free Kids
Cancer Information Service
Cape Cod Healthcare Cancer Services
Center for Information and Study on Clinical Research Participation (CISCRP)
Central MA Partnership to Improve Care at the End of Life
City of Newton Health Department
Compass Medical Group
Dana-Farber Cancer Institute
Dana-Farber/Harvard Cancer Center
Encore Plus
Exact Sciences
Fairview Hospital
Group Insurance Commission
Harvard School of Public Health
Harvard Center for Cancer Prevention
Harvard Vanguard Medical Associates
Hilltown Community Health Centers

Hospice and Palliative Care Federation
HospiceCare in the Berkshires, Inc.
Jordan Hospital
Latin American Health Institute
Massachusetts Association of Health Boards
Massachusetts Association of Health Plans
Massachusetts Breast Cancer Coalition
Massachusetts Coalition for a Healthy Future
Massachusetts Colorectal Cancer Working Group
Massachusetts Commission on End of Life Care
Massachusetts Compassionate Care Coalition
Massachusetts Dental Society
Massachusetts Department of Education
Massachusetts Department of Public Health
Massachusetts Dietetic Association
Massachusetts Division of Medical Assistance
Massachusetts General Hospital
Massachusetts League of Community Health Centers
Massachusetts Melanoma Foundation
Massachusetts Executive Office of Elder Affairs
Massachusetts Health Officers Association
Massachusetts Health Quality Partnership
Massachusetts Hospital Association
Massachusetts Nurses Association
Massachusetts Oral Cancer Partnership
Massachusetts Pain Initiative
Massachusetts Prostate Cancer Coalition (MPCC)
Massachusetts School Nurses Association
Massachusetts Skin Cancer Prevention Collaborative
Massachusetts State Laboratory
MassPRO
Mercy Medical Center
Millis Board of Health
Massachusetts Public Health Association
National Black Leadership Initiative on Cancer II
National Ovarian Cancer Coalition, MA Division
New England Coalition for Cancer Survivorship
New England Medical Center
Northeastern University Bouve College of Health Science
Palliative Care Nurses Association
Peabody Medical Associates
ProMutual Group
REACH Community Health Foundation
Risk Management Foundation
Simmons College
Southcoast Hospitals Group
Southeast Asian Health Program
Sickness Prevention Achieved Through Regional Collaboration (SPARC)
St. Elizabeth's Hospital

Sun Protection Foundation
The Black Ministerial Alliance
The Cam Neely Foundation for Cancer Care
The Leukemia and Lymphoma Society
The Medical Foundation
The Wellness Community—Greater Boston
Tobacco Free Mass: The Massachusetts Coalition for a Healthy Future
Tufts Health Plan
Tufts University
Tufts University School of Medicine
Tupper Research Institute
United Ostomy Association
University of Massachusetts Medical School
University of Massachusetts School of Public Health
VA Medical Center
VNA Care Network
VNA & Hospice of Cooley Dickinson
Whitehead Institute for Biomedical Research
Wilmington Community Advisory Committee
YWCA of Southeastern Massachusetts

## Special Thanks

Many organizations contributed significant resources, ensuring success for our collaborative effort. They include the American Cancer Society, the Massachusetts Department of Public Health, the Dana-Farber Cancer Institute, the American College of Surgeons, and the National Cancer Institute's Cancer Information Service.

## Funding

The development of this document was supported by Cooperative Agreement U55/CCU121937-03 from the Centers for Disease Control and Prevention. The content of this report is the responsibility of the authors and does not necessarily represent the official views of the Centers for Disease Control and Prevention.

# TAB 1

# EXECUTIVE SUMMARY

# EXECUTIVE SUMMARY

The Massachusetts Comprehensive Statewide Plan (Plan) is a product of the Massachusetts Comprehensive Cancer Control Coalition (Coalition), a collaboration of more than 100 academic, government, community, and survivor organizations dedicated to reducing cancer incidence, morbidity, and mortality in the Commonwealth. The Plan compares the cancer burden in the state to national data, evaluates accomplishments by the state related to cancer prevention and control, and identifies gaps, issues, barriers, and concerns specific to Massachusetts. The Plan also identifies, and recommends, evidence-based interventions. Data analysis, needs throughout the state, and evidence-based strategies form the framework for the Plan.

From 1998 to 2002 there were 171,729 newly diagnosed cases of cancer and 69,298 deaths from cancer among residents of Massachusetts. Both cancer incidence and mortality rates stabilized or changed only slightly during that period. However, incidence and mortality rates for all cancers were higher for Massachusetts than for the nation. The reasons for these discrepancies vary. One reason may be the disproportionate burden of cancer placed on the racial/ethnic minority population; another may be the size of the elderly population. While Massachusetts has a large population of White non-Hispanics, a majority of cancer cases and deaths were among Black non-Hispanics.

The most commonly diagnosed cancers among males were prostate, bronchus/lung, colorectal, and urinary bladder. The most commonly diagnosed cancers among females were breast, bronchus/lung, colorectal, and uterine. Lung/bronchus cancer was the leading cause of death for males and females, followed by cancer of the prostate (men) or breast (women), colon/rectum, and pancreas.

Cancer did not affect all Massachusetts residents equally. Black non-Hispanic males and White non-Hispanic females had the highest incidence rates of all cancer types combined for the years 1998–2002. Black non-Hispanic males and females had the highest age-adjusted mortality rate, with 345 deaths for every 100,000 males and 197 deaths for every 100,000 females.

Reducing the cancer burden in the Commonwealth is a daunting task. That is why the Massachusetts Comprehensive Cancer Coalition engaged in long-term planning, following guidelines established by the Centers for Disease Control and Prevention for comprehensive cancer control. This document is the result of that effort. Work groups were organized according to the cancer continuum, and the members focused on topics that became the outline for the Plan. Each work group, comprising cancer experts, cancer survivors, and other stakeholders, evaluated data, identified gaps, and formulated goals consistent with established evidence.

## Organization of the Plan

The Plan is organized according to the cancer continuum, from prevention through end of life. Because more people than ever are living with cancer, issues related to survivorship and palliative care were of importance to Coalition members and have their own sections in this document. The Plan pays particular attention to those populations who are disproportionately affected by cancer, and offers strategies to eliminate the barriers to quality prevention, treatment, and care for all. The members of the Massachusetts Comprehensive Cancer Control Coalition understand that in order to reduce the burden of cancer in the state, such disparities must be addressed.

The main content of the Plan is divided into seven areas from the cancer continuum: prevention; early detection; treatment; survivorship; palliative care; end of life care; and surveillance, evaluation, and research into practice.

### Prevention

This section addresses those factors that can be changed to reduce one's risk of developing cancer. According to the American Cancer Society, 60 percent of cancers could be avoided if people stopped using tobacco and adopted healthier lifestyles. Massachusetts seeks to reduce tobacco use and exposure to second-hand smoke with specific goals targeting all adults, pregnant women, and high school students.

The Plan also addresses the problems posed by the growing percentage of adults who do not have health insurance by establishing goals to make health insurance and a regular source of primary care available to all Massachusetts residents.

This section discusses many other issues important to reducing the cancer burden:

- The effect of weight, exercise, and alcohol on cancer rates
- Exposure to UV rays that cause malignant melanoma, a deadly skin cancer
- Growing public concern about environmental and occupational carcinogens, incorporating goals for reducing those agents that carry the greatest risk for increased cancer incidence
- The link to cancers caused by infectious agents such as human papillomaviruses, human immunodeficiency virus, hepatitis B and C viruses, and heliobacter pylori, and the potential for preventing them
- The complicated role of genetics in cancer risk, incorporating the goal of increasing early identification of people at risk for developing cancer due to genetic susceptibility or inherited predisposition

### Early Detection

This section focuses on three cancers—breast, cervical, and colorectal—for which procedures and tests can identify pre-cancer or cancer at the earliest possible stage. Goals for reducing these three cancers seek to increase screening rates for everyone. In addition, for each of these cancers, goals have been designed to reduce incidence among those populations who are at greatest risk.

The early detection section also addresses prostate cancer, ovarian cancer, and oral cancer. These three cancers do not have early detection methods approved by the National Cancer Institute or the U.S. Preventive Services Task Force. They do, however, have specific public health interventions with potential for reducing mortality rates.

This section ends with a brief discussion of emerging technologies, and includes a goal to monitor those advances for inclusion in cancer control efforts.

**Treatment**

This section emphasizes disparities in access to quality treatment. Disparities in access are particularly evident among racial/ethnic minorities, people of lower socioeconomic status, residents of rural areas, and other underserved populations for whom the unequal burden of cancer continues to be documented through the nation's cancer surveillance networks. Barriers may be financial, educational, informational, linguistic, or geographic. These populations often experience unacceptable delays in follow-up of abnormal findings, definitive diagnoses, and subsequent treatments. Therefore, the main goal of this section is to ensure that all residents of the Commonwealth have equal and immediate access to cancer information, treatment, and clinical trials that are based on nationally recognized best practice standards.

**Survivorship**

Nationally and in Massachusetts, the quality of life issues that affect survivors are not well known. Currently no surveillance system is in place to collect and monitor information on this topic. This section explores the physical, psychological, social, spiritual, and financial issues affecting people who have been diagnosed with cancer. The broad goal for the survivorship section is to ensure that all cancer survivors living in the Commonwealth have equal access to information and follow-up medical, rehabilitative, and psychosocial services.

**Palliative Care**

Palliative care directly affects the quality of life for cancer survivors and their loved ones. It includes the control of pain and other symptoms, beginning with the day of diagnosis and continuing to the end of life. This section of the Plan looks at results of current research as well as efforts by the state to provide palliative care and related concerns. It establishes the goal of increasing access to quality palliative care for all residents of the Commonwealth. Strategies include increasing the number of certified palliative care providers and the number of cancer centers with palliative care programs.

**End of Life Care**

This section addresses the needs of cancer survivors and their loved ones when the cancer cannot be cured. It covers the importance of advance care planning and the need for public and provider education. The end of life care section focuses attention on the wishes of the cancer survivors and their loved ones as they face death. This section addresses end of life needs of survivors of all ages, including children. It also discusses the disparities in end of life services such as hospice care. The broad goal for the end of life care section is to ensure that all residents of the Commonwealth have access to quality end of life care.

**Surveillance, Evaluation, and Research Into Practice**

This section examines the use of established surveillance systems, evaluation of programs and services, and improvement of methods by which research is translated into practice. The broad goal for this section is to take advantage of surveillance, evaluation, and research to make decisions about cancer control interventions.

The Plan will be carried out through a participatory process that will be defined in regional meetings across the state. The outcome of each goal will be monitored according to established measures. Most interventions will be evidence-based. However, the plan also suggests interventions with recommendations for further investigation to determine effectiveness.

The Massachusetts Comprehensive Cancer Coalition is committed to working with all organizations whose mission is to improve the life expectancy and quality of life for all residents. To accomplish this overarching goal the Commonwealth must think together, work together, and share information and resources to reach its goal of ending suffering and death due to cancer.

# INTRODUCTION

The Massachusetts Comprehensive Cancer Control Coalition (Coalition) is a network of more than 100 organizations dedicated to decreasing cancer incidence, morbidity, and mortality in the Commonwealth. The Massachusetts Department of Public Health (MDPH) is the current fiscal agent receiving seed money from the Centers for Disease Control and Prevention for cancer control efforts. MDPH uses this seed funding to facilitate the statewide efforts of the Coalition.

The Coalition is committed to an integrated, coordinated, collaborative approach encompassing prevention, early detection, treatment, survivorship, and palliation. The Massachusetts Coalition mirrors the national comprehensive cancer control model as established by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute.

Through a national study of comprehensive cancer control initiatives that included six states, four major reasons for establishing a Coalition were identified:

- No single organization or agency can control and prevent cancer.
- Cancer will become the number one killer in Massachusetts and the nation during this decade. It is already the number one killer for specific age groups and populations.
- Significant gaps exist between what is known and what is being done to solve cancer problems.
- Cancer affects some people more than others, which leads to significant health care disparities.

Any organization whose mission is consistent with the Coalition's may become a member and join the effort to reduce the burden of cancer in Massachusetts.

## Work Groups and the Planning Process

This statewide plan is the result of dedicated planning by the Coalition. Five work groups comprising cancer experts, cancer survivors, and other stakeholders focused on topics that were selected according to the cancer continuum:

### Prevention Work Group

This group focused on factors that, if modified, can reduce one's risk of developing cancer. These factors include tobacco use and exposure, access to quality preventive health care services and screening, nutrition, physical activity, alcohol use, infectious agents, exposure to ultraviolet rays, exposure to environmental carcinogens, and genetics.

### Early Detection Work Group

This group focused on three specific cancers for which there are procedures and tests to identify cancer in asymptomatic people at the earliest possible stage. The group also focused on the three cancers that do not have early detection methods approved by the National Cancer Institute or the U.S. Preventive Services Task Force but do have specific public health interventions with potential for reducing mortality rates.

### Treatment, Survivorship, and Palliation Work Group

This group addressed these three interrelated topics. For treatment, the group looked specifically at issues related to Massachusetts residents' access to quality treatment. For survivorship and palliation, the work group focused on the quality of life for cancer patients.

### End of Life Care Work Group

This group focused on the needs of cancer survivors and their loved ones, when curing the disease was no longer possible.

### Surveillance, Evaluation, and Research Into Practice Work Group

This group examined the use of established surveillance systems, evaluation of programs and services, and improvement of methods to translate research into practice.

Each work group began by examining the scientific evidence specific to each topic on the continuum. Members studied the gaps, issues, barriers, and concerns on the national level and identified similar problems in the Commonwealth. They then established broad goals that were consistent with the mission of improving the life expectancy and quality of life, devising evidence-based strategies to achieve those goals. The work groups also selected outcome measures to monitor progress toward each goal, using established surveillance systems whenever possible.

## Implementation

The Plan will be carried out in regional meetings. During these meetings, participants will examine the strategies and goals, and then determine, from a regional perspective, the best ways to accomplish them. A feasibility formula will enable each regional group to evaluate available resources and potential effect. The participants will choose those strategies that promise the greatest reach in their respective communities and regions.

## Evaluation

The Coalition will use a specific set of outcome measures to monitor progress toward each goal. Each outcome measure appears after its respective goal, and all appear together in surveillance table 1. Progress will be reported to the Coalition membership, to the Centers for Disease Control and Prevention (CDC), and to the residents of the Commonwealth.

# MASSACHUSETTS DEMOGRAPHICS

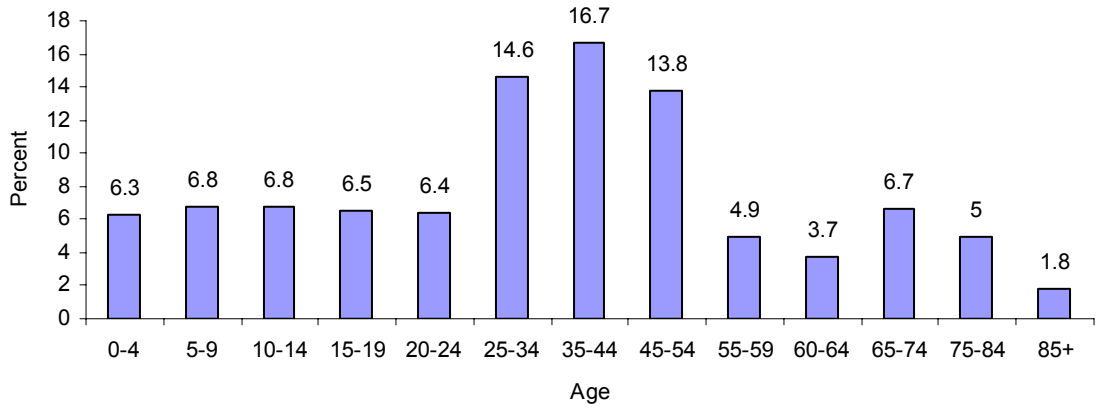
According to the U.S. Census, the population of Massachusetts was 6,349,097 in 2000. This represented a 5.5 percent increase in population from the years 1990–2000. The population increase in the U.S. during the same period was roughly 13.1 percent. With well over 550,000 people, Boston is Massachusetts' largest city. The second largest city is Worcester, with 172,648 people. The third and fourth largest cities in Massachusetts are Springfield and Lowell, with 152,082 and 105,167 people respectively.

## Age and Gender

Longer life expectancies coupled with falling birth rates mean the U.S. is supporting an aging population. In 2000 the median age among Massachusetts residents was 36.5, up from 33.5 in 1990 and slightly higher than the national median age of 35.3 in 2000.

In 2000 Massachusetts was very similar demographically to the U.S. Almost one-quarter of the population (23.6%) was under 18 years of age, mirroring the nation's population. Additionally, Massachusetts' population was nearly the same as the nation's with regard to persons 65 or older (13.5% vs. 12.4% respectively). As in the U.S., women outnumbered men in Massachusetts: 51.8 percent of the population was female and 48.2 percent was male. Distribution of age groups was nearly the same in Massachusetts as in the U.S., with 16.7 percent 35 to 44 years of age, 14.6 percent 25 to 34, and 13.8 percent 45 to 54 (demographics figure 1). More males (63.9%) than females (59.7%) were under 18, but more females (8.2%) than males (5.4%) were 65 or older.

**Demographics Figure 1. Massachusetts Population Percents By Age Category, 2000**

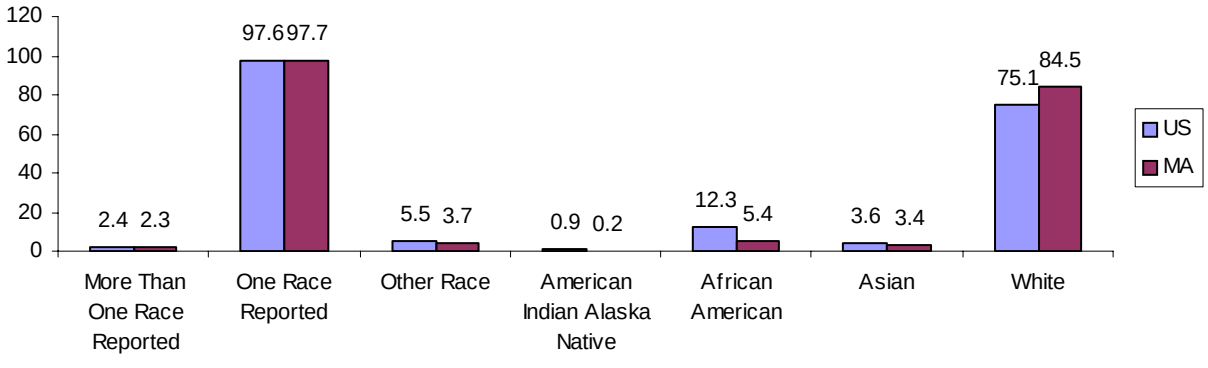



Source: U.S. Census, 2000

## Race

As demographics figure 2 shows, in 2000 the population of Massachusetts was mostly White (84.5%). This percentage was proportionately higher than that of the U.S. (75.1%). In addition, the percentage of Asians was slightly higher in Massachusetts (3.8%) than in the U.S. (3.6%). However, the population of African Americans was much higher in the U.S. (12.3%) than in Massachusetts (5.4%). The figures were slightly higher among American Indians and Alaska Natives living in the U.S. (0.9%) than in Massachusetts (0.2%). Fewer individuals reported "other race" in Massachusetts (3.7%) than in the U.S. (5.5%). Roughly the same proportion of individuals in Massachusetts reported that they were one race (97.7%) and more than one race (2.3%) than in the U.S. (97.6% one race, 2.4% more than one race).

**Demographics Figure 2. Population Percents by Various Race Categories, MA vs U.S., 2000**

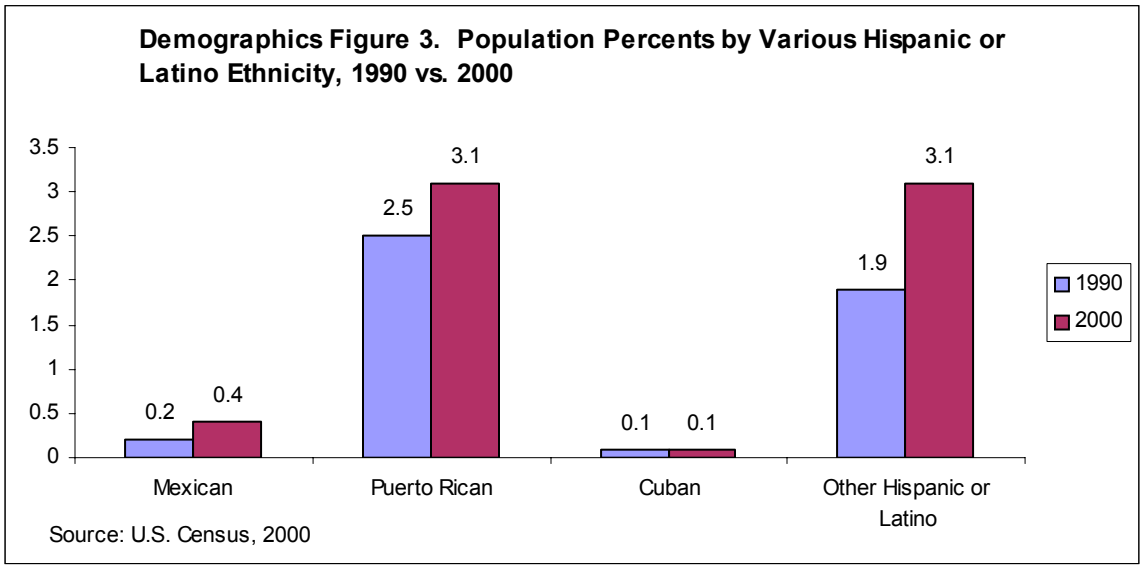



Source: U.S. Census, 2000

Since 1990, the number of individuals living in Massachusetts who report that they are White has decreased. In 1990, 89.8 percent reported that they were White; in 2000 that number went down to 84.5 percent. However, from 1990 to 2000, the proportion of both African Americans and Asians rose. In 1990, 5 percent of the population reported that they were African American; in 2000 that number rose to 5.4 percent. In 1990, 2.4 percent of the population reported that they were Asian, compared to 3.8 percent in 2000.

## Hispanic Ethnicity

In the 2000 census, 6.8 percent of the total population of Massachusetts reported that they were of Hispanic or Latino ethnicity. Even though this reflected an increase from 1990 (4.8%), it was much lower than the percentage of people in the U.S. (12.5%) who identified themselves as being of Hispanic or Latino ethnicity. The 2000 census recorded the ethnicity of other Massachusetts residents as follows: 0.4 percent Mexican, 3.1 percent Puerto Rican, 0.1 percent Cuban, and 3.1 percent other Hispanic or Latino (figure 3, next page).




## Income

The 2000 Census asked about total household income for 1999. For Massachusetts the median household income for 1999 was $50,502, a dramatic increase from the median income of $36,952 in 1989. Approximately 20.1 percent of the population of Massachusetts reported a household income of $50,000 to $74,000, and 14.5 percent reported a household income of $35,000 to $49,000. The reported median household income for the U.S. in 1999 was $41,486.

In 1999 the median family income was $61,664 and per capita income was $25,952. Ten years earlier the median family income was far less, $44,367, and the non-family household per capita income was $17,224.

Unemployment rates in Massachusetts were lower in 2000 than in 1990 by only 1.5 percent. In 2000, 3 percent of the population 16 or older was unemployed, down from 4.5 percent in 1990. The percentage of unemployed people 16 or older in Massachusetts was only slightly lower than the U.S. estimate of 3.5 percent.

## Education

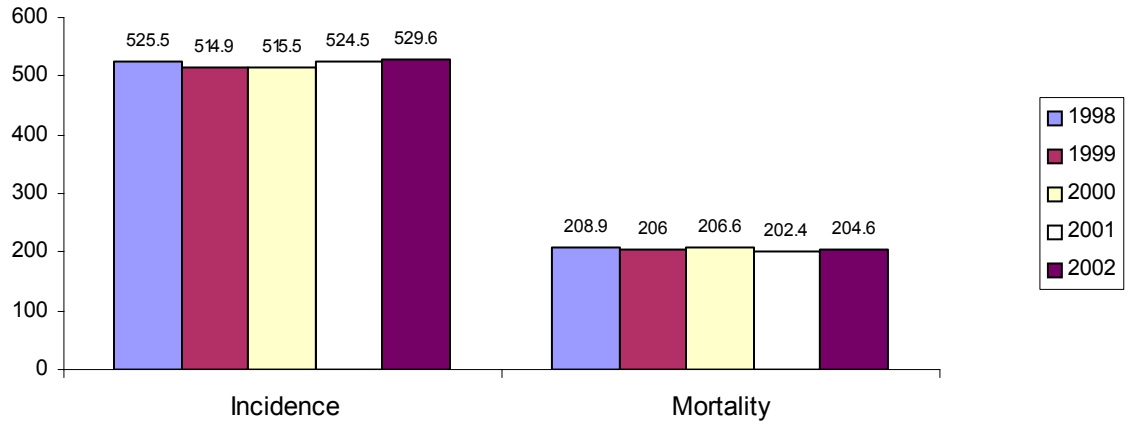
In 2000 Massachusetts exceeded the U.S. average for the percentage of high school graduates or higher and those with bachelor's degrees or higher. In Massachusetts 84.8 percent of the population had attained an educational level of high school graduate or higher, while 80.4 percent of the U.S. population had done the same. Similarly, 33.2 percent of the Massachusetts population had received a bachelor's degree or higher, but only 24.4 percent of the U.S. population attained the same levels. Twenty-seven percent of the Massachusetts population reported that they had graduated high school (not attaining a higher level), slightly lower than the U.S. figure of 28.6 percent. However, 19.5 percent of Massachusetts adults completed bachelor's degrees compared to 15.5 percent of adults in the U.S. In addition, 13.7 percent of the Massachusetts population received a graduate or professional degree, far higher than 8.9 percent in the U.S.

# THE BURDEN OF CANCER IN MASSACHUSETTS

From 1998 to 2002 there were 171,729 newly diagnosed cases of cancer and 69,298 deaths from cancer among Massachusetts residents. The average annual age-adjusted incidence rate was 555 cases for every 100,000 persons, and the mortality rate was 206 deaths for every 100,000 persons (burden figure 1).

During those same years, overall cancer incidence remained relatively stable. For both males and females, the average annual change in incidence rates did not exceed 0.6 percent. Cancer mortality rates for all sites combined varied only slightly as well (figure 1).

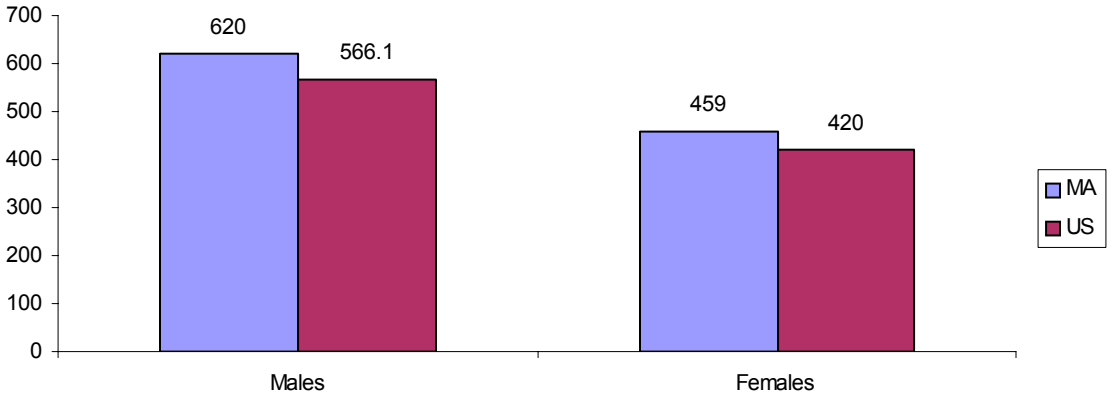
**Burden Figure 1. Annual Age-Adjusted Incidence and Mortality Rates* For All Sites Combined, MA 1998 - 2002**




*Rates are age-adjusted to the 2000 U.S. Standard Population, per 100,000 Source: MCR 2005

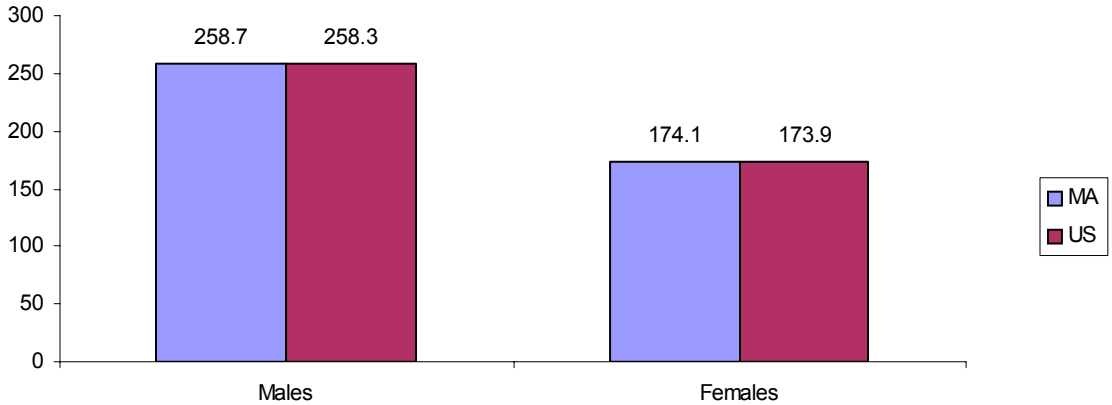
For both sexes and for all cancer sites combined, age-adjusted incidence rates were higher in Massachusetts when compared to national data (figure 2, next page). In addition, age-adjusted incidence rates in Massachusetts were slightly higher than national rates for female bronchus and lung, colorectal, breast (women), prostate (men), and uterine cancer. As figure 3 shows (next page), age-adjusted mortality rates for Massachusetts were slightly higher than the age-adjusted mortality rate in the United States for all cancer sites combined (259 per 100,000 versus 258 per 100,000 for males, and 174.1 per 100,000 versus 173.9 per 100,000 in females). The rates of mortality for cancer of the bronchus and lung among females were higher in Massachusetts than in the nation but were lower for bronchus and lung cancer among males and cervical cancer among females.[1]

**Burden Figure 2. Age-Adjusted Incidence Rates* For All Cancer Sites Combined by Gender, U.S. and MA 1998-2002**




*Rate age-adjusted to the 2000 U.S. Standard Population per 100,000. Source: MCR 2005

**Burden Figure 3. Age-Adjusted Mortality Rates* For All Cancer Sites Combined by Gender, U.S. and MA 1998-2002**




*Rates are age-adjusted to the 2000 U.S. Standard Population per 100,000. Source: MCR 2005

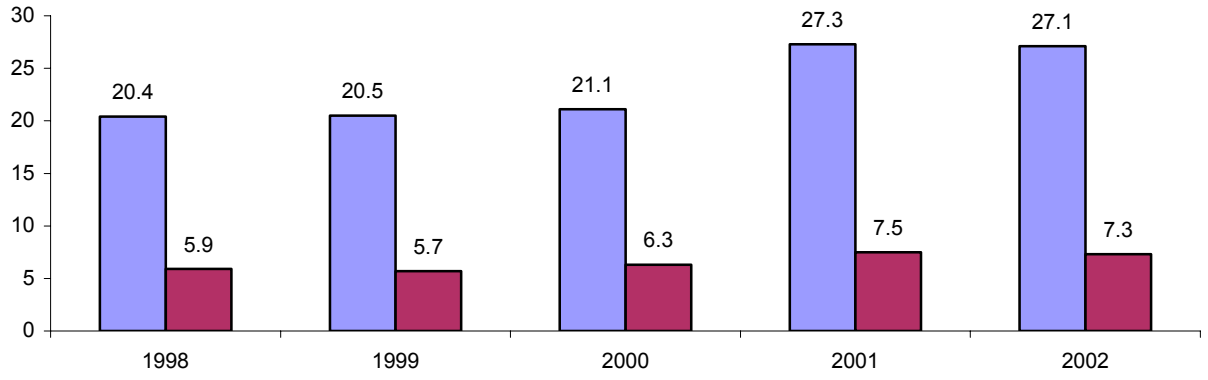
From 1998 to 2002, the most commonly diagnosed type of cancer among males was prostate (186 cases per 100,000), followed by bronchus and lung (91 cases per 100,000), colorectal (73 cases per 100,000), and urinary bladder (47 cases per 100,000). These four cancers represent an estimated 64 percent of newly diagnosed cancer cases among males in Massachusetts. During this same period, the type of cancer most commonly diagnosed among women was breast (145 cases per 100,000), followed by bronchus and lung (61 cases per 100,000), colorectal (51 cases per 100,000), and uterine (29 cases per 100,000). These four types of cancers represent roughly 62 percent of newly diagnosed cases in Massachusetts females.

While prostate (males) and breast (females) were the most commonly diagnosed cancers in Massachusetts, cancer of the bronchus and lung was the leading cause of death for both males (73 deaths per 100,000) and females (44 deaths per 100,000) between 1998 and2002. Cancer of the bronchus and lung accounted for 29 percent of all cancer deaths in males and 25 percent in females. Following bronchus and lung were prostate (males, 31 deaths per 100,000) and breast (females, 27 deaths per 100,000). The third and fourth most common causes of death among Massachusetts males and females were cancers of the colon/rectum (28 deaths per 100,000 males

and 19 deaths per 100,000 females) and pancreas (13 deaths per 100,000 males and 10 deaths per 100,000 females). These four cancers accounted for roughly 56 percent of cancer deaths occurring among males and females overall in Massachusetts during 1998–2002.[2]

Incidence rates for melanoma and multiple myeloma increased among both males and females in Massachusetts. The increases are important to note, but they may be related to new sources of cases, such as dermatologists' offices.[3]

**Burden Figure 4. Annual Age-Adjusted Incidence Rates* of Melanoma and Mulitiple Myeloma, MA 1998-2002**

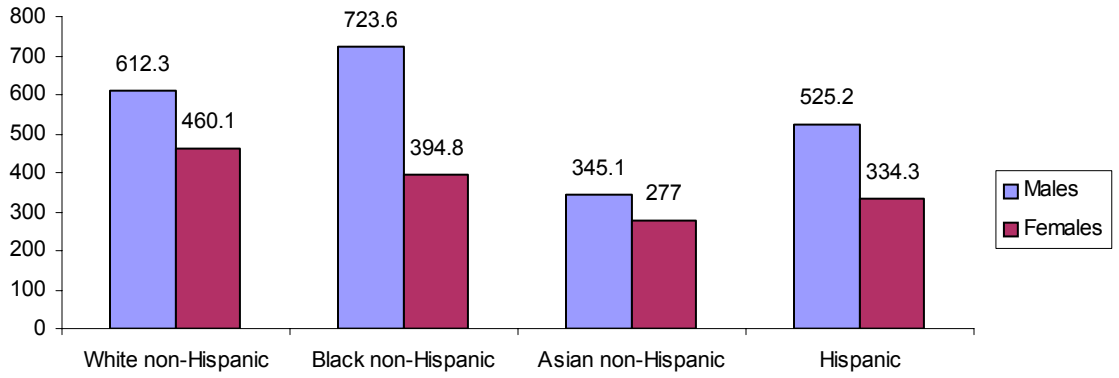



*Rates are age-adjusted to the 2000 U.S. Standard Population per 100,000. Source: MCR 2005

Black non-Hispanic males and White non-Hispanic females in Massachusetts had the highest incidence rates of all cancer types combined for the years 1998–2002 (724 cases per 100,000 and 460 cases per 100,000 respectively). When compared to national data, cancer incidence rates for Black non-Hispanic males and White non-Hispanic females were higher in Massachusetts than in the U.S. (683 cases per 100,000 and 429 cases per 100,000 respectively). For Massachusetts, cancer incidence rates for Black non-Hispanic males were found to be significantly higher than the incidence rates for all other race/ethnicity groups (p-value $\leq 0.05$). Asian non-Hispanic males and females had the lowest incidence rates (351 cases per 100,000 and 277 cases per 100,000 respectively).[4]

(continued on next page)

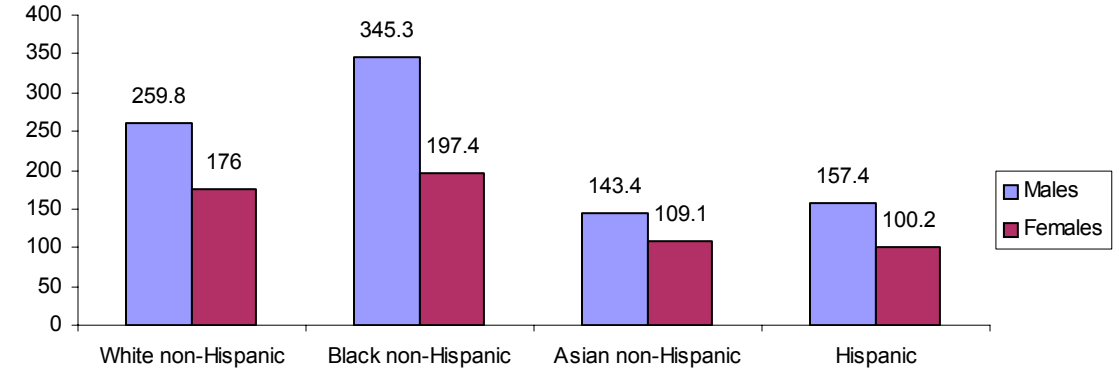
**Burden Figure 5. Age Adjusted Incidence Rates* For All Cancer Sites Combined by Race/Ethnicity and Gender, MA 1998-2002**




*Rates are age-adjusted to the 2000 U.S. Standard Population per 100,000. Source: MCR 2005

Black non-Hispanic males and females in Massachusetts had the highest age-adjusted cancer mortality rate, with 345 deaths for every 100,000 males and 197 deaths for every 100,000 females. Consistent with national data (339 deaths per 100,000 Black non-Hispanic males and 194 deaths per 100,000 females),[5] these findings suggest that Black non-Hispanic individuals may not have received the same screening and/or treatment as White non-Hispanic individuals.[6]

**Burden Figure 6. Age-Adjusted Mortality Rates* For All Cancer Sites Combined by Race/Ethnicity and Gender, MA 1998-2002**




*Rates are age-adjusted to the 2000 U.S. Standard Population per 100,000. Source: MCR 2005

# TAB 2

# Cancer Prevention

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## CANCER PREVENTION

The National Cancer Institute (NCI) defines prevention as "the reduction of cancer mortality via reduction in the incidence of cancer. This can be accomplished by avoiding a carcinogen or altering its metabolism; pursuing lifestyle or dietary practices that modify cancer-causing factors or genetic predisposition; and/or medical intervention (e.g., chemoprevention) to successfully treat pre-neoplastic lesions."[7] This section of the plan focuses on key areas that can prevent or lower the risk of cancer. This includes stopping the use of and exposure to tobacco, having access to timely and quality health care services, maintaining a healthy diet, staying physically active, reducing alcohol consumption, reducing exposure to infectious agents and environmental and occupational carcinogens, and knowing one's family medical history.

Tobacco use and exposure is the leading preventable cause of death in the U.S.[8] According to the American Cancer Society (ACS), 60 percent of cancers could be avoided if people stopped using tobacco and adopted healthier lifestyles. The ACS estimates that in 2005, 175,000 cancer deaths in America will be caused by tobacco use alone. This represents 30 percent of cancer deaths. Since the first published Surgeon General's report on smoking and health in 1964, there have been more than 12 million premature deaths in the U.S. attributable to smoking.[9] The tragedy, of course, is that cancers caused by tobacco use are preventable.

A major barrier to cancer prevention for many Americans is their inability to pay for preventive health care services. More than 43 million Americans (one in seven) under age 65 do not have health insurance. Lack of health insurance contributes to 18,000 unnecessary deaths in America every year. It contributes to larger numbers of people suffering pain and disability from the cancer and its side effects. Lack of insurance erodes the financial stability of families and the entire health care system. Although America leads the world in health care spending, it is the only wealthy, industrialized nation that does not ensure that all its citizens have health care coverage.[10]

ACS has estimated that about one-third of the 570,280 estimated cancer deaths in the U.S. for 2005 will be attributed to poor nutrition, physical inactivity, overweight or obesity, and other lifestyle factors.[11] Another modifiable lifestyle factor, alcohol, is not what most people think of when they think about cancer prevention. But when consumed in excess, alcohol can increase the risk of cancers in the mouth, esophagus, pharynx, larynx, and liver in men and women, and of breast cancer in women.[12]

No discussion about lifestyles and cancer prevention would be complete without mention of exposure to ultraviolet rays. The intensity of ultraviolet rays is responsible for more than a million cases of non-melanoma skin cancer annually. Fortunately, non-melanoma skin cancers are highly curable. Melanoma, on the other hand, is a deadly cancer that is associated with exposure to ultraviolet rays and will account for about 7,800 deaths in the U.S. in 2005.[13]

Although the connection between exposure to environmental and occupational carcinogens and an increase in the cancer incidence rate is difficult to document, it is a growing public concern. The concentration, intensity, and duration of an adverse exposure will determine its risk. One exposure that is a known human carcinogen and that can be prevented is environmental tobacco smoke. There is also an increased cancer risk for workers who have been exposed to high concentrations of ionizing radiation, certain chemicals and metals, and other

substances. Non-occupational exposures from radiation accidents and nuclear bombs can also increase cancer risk.[14] The World Health Organization's International Agency for Research on Cancer (IARC) has classified 150 chemical or biological agents as known or probable human carcinogens. Exposures to many of these carcinogens (e.g., asbestos, cadmium, and benzene) occur in occupational settings. The IARC defines occupational exposure as "any contact between the human body and a potentially harmful agent or environment in the workplace." It is estimated that roughly 20,000 cancer deaths a year are related to occupational exposure; therefore, approximately 4 percent of cancers in the United States can be related to occupation.[15,16]

Cancers attributable to infectious agents can be prevented. The ACS estimates that in 2005, infectious agents will cause fewer than 10 percent of all cancers in the United States and other developed countries. Cancers caused by infections are thought to result from one or more of the following: chronic inflammation, immune suppression, and chronic stimulation. Infectious agents such as hepatitis B (HBV), human papillomavirus (HPV), human immunodeficiency virus (HIV), and other infectious diseases have been shown to have causal links to certain cancers. HBV accounts for 6.2 percent of liver cancer in North America. Hepatitis C (HCV) is responsible for 23 percent of liver cancer in North America. In the United States, cervical cancer will account for 10,370 new cases in 2005; nearly 100 percent of those women with cervical cancer have evidence of infection with HPV. Cancers related to infectious agents could be prevented through behavioral changes, vaccines, and antibiotics.[17]

Family history continues to be an important risk factor for most cancers including breast, colon, prostate, and ovarian cancers. Individuals who know they have a family history of a particular cancer may be able to gain access to screening and other medical technologies to help with prevention or early detection of the disease. However, most Americans don't keep track of their family medical history. Researchers from the Centers for Disease Control and Prevention recently found that only 30 percent of people actively collect this information, even though more than 96 percent think that doing so is important for their own health.[18]

# Tobacco Use and Exposure

Between 1995 and 1999, tobacco use was responsible for nearly one in five deaths—an estimated 440,000 deaths—in the U.S.[19] Smoking tobacco accounts for at least 30 percent of cancer deaths and 87 percent of lung cancer deaths. It is also associated with increased risk for at least fifteen other types of cancers such as cancer of the nasopharynx, nasal cavity and paranasal sinuses, lip, oral cavity, pharynx, larynx, lung, esophagus, pancreas, uterine cervix, kidney, bladder, and stomach, as well as acute leukemia.[20]

In 2002, 25.2 percent of the male population and 20 percent of the female population were current smokers. Among high school students, 22 percent in 2003 reported current cigarette smoking. By age 13, 18 percent of high school students had smoked a whole cigarette while 58 percent of high school students had tried smoking. Among adults 18 or older, 6 percent of men and 1 percent of women reported being current users of smokeless tobacco, while 11 percent of male high school students in the U.S. were also using smokeless tobacco. Cigarette smoking among adults 18 and older declined by nearly half between 1965 (42%) and 2002 (23%). Current smoking among high school students in the U.S. increased significantly from 28 percent in 1991 to 36 percent in 1997, then declined to 22 percent in 2003. [21]

The *Guide to Community Preventive Services (*the *Community Guide)* has outlined effective evidence-based interventions for reducing tobacco use. Recommended interventions with strong scientific proof of effectiveness consist of banning and restricting smoking, increasing the unit price for tobacco products, and combining mass media education campaigns with other interventions (prevention table 1).

**Prevention Table 1. Tobacco Use, Prevention, and Control**

| Strategies | Level of Evidence |
|---|---|
| **Strategies to Reduce Exposure to Environmental Tobacco Smoke (ETS)** | |
| 1. Smoking bans and restrictions | Recommended (strong evidence) |
| 2. Community education to reduce ETS exposure in the home environment | Insufficient evidence to determine effectiveness |
| **Strategies to Reduce Tobacco Use Initiation by Children, Adolescents, and Young Adults** | |
| 3. Increasing the unit price for tobacco products | Recommended (strong evidence) |
| 4. Mass-media education (campaigns) when combined with other interventions | Recommended (strong evidence) |
| **Strategies to Increase Tobacco Cessation** | |
| 5. Increasing the unit price for tobacco products | Recommended (strong evidence) |
| 6. Mass-media education (campaigns) when combined with other interventions | Recommended (strong evidence) |
| 7. Smoking cessation series | Insufficient evidence to determine effectiveness |
| 8. Interventions appropriate for health care systems<br>Provider reminder systems (alone)<br>Provider education programs (alone)<br>Provider reminder plus provider education (with or without patient education) | <br>Recommended (sufficient evidence)<br>Insufficient evidence to determine effectiveness<br>Recommended (strong evidence) |
| 9. Provider feedback system | Insufficient evidence to determine effectiveness |
| 10. Reducing patient out-of-pocket costs for effective treatments for tobacco use and dependence | Recommended (sufficient evidence) |
| 11. Patient telephone support (quit lines) when combined with other interventions | Recommended (strong evidence) |

Adapted from "Tobacco Use Prevention and Control." *Guide to Community Preventive Services.*
Available from http://www.thecommunityguide.org/tobacco/default.htm.

## Tobacco Use and Exposure in Massachusetts

In Massachusetts the percentage of adults identifying themselves as current smokers has decreased since 1990.[22] Prevention table 2 shows that in a recent survey of Massachusetts residents, 19 percent of adults reported that they were current smokers, and 2 percent reported that they were heavy smokers (smoking more than 20 cigarettes per day). Men were more likely to report that they were current smokers (20%) and heavy smokers (3%), compared to females who reported current smoking (19%) and heavy smoking (2%).

**Prevention Table 2. Age-Adjusted Rates and 95% Confidence Limits for Tobacco Use Among Massachusetts Adults by Gender, 2003**

| | Current Smoker | Heavy Smoker |
|---|---|---|
| **Number of Adults Overall** | 19.4 (18.2-20.5) | 2.0 (1.3-2.8) |
| **Gender** | | |
| Male | 19.8 (18.0-21.7) | 2.5 (1.2-3.7) |
| Female | 18.9 (17.5-20.4) | 1.5 (1.0-2.1) |

* Rates are age-adjusted
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.
BRFSS, 2004.

White non-Hispanic adults (20%) were more likely to report that they were current smokers compared to Hispanic (19%), Black non-Hispanic (17%), and Asian (9%) adults (prevention table 3). Black non-Hispanic adults (1%) were less likely to report heavy smoking when compared to Hispanic (4%) and White non-Hispanic (2%) adults (table 3). Percentages of adults reporting current smoking decreased with increasing education, income, and age.[23]

**Prevention Table 3. Age-Adjusted Rates and 95% Confidence Limits for Tobacco Use by Race/Ethnicity, 2003**

| | Current Smoker | Heavy Smoker |
|---|---|---|
| **White non-Hispanic** | 20.0 (18.7–21.4) | 2.1 (1.3–2.9) |
| **Black non-Hispanic** | 16.6 (12.1–21.2) | 1.2 (0.3–4.8) |
| **Hispanic** | 18.6 (14.2–23.0) | 4.4 (0.5–8.3) |
| **Asian non-Hispanic** | 8.7 (3.9–13.5) | † |

* Rates are age-adjusted
† Insufficient numbers
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.

As prevention table 4 shows (next page), current smoking and heavy smoking varied slightly by geographic region, with the Western region (23%) more likely and the Metro West (15%) less likely to report current smoking. In addition, the Central region was more likely to report heavy smoking (4%), while the North East region was less likely to report heavy smoking (0.7%).

**Prevention Table 4. Age-Adjusted Rates and 95% Confidence Limits for Tobacco Use by Region, 2003**

| | Current Smoking | Heavy Smoking |
|---|---|---|
| **Boston** | 18.5 (15.8–21.3) | 1.5 (0.4–2.6) |
| **Central** | 21.2 (17.9–24.4) | 4.1 (1.4–6.8) |
| **Metro West** | 15.1 (12.5–17.7) | 2.5 (0.2–4.9) |
| **North East** | 18.7 (16.1–21.3) | 0.7 (0.2–1.3) |
| **South East** | 22.1 (19.4–24.9) | 2.3 (1.2–3.4) |
| **Western** | 22.7 (19.4–25.9) | 1.3 (0.3–2.3) |

* Rates are age-adjusted
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.

Among public high school students in Massachusetts, tobacco use has decreased significantly over the past ten years. The number of students who reported having tried smoking cigarettes in their lifetime decreased from 72 percent in 1995 to 53 percent in 2003, while current cigarette smoking decreased from 36 percent in 1995 to 21 percent in 2003. Additionally, daily cigarette smoking decreased from 15 percent in 1995 to 7 percent in 2003. Smoking before the age of 13 or early initiation of cigarette smoking decreased as well, from 24 percent in 1997 to 15 percent in 2003.[24]

The highest rates of lifetime cigarette smoking (63%), early initiation of cigarette smoking (29%), current cigarette smoking (25%), and daily cigarette smoking (9%) were found among students categorized as "other" or "multiple ethnicity." Compared to White non-Hispanic, Black non-Hispanic, and Asian non-Hispanic students, Hispanic students were more likely to report lifetime cigarette smoking (60%) and early initiation of cigarette smoking (17%).[25]

In 2003 male and female students were equally likely to have smoked cigarettes in their lifetimes, and males and females were equally likely to have smoked a cigarette before the age of 13. Twenty-five percent of male students were current smokers, and 22 percent of female students were current smokers.[26]

In 2005 the Massachusetts Cancer Registry (MCR) released its statewide report on cancer incidence and mortality between 1998 and 2002.[27] According to that report, lung cancer, one of the major cancers associated with tobacco smoke, was the second most frequently diagnosed cancer and the number one cause of cancer death among males and females. Lung cancer accounted for 15 percent of estimated new cases of cancer in males and 14 percent in females. Lung cancer also accounted for 29 percent of estimated cancer deaths in males and 25 percent in females. These deaths were preventable.

From 1998 to 2002, according to the MCR report, the annual age-adjusted incidence rate for lung cancer fell from 98 cases for every 100,000 males to 91 cases for every 100,000 males. During this same period, the annual age-adjusted incidence rates for lung cancer among females rose slightly from 60 cases for every 100,000 to 62 cases for every 100,000. As prevention table 5 shows, Massachusetts males were nearly twice as likely to die from lung cancer (73 deaths per 100,000) compared to females (44 deaths per 100,000).

**Prevention Table 5. Bronchus and Lung Cancer Age-Adjusted Incidence and Mortality Rates and 95% Confidence Limits by Sex, Massachusetts 1998-2002**

| | Males | Females |
|---|---|---|
| **Incidence** | 91.1 (89.5–92.7) | 61.1 (60.0–62.2) |
| **Mortality** | 73.1 (71.6–74.5) | 44.1 (43.2–45.1) |

*Per 100,000, age-adjusted to the 2000 U.S Standard population, 95% Confidence Limits.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report.* Boston, MA: 2005.

Incidence rates were highest among males 75–79 and 80–84, with an age-specific incidence rate of 598 cases for every 100,000; female age-specific incidence rates were highest among those 75–79 (353 cases per 100,000). Seventy-one was the median age among both males and females developing lung cancer from 1998 to 2002.[28]

Black non-Hispanic males and White non-Hispanic females have the highest lung cancer incidence rates: 98 for every 100,000 (prevention table 6) and 62 for every 100,000 respectively (prevention table 7). Black non-Hispanic males and White non-Hispanic females also have the highest rates of mortality from lung cancer: 94 for every 100,000 (table 6) and 46 for every 100,000 (table 7) respectively. Incidence rates for Black non-Hispanic males are twice as high as rates for Asian non-Hispanic males (table 6), and incidence rates for White non-Hispanic females are almost three times as high as those for Hispanic females (table 7).

**Prevention Table 6. Bronchus and Lung Cancer Age-Adjusted Incidence and Mortality Rates and 95% Confidence Limits For Males by Race/Ethnicity[1], Massachusetts 1998-2002**

| | White non-Hispanic | Black non-Hispanic | Asian non-Hispanic | Hispanic |
|---|---|---|---|---|
| **Incidence** | 91.2 (89.5–92.7) | 98.1 (88.2–107.9) | 57.1 (46.9–67.3) | 60.8 (51.5–70.0) |
| **Mortality** | 73.8 (72.3–75.3) | 94.4 (84.6–104.3) | 39.4 (30.8–48.0) | 36.8 (29.5-44.2) |

*Per 100,000, age-adjusted to the 2000 U.S Standard population.
[1] Race/ethnicity categories are mutually exclusive
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report.* Boston, MA: 2005.

**Prevention Table 7. Bronchus and Lung Cancer Age-Adjusted Incidence and Mortality Rates and 95% Confidence Limits For Females by Race/Ethnicity[1], Massachusetts 1998-2002**

| | White non-Hispanic | Black non-Hispanic | Asian non-Hispanic | Hispanic |
|---|---|---|---|---|
| **Incidence** | 62.2 (61.0–63.4) | 51.2 (45.5–57.0) | 33.0 (26.2–39.8) | 26.1 (21.2–31.0) |
| **Mortality** | 45.5 (44.4–46.5) | 38.5 (33.5–43.5) | 23.8 (17.9–29.7) | 14.5 (10.6–18.3) |

*Per 100,000, age-adjusted to the 2000 U.S Standard population.
[1] Race/ethnicity categories are mutually exclusive
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report.* Boston, MA: 2005.

The incidence and mortality rates for bronchus and lung cancer among males are roughly the same for Massachusetts as they are for the nation (prevention table 8). The incidence rate among females is higher in Massachusetts, but the mortality rate is roughly the same when compared to national numbers (table 8, next page).

**Prevention Table 8. Age-adjusted Incidence and Mortality Rates for Melanoma by Gender, Massachusetts (1998-2002) and NAACCR Registries (1997-2001)**

| | Males | | Females | |
|---|---|---|---|---|
| | ***Massachusetts*** | ***National*** | ***Massachusetts*** | ***National*** |
| **Incidence** | 91.1 | 90.0 | 61.1 | 54.0 |
| **Mortality** | 73.1 | 73.2 | 44.1 | 43.5 |

*Per 100,000, age-adjusted to the 2000 U.S Standard population.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report.* Boston, MA: 2005.

## Highlights of Activities

Massachusetts made remarkable strides in the 1990s, leading the nation in efforts to eradicate the deadly use of tobacco. The accomplishments included a reduction in the prevalence of smoking among adults, from 24 percent in 1990 to 18.9 percent in 2002, and a decline in average daily consumption of cigarettes among adults, from 16.1 a day in 1994 to 14.7 a day in 2002. Massachusetts has also seen decreases in tobacco use and the age of initiation of use by children, adolescents, and young adults. According to the 2003 Youth Risk Behavior Survey, 15 percent of high school students reported having their first cigarette before the age of 13.[29] This was down from 19 percent in 2001. In addition, cigarette smoking among youth decreased from 35.7 percent in 1995 to 20.9 percent in 2003.

Tobacco control efforts span many chronic disease initiatives. Statewide initiatives to reduce heart disease, stroke, or asthma, for example, all have anti-tobacco strategies. Many coalitions in Massachusetts are working with key tobacco control leaders to reduce the prevalence of tobacco use and to decrease initiation. This includes a number of committed local groups including Tobacco Free Mass, a coalition of more than forty members with a focus on advocacy, and the Massachusetts Tobacco Control Program (MTCP), located at the Department of Public Health, with a focus on programmatic implementation. Massachusetts' efforts in tobacco prevention and control have been consistent with evidence-based recommendations by the CDC.

Massachusetts' accomplishments include passage and enforcement of a number of public policies. One of the more recent policies is the Smoke-free Workplace Law that went into effect July 5, 2004. In the first year of the law's passage, the state saw 90 percent compliance by workplaces, bars, and restaurants. These data were collected internally from local board of health enforcement officers. Massachusetts expects continued improvement in compliance with the Workplace Law. Massachusetts also adhered to the CDC recommendation to increase the unit price of cigarettes to discourage initiation of tobacco use by youth. Between 1992 and 2005, the price of cigarettes was increased three times. The latest increase, 75 cents, took place in 2002.

The Commonwealth of Massachusetts has been a leader in the use of mass media to discourage initiation of tobacco use by youth and to discourage continued smoking by adults. From 1994 to 2002, Massachusetts ran a nationally known and innovative media education campaign called "Make Smoking History" that was targeted to youth and adults. Much of that effort was paid for with funding from cigarette taxes and with money won in a nationwide lawsuit against the country's five largest cigarette manufacturers. In 2002, however, the state budget was reduced significantly, and media education campaigns were eliminated. In fact, the CDC recommended that Massachusetts spend a minimum of $35.2 million annually to have an effective, comprehensive tobacco control program, but currently the state allocates only $3.8

million a year for tobacco prevention. Therefore, despite evidence of the effectiveness of a number of interventions in Massachusetts, many of them had to be substantially reduced or eliminated.

Following a CDC recommendation to focus on providers, Massachusetts developed and introduced a program called QuitWorks (http://www.quitworks.org/), an intervention for health care providers to help patients quit smoking. With consent, providers refer the patient's contact information to free telephone-based counseling for as long as the patient is interested in being enrolled. QuitWorks also provides monthly follow-up reports to the patient's provider. QuitWorks has been in operation since 2002 and has shown strong results in terms of number of "quit attempts" and "short-term quit rates."

QuitWorks is operated by the Try-To-STOP TOBACCO Resource Center, established as part of the Massachusetts Tobacco Control Program that began in 1993. The resource center offers tobacco cessation counseling in person, over the phone, and through the Web site (www.trytostop.org), and maintains Quit Tips, a 24-hour toll-free helpline with pre-recorded motivational messages.

The CDC also recommended reducing patient out-of-pocket costs for effective treatments. In Massachusetts, those who shoulder the highest burden of tobacco use have an income of less than $49,000 and an education level at high school diploma or less, and are unable to pay for smoking cessation and treatment programs. Through a program called "Ready, Set, Quit," the state distributed free nicotine replacement patches in those regions of Massachusetts that reported high prevalence of smoking. This free program was well received by the community, and preliminary data was expected to be published late in 2005. Massachusetts remains hopeful that public health plans such as Medicaid will eventually cover the cost of tobacco treatment.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Massachusetts has several gaps, issues, barriers, and concerns that the work group identified. One concern is cigar smoking among high school students. An average of 12 percent of high school students reported smoking a cigar in the last thirty days, and 20 percent of multiple ethnicity high school students reported cigar use in the last thirty days. Increased access to youth cessation services is required to address this trend. A statewide pilot project in which nurses delivered cessation services in schools was developed by the MCTP and was restructured in 2000. Budget restrictions resulted in lack of continued funding after 2002, and the program was discontinued. Currently no other option exists for youth who want to quit smoking.

Another area in need of attention is smoking during pregnancy. The MTCP would like to consider a pilot campaign to help pregnant women quit smoking. The rate of smoking during pregnancy, regardless of age, was 7.7 percent in 2003. Among teens the rate of smoking during pregnancy was 17.4 percent for 2002. The national rate of smoking during pregnancy, regardless of age, was 11.4 percent for 2002, and the rate of teens smoking during pregnancy was 17.1 percent. While the rate of smoking during pregnancy decreased by more than 60 percent for all mothers, the rate of smoking for the younger mothers over the same year was 15 percent.[30] A pilot tobacco-cessation program for pregnant women could help reduce this gap.

Finally, data collection, particularly for specific cultural and ethnic groups, needs to be improved. At present, populations such as Cape Verdeans, Vietnamese, or Haitians are subsumed in broad cultural groups such as White, Asian, Hispanic, and Black non-Hispanic. There is concern that the burden of tobacco among these groups is unknown and that they may require culturally sensitive, evidence-based interventions.

Following are the goal, outcome measures, and evidence-based strategies identified by the prevention work group. Outcome measures will be tracked once a year to evaluate progress toward the goal, particularly changes in health disparities. The statewide Tobacco Coalition and the MTCP will take the lead in these areas and will be joined by the multiple coalitions representing chronic disease to eradicate tobacco use and exposure.

## Goal: To reduce the effect of tobacco use and exposure to second-hand smoke on cancer incidence and mortality in Massachusetts.

**Outcome Measure 1: By 2011, reduce the percentage of all adult smokers to 12 percent.**
Healthy People 2010: 12%
Baseline All: 19% Database: BRFSS 2003

| | | | |
|---|---|---|---|
| White non-Hispanic | 19% | Hispanic | 19% |
| Black non-Hispanic | 18% | Asian non-Hispanic | 13% |

| | | | |
|---|---|---|---|
| <High School | 31% | College 1–3 yrs | 22% |
| High School | 29% | College 4+ | 12% |

| | | | | | |
|---|---|---|---|---|---|
| <$25,000 | 31% | $35–49,000 | 25% | $75,000 | 12% |
| $25–34,999 | 25% | $50–74,999 | 18% | | |

| | | | |
|---|---|---|---|
| Boston | 18.5% | Northeast | 19% |
| Central | 21.% | Southeast | 22% |
| Metrowest | 15% | Western | 23% |

**Outcome Measure 2: By 2011, reduce cigarette smoking among pregnant women during their last three months of pregnancy to 1 percent.**
Healthy People 2010: 1%
Baseline All: 13% Database: Vital Statistics 6/30/2005

| | | | |
|---|---|---|---|
| Teens under 20 years | 16.6% | | |
| Women 20 years | 7.1% | | |
| White non-Hispanic | 8.6% | Hispanic | 5.9% |
| Black non-Hispanic | 6.5% | Asian non-Hispanic | 1.4% |
| Less than High School | 20.3% | Some college | 8.1% |
| High school or equivalent | 13.9% | College graduate plus | .9% |
| Boston | 4.0% | Northeast | 7.5% |
| Central | 8.5% | Southeast | 11.1% |
| Metrowest | 3.1% | Western | 14.3% |

**Outcome Measure 3: By 2011, reduce the proportion of high school students who are current smokers (smoked at least one cigarette in the last 30 days) to 16 percent.**
Healthy People 2010: no objective
Baseline All: 21% (26% in 2001) Database: YRBS 2003

| | | | | | |
|---|---|---|---|---|---|
| White non-Hispanic | 23% | Hispanic | 18% | Other & multiple | 25% |
| Black non-Hispanic | 10% | Asian non-Hispanic | 18% | ethnicity | |

**Outcome Measure 4: By 2011, reduce the proportion of high school students who are daily smokers to 6 percent.**
Healthy People 2010: 16%
Baseline All: 7% (10% in 2001) Database: YRBS 2003

| | | | | | |
|---|---|---|---|---|---|
| White non-Hispanic | 8% | Hispanic | 8% | Other & multiple | 9% |
| Black non-Hispanic | 3% | Asian non-Hispanic | 6% | ethnicity | |

**Outcome Measure 5: By 2011, reduce the proportion of high school students who report using smokeless tobacco in the past thirty days to 1 percent.**
Healthy People 2010: 1%
Baseline All: 4% Database: YRBS 2003

| | | | | | |
|---|---|---|---|---|---|
| White non-Hispanic | 4% | Hispanic | 4% | Other & multiple | 10% |
| Black non-Hispanic | 5% | Asian non-Hispanic | 7% | ethnicity | |

**Outcome Measure 6: By 2011, reduce the proportion of high school students who report smoking cigars in the past thirty days to 8 percent.**
Healthy People 2010: 8%
Baseline All: 12% Database: YRBS 2003

| | | | | | |
|---|---|---|---|---|---|
| White non-Hispanic | 12% | Hispanic | 4% | Other & multiple | 20% |
| Black non-Hispanic | 7% | Asian non-Hispanic | 10% | ethnicity | |

**Outcome Measure 7: By 2011, reduce the proportion of high school students who report having their first cigarette before the age of thirteen to 12 percent.**
Healthy People 2010: no objective
Baseline All: 15% (19% in 2001) Database: YRBS 2003

| | | | | | |
|---|---|---|---|---|---|
| White non-Hispanic | 15% | Hispanic | 17% | Other & multiple ethnicity | 29% |
| Black non-Hispanic | 16% | Asian non-Hispanic | 15% | | |

**Outcome Measure 8: By 2011, decrease the percentage of public middle school students, grades 6–8, who have smoked in the last thirty days to 5 percent.**
Healthy People 2010: no objective
Baseline All: 7.1% Database: MA Youth Health Survey 2004

| | | | | | |
|---|---|---|---|---|---|
| White non-Hispanic | 15% | Hispanic | 17% | Other & multiple ethnicity | 29% |
| Black non-Hispanic | 16% | Asian non-Hispanic | 15% | | |

| | | | | | |
|---|---|---|---|---|---|
| 6th Grade | 2.5% | 7th Grade | 6.7% | 8th Grade | 11.4% |

| | | | |
|---|---|---|---|
| Female | 7.7% | Male | 6.4% |

| | | | |
|---|---|---|---|
| White non-Hispanic | 6.1% | Hispanic | 12.8% |
| Black non-Hispanic | 10.3% | Asian non-Hispanic | 9.5% |

**Outcome Measure 9: By 2011, increase the number of adults living in households where smoking is not allowed to 80 percent.**
Healthy People 2010: no objective
Baseline All: 71% Database: BRFSS 2003

| | | | |
|---|---|---|---|
| White non-Hispanic | 71% | Hispanic | 73% |
| Black non-Hispanic | 73% | Asian non-Hispanic | 83% |

| | | | |
|---|---|---|---|
| <High School | 62% | College 1–3 yrs | 70% |
| High School | 61% | College 4+ | 79% |

| | | | | | |
|---|---|---|---|---|---|
| <$25,000 | 64% | $35–49,000 | 61% | $75,000 | 80% |
| $25–34,999 | 66% | $50–74,999 | 75.5% | | |

| | | | |
|---|---|---|---|
| Boston | 72% | Northeast | 69% |
| Central | 68% | Southeast | 11.1% |
| Metrowest | 76% | Western | 70% |

**Strategies to Achieve the Goal**

The work group selected the following strategies, based on prevention table 1:

- Support funding of the statewide Tobacco Program at the level recommended by CDC.
- Maintain support and ensure the effective fulfillment and evaluation of the smoke-free workplace legislation.
- Provide and promote smoking cessation services to all Massachusetts residents through changes in Medicaid and health insurance coverage.
- Increase affordable and accessible treatment resources for smoking cessation and then market these resources.
- Increase awareness and use of the Try-To-STOP TOBACCO Resource Center and QuitWorks.
- Introduce a public education campaign that increases people's desire to quit smoking.
- Increase use of mass media and reduce cost of tobacco cessation efforts for young adults 18–24.
- Create unique partnerships to carry out tobacco control strategies.
- Determine the burden for portions of the population who are not specifically identified in surveillance data, and increase culturally sensitive, evidence-based interventions for them.

## Access to and Use of Preventive and Primary Care

Universal health care coverage has been in the forefront of the debate about rising health care costs in America. The United States is the only industrialized nation that does not provide universal health care insurance. More than 43 million Americans are uninsured, and evidence has shown that those who are uninsured receive less preventive care, are often diagnosed at more advanced stages of disease, and once diagnosed are less likely to receive therapeutic care, such as drugs and surgical interventions, as those who are insured. According to one estimate, "we could reduce mortality rates for the uninsured by 10–15% if we provided health insurance."[31] To help curb rising health care costs and to reduce mortality rates, the United States must put into effect a system that provides health care coverage to all.

A committee formed by The Institute of Medicine (IOM) developed a series of reports documenting the consequences of lack of health insurance coverage in America. The committee culled the following salient points from that research:

- Uninsured Americans receive about half the medical care as those with health insurance. As a result, they tend to be sicker and die sooner.
- About 18,000 unnecessary deaths occur each year because of lack of health insurance.
- Only one-half of all uninsured children visited a physician during 2001, compared with three-quarters of all insured children. Lack of regular care can result in more expensive care for preventable or treatable conditions and disruptions in learning and development.
- When even one family member is uninsured, the entire family is at risk for the financial consequences of a catastrophic illness or injury.
- Tax dollars paid for an estimated 85 percent of the roughly $35 billion in non-reimbursed medical care for the uninsured in 2001.
- The burden of uncompensated care has been a factor in the closure of some hospitals and the unavailability of services in others.
- Disruptions in service can affect all who are served by a facility, even those who have health insurance.

The United States loses the equivalent of $65 billion to $130 billion annually as a result of the poor health and early deaths of uninsured adults. With health insurance providing access to preventive and primary care and early detection services, many cancers can be prevented or detected at an earlier stage, thus saving lives and reducing health care costs.[32]

### Access and Use in Massachusetts

According to the Behavioral Risk Factor Surveillance System (BRFSS) of 2004, the percentage of Massachusetts adults 18–64 with no health insurance decreased from 12 percent in 1996 to 6 percent in 2000. The same report documented a rise in the percentage of adults in that age group without health insurance from 6 percent in 2000 to 8 percent in 2003.[33]

In Massachusetts, approximately 9 percent of adults 18–64 reported that they were uninsured. In 2003 men (11%) were more likely than women (6%) were to report that they were without health insurance. Hispanic (21%) and Black non-Hispanic (16%) adults were more likely to report that they were uninsured compared to Asian non-Hispanic (12%) and White non-

Hispanic (7%) adults. In addition, being uninsured increased with both decreasing education and income. Those living in the South East region (12%) of Massachusetts were more likely to report no health insurance compared to those living in the Metro West (5%) region of the state (prevention table 9, next page).

**Prevention Table 9. Age-Adjusted Rates and 95% Confidence Limits of Uninsured Adults (Ages 18–64) in Massachusetts, 2003**

| | Age-Adjusted Rates and 95% Confidence Limits |
|---|---|
| **Total Adults** | 8.5 (7.5–9.6) |
| **Gender** | |
| Male | 11.2 (9.5–12.9) |
| Female | 6.0 (4.9–7.0) |
| **Race/Ethnicity** | |
| White non-Hispanic | 6.8 (5.8–7.8) |
| Black non-Hispanic | 15.6 (9.6–21.7) |
| Hispanic | 21.0 (16.2-25.8) |
| Asian non-Hispanic | 11.5 (2.6–20.3) |
| **Education** | |
| Less than High School | 18.4 (13.7–23.0) |
| Four or More Years of College | 3.9 (2.7–5.1) |
| **Income** | |
| Less than $25,000 | 22.4 (18.9–25.9) |
| $75,000 or More | 1.3 (0.6–2.1) |
| **Region** | |
| South East | 11.7 (9.1–14.4) |
| Metro West | 5.1 (2.9–7.2) |
| Western | 8.5 (6.1–10.9) |
| Central | 8.3 (5.6–11.1) |
| North East | 9.3 (6.9–11/7) |
| Metro West | 5.1 (2.9–7.2) |

* Rates are age-adjusted
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.

## Highlights of Activities

Massachusetts offers a health insurance program that is the state's version of Medicaid. Known as MassHealth, it provides comprehensive health insurance (or assistance in paying for private health insurance) to nearly one million Massachusetts low- and medium-income children, families, seniors, people with disabilities, and HIV-positive individuals. The program also manages the Insurance Partnership for small businesses, the Children's Medical Security Plan, Healthy Start, and the Special Kids/Special Care Pilot Program, cosponsored with the Department of Social Services. Without MassHealth, many in this state would be without access to needed medical care.[34]

Another component of the health care system in Massachusetts is the community health center network, through which 53 community health centers provide local health services in 185 sites. The non-profit Massachusetts League of Community Health Centers (the League) is the membership association for these community health centers and is recognized by the federal Bureau of Primary Health Care as the state's Primary Care Association. The League is a founding member of the Neighborhood Health Plan, a managed care organization that serves more than 100,000 MassHealth members.

Under- and uninsured residents of Massachusetts have access to two cancer-related programs. The Women's Health Network (WHN) provides free breast and cervical cancer screening and diagnostic services, and health education services to low income, uninsured women at more than 90 locations throughout the state. The Massachusetts Department of Public Health Men's Health Partnership is a state legislature-funded program serving uninsured and underinsured men by providing outreach, education, clinical screenings, risk-factor reduction counseling, and linkage to follow-up care in the areas of cardiovascular disease and prostate cancer. The Partnership delivers its services through a network of thirteen community-based provider organizations with a focus on male populations at highest risk.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Despite the availability of services for the uninsured in the state, many residents are still without access to health care. In Massachusetts, the Division of Health Care Finance and Policy (DHCFP) produces a report on the uninsured every other year. In 2004 the report noted that 7.4 percent of the population was uninsured. This was an increase from 2002 when the uninsured rate was 6.7 percent. The uninsured rate for residents 64 and under was 10.6 percent. Again, this was up from 9.2 percent in 2002. Young adults who could benefit from regular health checks and provider education about cancer risk factors have the highest rate of being uninsured: 25 percent in 2004. In 2002 this rate was 20 percent. Hispanic and multiple-race ethnicities had the highest rates of all races/ethnicities: 15.1 percent and 11.6 percent respectively. Although the rate decreased in 2004, 73 percent of the uninsured are working. For insured adults who needed medical care, 94 percent reported receiving it. However, only 56 percent of the uninsured adults reported receiving medical care when they needed it. The DHCFP indicated that 75 percent of the uninsured said they would pay $100 a month for health insurance, an inadequate amount to cover costs.[35]

**Goal: Ensure that all residents of the Commonwealth visit a primary care provider for regular prevention and early detection services.**

**Outcome Measure 10: By 2011, increase the percentage of Commonwealth residents who report having a usual source of primary care to 100 percent.**
Healthy People 2010: 96%
Baseline All: 87% Database: BRFSS 2003

| | | | | | |
|---|---|---|---|---|---|
| Female | 92% | Male | 81% | | |
| White non-Hispanic | 89% | Hispanic | 67% | | |
| Black non-Hispanic | 83% | Asian non-Hispanic | 73% | | |
| <High School | 76% | College 1–3 yrs | 89% | | |
| High School | 82% | College 4+ | 90% | | |
| <$25,000 | 77% | $35–49,000 | 87% | $75,000 | 93% |
| $25–34,999 | 81% | $50–74,999 | 90% | | |
| Boston | 81% | Northeast | 88% | | |
| Central | 90% | Southeast | 85% | | |
| Metrowest | 87% | Western | 87% | | |

**Outcome Measure 11: By 2011, increase the percentage of Commonwealth residents who have health insurance to 100% percent.**
Healthy People 2010: 100%
Baseline All: 92% Database: BRFSS 2003

| | | | | | |
|---|---|---|---|---|---|
| White non-Hispanic | 94% | Hispanic | 77% | | |
| Black non-Hispanic | 83% | Asian non-Hispanic | 92% | | |
| Ages 18–24 | 82% | | | | |
| <High School | 82% | College 1–3 yrs | 92% | | |
| High School | 86% | College 4+ | 96% | | |
| <$25,000 | 78% | $35–49,000 | 93% | $75,000 | 99% |
| $25–34,999 | 83% | $50–74,999 | 95% | | |
| Boston | 90% | Northeast | 88% | | |
| Central | 92% | Southeast | 88% | | |
| Metrowest | 95% | Western | 92% | | |

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Guarantee that all Commonwealth residents have access to and use regular primary and preventive care and screening services.
- Increase primary provider cancer prevention and early detection efforts throughout the state.
- Increase health insurance coverage of regular health checks for the underinsured.
- Distribute health check decision guides that are appropriate to the individual's culture, language, and literacy level.

## Lifestyle: Body Weight, Physical Activity, Alcohol Use

This section focuses on three other modifiable factors that could reduce an individual's risk of cancer by more than 30 percent. The first is maintaining a health body weight. The second is staying physically active, and the third is limiting alcohol consumption to not more than one drink a day for women and not more than two drinks a day for men.

## Body Weight

Obesity is associated with increased death rates for all cancers combined and for cancers at a number of specific sites. According to a 2003 article in the *New England Journal of Medicine,* the relative risks for increased cancer mortality for men and women who were obese were 1.52 and 1.62 respectively.[36] A healthful diet and a physically active lifestyle are keys to maintaining a healthy weight.

The United States Department of Agriculture released a new set of science-driven "Dietary Guidelines for Americans" on January 12, 2005. The new guidelines replace the old food guide pyramid and provide key recommendations on the components of a healthy diet. Information is provided on necessary nutrients, caloric needs, weight management, and physical activity. The new guidelines also offer key recommendations for specific population groups[37].

The American Cancer Society recommends a diet filled with fruits and vegetables to prevent cancer risk. In addition, the National Cancer Institute promotes the 5-A-Day program, an initiative established in 1991 in partnership with the Produce for Better Health Foundation. The program encourages people to eat five to nine servings of fruits and vegetables daily to reduce risk for chronic disease.[38] Although at this time no data directly links consumption of fruits and vegetables with reduced cancer risk, a diet high in fruits and vegetables can help one maintain a healthy weight.

People who develop good eating and exercise habits in childhood are more likely to maintain a healthy weight throughout their lifetime. That is why many healthy-weight programs are targeting children. Recently the U.S. Congress passed a law requiring each school district participating in the National School Lunch and/or Breakfast Program to establish a local wellness policy by the beginning of School Year 2006-2007. According to the requirements for the Local Wellness Policy, school districts must set goals for nutrition education, physical activity, campus food provision, and other school-based activities designed to promote student wellness. Additionally, school districts are required to involve a broad group of individuals in policy development and to have a plan for measuring policy implementation.[39]

The CDC's Maternal and Child Nutrition Branch of the Division of Nutrition and Physical Activity is involved in outcomes research to assess the relationship between breastfeeding and development of pediatric overweight. Using longitudinal data from the Pediatric Nutrition Surveillance System, the CDC is trying to determine whether not breastfeeding at all or breastfeeding for a shorter duration increases the chances that a child will become overweight in the preschool years.[40] Depending on the result of this research, public policy concerning breastfeeding may require some consideration.

The independent Task Force on Community Preventive Services is working with a group of experts to conduct a systematic review of studies regarding population-based interventions focusing on the areas identified in prevention table 10. Once the meta-analysis is complete, evidence-based interventions will be identified.

**Prevention Table 10. Systematic review of studies regarding population-based interventions**

| Review | Expected Completion |
|---|---|
| School-based nutrition programs | Winter 2004 |
| Community approaches to increase fruit and vegetable intake | Summer 2005 |
| Food and beverage advertising to children | Fall 2005 |
| Food and beverage availability, price, portion size, and labeling in restaurants | Winter 2005 |

Adapted from "Nutrition." *Guide to Community Preventive Services.*
Available from http://www.thecommunityguide.org/nutrition/default.htm.

## Body Weight in Massachusetts

Fifty-three percent of Massachusetts adults are overweight (body mass index 25–29.9), with men (63%) being more likely to be overweight compared to women (43%). Black non-Hispanic adults (64%) and Hispanic adults (63%) were more likely to be overweight than White non-Hispanic (52%) and Asian non-Hispanic (39%) adults. In addition, adults having four or more years of college education (46%) were less likely to be overweight compared to those with less education. Those adults living in the Metro West region (47%) were less likely to report being overweight compared to those living in the other five regions (prevention table 11,).

### Prevention Table 11. Age-Adjusted Rates and 95% Confidence Limits of Overweight Adults in Massachusetts, 2003

| | Age-Adjusted Rates and 95% Confidence Limits |
|---|---|
| **Total Adults** | 52.8 (51.3–54.2) |
| **Gender** | |
| Male | 63.0 (60.9–65.2) |
| Female | 42.6 (40.6–44.5) |
| **Race/Ethnicity** | |
| White non-Hispanic | 52.0 (50.4–53.6) |
| Black non-Hispanic | 63.8 (57.6–69.9) |
| Hispanic | 63.3 (57.7–68.9) |
| Asian non-Hispanic | 39.4 (25.9–53.0) |
| **Education** | |
| Less than High School | 66.5 (61.5–71.5) |
| High School | 58.4 (55.5–61.4) |
| One to Three Years of College | 55.3 (52.3–58.2) |
| Four or More Years of College | 46.1 (43.6–48.6) |
| **Region** | |
| Western | 51.9 (48.1–55.8) |
| Central | 59.6 (55.7–63.6) |
| North East | 50.8 (47.5–54.1) |
| Metro West | 47.0 (43.5–50.4) |
| South East | 57.3 (53.9–60.7) |
| Boston | 51.1 (47.3–54.8) |

* Rates are age-adjusted
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.

According to the results of the BRFSS of 2004, approximately 17 percent of Massachusetts adults are obese (body mass index 30 or higher). Men (18%) are slightly more likely to be obese compared to women (16%). Black non-Hispanic (28%) and Hispanic (25%) adults are more likely to be obese compared to White non-Hispanic (16%) and Asian non-Hispanic (14%) adults. Obesity rates decrease as education levels increase. In addition, adults with incomes of less than $25,000 (24%) are more likely to be obese compared to those with incomes of $75,000 (12%). Obesity rates vary by region with the lowest rates in Metro West (13%) and the highest rates in both the Central (21%) and South East (21%) regions (prevention table 12).

**Prevention Table 12. Age-Adjusted Rates and 95% Confidence Limits of Obese Adults in Massachusetts, 2003**

| | Age-Adjusted Rates and 95% Confidence Limits |
|---|---|
| **Total Adults** | 16.7 (15.6–17.8) |
| **Gender** | |
| Male | 17.9 (16.2–19.6) |
| Female | 15.5 (14.2–16.9) |
| **Race/Ethnicity** | |
| White non-Hispanic | 16.0 (14.8–17.2) |
| Black non-Hispanic | 28.2 (22.3–34.1) |
| Hispanic | 25.1 (19.7–30.6) |
| Asian non-Hispanic | 14.4 (3.8–25.0) |
| **Education** | |
| Less than High School | 27.6 (22.6–32.7) |
| High School | 20.8 (18.3–23.2) |
| One to three Years of College | 18.1 (15.9–20.3) |
| Four or More Years of College | 11.8 (10.2–13.4) |
| **Income** | |
| Less than $25,000 | 23.8 (20.8–26.8) |
| $25–34,999 | 19.1 (15.2–23.0) |
| $35–49,999 | 19.4 (16.1–22.8) |
| $50–74,999 | 16.6 (14.0–19.3) |
| $75,000 or More | 11.6 (9.6–13.7) |
| **Region** | |
| Western | 16.2 (13.5–18.8) |
| Central | 20.6 (17.2–24.0) |
| North East | 14.9 (12.6–17.2) |
| Metro West | 12.7 (10.5–14.9) |
| South East | 20.6 (17.8–23.4) |
| Boston | 17.8 (14.9–20.6) |

* Rates are age-adjusted
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.

## Highlights of Activities

Massachusetts claims a number of accomplishments for actively combating overweight and obesity. These include collaborations and programs targeting populations across the state and throughout lifespans.

One major endeavor is the collaborative known as the Massachusetts Partnership for Health Weight (PHW). The PHW is the community outgrowth of the CDC's Overweight Prevention and Control Initiative and comprises agencies, community groups, and individuals from the fields of health, education, research, nutrition, and physical activity. The goal of the

PHW is to prevent and control overweight and obesity throughout the state. The Massachusetts Department of Public Health (DPH) supports the work of the PHW, serving as an active executive committee member and providing administrative support, especially around the main activity of the PHW: the development and fulfillment of a statewide nutrition and physical activity plan that addresses obesity. The Partnership for Healthy Weight will be the lead coalition on all prevention issues relating to nutrition and physical activity in the state. The parallel Cancer Control Coalition will lend additional support when necessary.

The DPH also provides support staff to the Massachusetts 5-A-Day Coalition, a partnership that comprises nutrition and other health professionals who collaborate to promote eating fruits and vegetables. The coalition has sponsored a number of activities including training for working with the local media to promote fruit and vegetable consumption, a 5-A-Day resource directory, and a statewide 5-A-Day conference. Although at this time there appears to be no direct relationship between consumption of vegetables and reduced risk of cancer, fruits and vegetables are an important part of a healthy diet and an important strategy toward maintaining a healthy weight.

Because the interest level and commitment to making important changes in both nutrition and physical activity are high, the Massachusetts Overweight Prevention and Control Initiative (MOPCI) at DPH is also working on a Community Inventory of Physical Activity and Nutrition initiatives occurring throughout the state. MOPCI is working with Tufts University to create a database that can be developed into a searchable Web site for communities to use. The obesity epidemic is of concern throughout the state, and many communities are now developing their own local interventions to address nutrition and physical activity issues for their residents.

In an effort to reach people at specific workplaces where overweight is prevalent and programmatic need is high, MOPCI awarded mini-grants to five police and fire departments to implement workplace wellness programs. Each department developed its own program to address unique nutrition and physical activity needs. MOPCI assists each department and is also responsible for evaluating each program.

A number of organizations have established programs targeting elders, since elders are at risk for increased weight and decreased physical activity. One organization, Action for Boston Community Development (ABCD), offers Project Healthy Exercise Plus (PHEP). Funded by the Older Americans Act, this program has established more than twenty classes in ten neighborhoods. Twenty-four volunteer older trainers bring therapeutic exercise and osteoporosis exercise using portable weights to more than 300 elders weekly. The program's wellness discussion groups help elders take control of their lives as they age. Wellness materials are developed each year in collaboration with the first-year medical students at Tufts University School of Medicine. Many elders have made significant gains in both physical activity and positive lifestyle changes, and have also benefited from socializing with their peers.

Massachusetts has many model initiatives to address nutrition and physical activity at the other end of the age spectrum as well. One of these initiatives, Healthy Choices Program, is a nutrition and physical activity program for middle schools. The program is a collaborative project of the MDPH and the Jump Up and Go! program at Blue Cross/Blue Shield of Massachusetts. Seventy middle schools are involved in this program, and up to fifty more are to be added. Models are being explored for introducing the Healthy Choices Program in elementary schools.

Due to concern for adolescents who are at risk for overweight, DPH has partnered with the YMCA Alliance and University of Massachusetts in Boston to pilot Physical Activity Clubs (PACs) in five YMCAs across the state. The PACs match adolescents at risk for overweight and their parents with a personal coach who works with them for 12 weeks on adopting healthier lifestyles. Participants in the free program are referred by schools, local YMCAs, and concerned parents.

Massachusetts organizations have also been engaged in a number of policy-related endeavors. For example, the Harvard Prevention Research Center and the Legislative Children's Caucus of the Massachusetts Legislature formed The Coalition on Obesity Prevention and Education (MA COPE). The coalition is dedicated to reducing the prevalence of childhood obesity in the Commonwealth by translating current research into action. Educating policymakers is a major focus of the coalition.

Public policy initiatives have addressed healthful foods in schools. For the 2005–2006 legislative session, State Representative Peter Koutoujian filed a petition for legislation to promote proper school nutrition (HB 1457),[41] and Senator Richard Moore filed a petition for legislation to promote healthy alternatives in public school food programs (SB 107).[42] The bills would ensure that all food and beverages sold on school property meet nutrition standards established by the Massachusetts Dept. of Education working with MDPH. (Rep. Koutoujian's bill excludes those foods sold for the School Breakfast and Lunch Programs). The bills would prohibit the sale of sodas and other highly sweetened beverages, and of high-fat, high-calorie junk foods in school stores, vending machines, a la carte lines, and fundraisers. Senator Moore's bill would introduce these standards in a five-year pilot program.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Although Massachusetts may lead the nation in its effort to make sustainable changes in nutrition and physical activity, many gaps, issues, and barriers remain, and they mirror those occurring on the national level. This includes lack of public knowledge about the increased risk of cancer for individuals who are overweight or obese. It is important to educate adults and children about healthful eating and to counteract mass media promotion of unhealthful foods. In addition, today's environment of long workdays, limited time for food shopping and meal preparation, and the abundance of affordable fast foods contribute to poor eating. We must make sure that restaurant menus offer clearly labeled, healthful choices, and that employers know about workplace policies such as providing food choices that will contribute to improved health among the work force.

Massachusetts surveillance systems and obesity research both need improving if the prevalence of obesity is to be reversed. For example, childhood trends toward unhealthy weight and interventions to combat the problem should be monitored, but Massachusetts does not have a uniform system to collect height and weight data in schools statewide. In addition, research needs to be conducted on the connection between little or no breastfeeding and later childhood obesity, so that mothers can engage in the best behaviors for the health of their children.

## Goal: Ensure that all residents of the Commonwealth are eating healthy and maintaining a healthy weight.

**Outcome Measure 12: By 2011, reduce the prevalence of obese adults to 15 percent and of overweight adults to 40 percent.**
Healthy People 2010: 15 % for obese, none for overweight
Baseline All: 70% Database: BRFSS 2003

| | | | |
|---|---|---|---|
| White non-Hispanic Overweight | 52% | Hispanic Overweight | 63% |
| White non-Hispanic Obese | 16% | Hispanic Obese | 25% |
| White non-Hispanic Overweight & Obese | 68% | Hispanic Overweight & Obese | 88% |
| | | | |
| Black non-Hispanic Overweight | 64% | Asian non-Hispanic Overweight | 40% |
| Black non-Hispanic Obese | 28% | Asian non-Hispanic Obese | 14% |
| Black non-Hispanic Overweight & Obese | 92% | Asian non-Hispanic Overweight & Obese | 54% |

**Outcome Measure 13: By 2011, decrease the percentage of students ages 12–19 who are at risk or are currently overweight to 5 percent.**
Healthy People 2010: 5%
Baseline All: 24% Database: YRBS 2003

| | | | | | |
|---|---|---|---|---|---|
| White non-Hispanic at risk | 13% | overweight | 9% | at risk & overweight | 22% |
| Black non-Hispanic at risk | 20% | overweight | 13% | at risk & overweight | 33% |
| Hispanic at risk | 18% | overweight | 12% | at risk & overweight | 30% |
| Asian non-Hispanic at risk | 8% | overweight | 5% | at risk & overweight | 13% |
| Other & mult. ethnicity at risk | 18% | overweight | 14% | at risk & overweight | 32% |

**Strategies to Achieve the Goal.**

The work group selected the following strategies:

- Promote the strategies and efforts of the Massachusetts Partnership for Healthy Weight.
- Encourage employers to establish policies that support their employees' reaching and obtaining a healthy lifestyle.
- Raise public knowledge of the increased cancer risk due to being overweight or obese.
- Support policy changes that help children maintain a healthy weight.
- Increase access to healthful foods in schools, community organizations, municipalities, and businesses.
- Encourage community gardens throughout the state.
- Design a system to communicate the results of the many programs happening throughout the state.
- Encourage efforts that educate the public on following the USDA food guidelines.
- Encourage efforts that incorporate healthy-lifestyle education in schools.

## Physical Activity

Regular physical activity is associated with healthier, longer life. According to the 2003 BRFSS, roughly 77 percent of adults in the U.S. reported any leisure-time physical activity (participating in any physical activity, other than one's regular job, in the past month). Only 27 percent reported vigorous physical activity in the past month (activity that causes large increases in breathing and heart rate).[43] According to the American Cancer Society, adults who engage in at least 30 minutes or more of moderate to vigorous activity five or more days of the week may reduce their risk of breast and colon cancer.[44]

Children who regularly engage in physical activity create healthy habits for life and help avoid obesity, a risk for some cancers. It is recommended that children and adolescents engage in at least 60 minutes of moderate to vigorous physical activity a day at least five days per week.[45] Unfortunately, in the U.S. only 26 percent of adults and 27 percent of high school students get moderate physical activity (activity that causes some increase in breathing and heart rate).[46]

The CDC has initiated a number of programs and tools to increase physical activity and healthy habits. One program established in schools is based on the premise that improving student health and safety can increase students' capacity to learn, reduce absenteeism, and improve physical fitness and mental alertness. The School Health Index is a self-assessment and planning guide. This tool can be used to identify the strengths and weaknesses of school policies and programs for promoting health and safety, to develop an action plan, and to involve teachers, parents, students, and the community in the process.[47]

The Guide to Community Preventive Services has evaluated evidence-based interventions to increase physical activity. Recommended interventions include community-wide campaigns, health behavior changes adapted to the individual, and school-based interventions. Other recommended strategies are non-family social support and the creation of and/or enhanced access to places for physical activity combined with informational outreach activities (prevention table 13, next page).

**Prevention Table 13. Recommended Interventions to Promote Physical Activity**

| Strategies | Level of Evidence |
|---|---|
| **Informational approaches to increasing physical activity** | |
| 1. Community-wide campaigns | Recommended (strong evidence) |
| 2. "Point-of-decision" prompts | Recommended (sufficient evidence) |
| 3. Classroom-based health education focused on providing information | Insufficient evidence to determine effectiveness |
| 4. Mass-media campaigns | Insufficient evidence to determine effectiveness |
| **Behavioral and social approaches to increasing physical activity** | |
| 5. Individually adapted health behavior change | Recommended (strong evidence) |
| 6. Health education with TV/Video game turnoff component | Insufficient evidence to determine effectiveness |
| 7. College-age physical education/health education | Insufficient evidence to determine effectiveness |
| 8. Family-based social support | Insufficient evidence to determine effectiveness |
| 9. School-based physical education | Recommended (strong evidence) |
| 10. Non-family social support | Recommended (strong evidence) |
| **Environmental and policy approaches to increase physical activity** | |
| 11. Creation and/or enhanced access to places for PA combined with informational outreach activities | Recommended (strong evidence) |
| 12. Transportation policy and infrastructure changes to promote non-motorized transit | In progress |
| 13. Urban planning approaches—zoning and land use | In progress |

Adapted from "Promoting Physical Activity." *Guide to Community Preventive Services.*
Available from http://www.thecommunityguide.org/pa/default.htm.

## Physical Activity in Massachusetts

According to the BRFSS of 2004, 78 percent of Massachusetts adults reported being involved with any leisure time physical activity in the past month. Men (81%) were more likely than women (76%) to report any leisure time physical activity in the past month. White non-Hispanic adults (81%) were more likely than Black non-Hispanic (70%), Hispanic (60%), and Asian non-Hispanic (74%) adults to report any leisure time physical activity. Any leisure time physical activity in the past month increased with both increasing education and income (prevention table 14, next page).

As table 14 shows, approximately 53 percent of adults reported engaging in regular physical activity. White non-Hispanic adults (55%) were more likely to report regular physical activity compared to Black non-Hispanic (40%), Hispanic (33%), and Asian non-Hispanic (46%) adults. Regular physical activity increased with more education. Adults with household incomes of $75,000 or more (62%) were more likely to report regular physical activity compared to those with household incomes of $25,000 or less (43%).

**Prevention Table 14. Age-Adjusted Rates and 95% Confidence Limits of Any Leisure Time Physical Activity and Regular Physical Activity among Adults in Massachusetts, 2003**

| | Any Leisure Time Physical Activity | Regular Physical Activity |
|---|---|---|
| **Total Adults** | 78.4 (77.2–79.6) | 52.3 (51.3–54.2) |
| **Gender** | | |
| Male | 81.4 (79.7–83.2) | 53.5 (51.2–55.8) |
| Female | 75.9 (74.3–77.5) | 52.4 (50.4–54.3) |
| **Race/Ethnicity** | | |
| White non-Hispanic | 81.4 (80.2–82.6) | 55.0 (53.4–56.7) |
| Black non-Hispanic | 70.0 (64.1–75.9) | 40.3 (33.8–46.8) |
| Hispanic | 59.5 (54.2–64.9) | 32.6 (27.1–38.0) |
| Asian non-Hispanic | 73.9 (64.0–83.8) | 46.1 (32.3–59.9) |
| **Education** | | |
| Less than High School | 53.6 (48.2–59.1) | 37.5 (32.1–43.0) |
| High School | 68.1 (65.3–70.8) | 48.7 (45.7–51.7) |
| One to Three Years of College | 78.6 (76.3–80.9) | 54.1 (51.1–57.1) |
| Four or More Years of College | 89.4 (88.1–90.8) | 57.7 (55.3–60.2) |
| **Income** | | |
| Less than $25,000 | 62.3 (59.1–65.5) | 42.8 (39.3–46.3) |
| $25–34,999 | 69.7 (65.3–74.1) | 50.6 (45.7–55.4) |
| $35–49,999 | 76.8 (73.3–80.3) | 48.4 (44.2–52.6) |
| $50–74,999 | 83.9 (81.2–86.6) | 57.0 (53.3–60.7) |
| $75,000 or More | 90.3 (88.4–92.3) | 61.6 (58.3–64.9) |

* Rates are age-adjusted
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.

## Highlights of Activities

Efforts in Massachusetts to increase physical activity are particularly notable in the political and public policy arena. In November 2004, in response to Massachusetts Department of Public Health (MDPH) data demonstrating the need for Massachusetts residents to make healthier choices and increase their physical activity, Governor Mitt Romney expanded the existing Massachusetts Governor's Committee on Physical Fitness and Sports. The Committee comprises fitness, marketing, and medical professionals. They are charged with creating an outreach initiative to encourage the state's youth to participate in sports and physical fitness activities, launching a public awareness campaign to enhance overall participation in sports and physical fitness, and educating the Commonwealth's citizens about the benefits of being healthy and active.[48]

Two pieces of legislation regarding physical education in Massachusetts schools were filed for the 2005–2006 legislative session, but they differ in scope and content. The first, a bill based on the National Association for Sport and Physical Education (NASPE) standards, was filed by the Massachusetts Alliance for Health, Physical Education, Recreation & Dance (MAHPERD) and its coalition. If passed, this bill, "An Act to Improve Quality Physical Education" (SB 334), would:

- Require physical education instruction in grades K-12.
- Require not less than 150 minutes of physical education per week at the elementary level and 225 minutes per week in middle and high school levels.
- Allow no substitution of other instruction for physical education instruction.

- Require that course work be regulated under the NASPE national standards and guidelines for physical education instruction.
- Require that all courses be taught by certified physical education teachers.
- Require that regular assessment of physical education instruction be conducted at both the student and school level and be a component of the student's permanent record.[49]

A second piece of legislation, "An Act to Promote Physical Activity in Public Schools" (HB 1127), was filed by State Representative Peter Koutoujian. This legislation addresses the physical activity requirements mandated by the department of education. The bill would require a minimum of 120 hours of combined physical education and physically active lunch or recess period and a minimum of 50 hours of nutrition and wellness programs each year in public schools, during and after school.

**Highlights of Gaps, Issues, Barriers, and Concerns**

The gaps, issues, barriers, and concerns in Massachusetts are similar to those at the national level. The public lacks knowledge of the decreased risk of cancer for individuals who maintain at least a moderate level of physical activity. Work schedules and environments are not conducive to physical activity. Many residents of the Commonwealth do not have access to areas that are safe for biking and walking. Children learn from their parents, and they are more likely to be active if their parents are active. However, children also require daily fun and non-competitive physical activity as part of their school curriculum. Massachusetts Partnership for Healthy Weight will take the lead in coordinating and integrating statewide interventions to increase physical activity. The full range of chronic disease physical activity initiatives and Coalition activities will be integrated and coordinated with the efforts of the Partnership for Healthy Weight.

## Goal: Ensure that all Commonwealth residents are maintaining a healthy level of physical activity.

**Outcome Measure 14: By 2011, increase the proportion of adults who report regular moderate physical activity (physical activity five or more sessions per week for 30 minutes or more per session regardless of intensity) to 70 percent.**
Healthy People 2010: 70%
Baseline All: 53% Database: BRFSS 2003

| | | | |
|---|---|---|---|
| White non-Hispanic | 55% | Hispanic | 39% |
| Black non-Hispanic | 44% | Asian non-Hispanic | 46% |

**Outcome Measure 15: By 2011, increase the proportion of high school students who report regular vigorous physical activity to 85 percent and those who report regular moderate physical activity to 35 percent.**

Healthy People 2010: vigorous 85%, moderate 35%

Baseline All: vigorous 61%, moderate 24%, total 85%  Database: YRBS 2003

| | | | | | | |
|---|---|---|---|---|---|---|
| White non-Hispanic | vigorous | 23% | moderate | 65% | total | 83% |
| Black non-Hispanic | vigorous | 14% | moderate | 46% | total | 60% |
| Hispanic | vigorous | 17% | moderate | 50% | total | 67% |
| Asian non-Hispanic | vigorous | 18% | moderate | 57% | total | 75% |
| Other & multiple ethnicity | vigorous | 23% | moderate | 63% | total | 86% |

**Strategies to Achieve the Goal**

The work group selected the following strategies, based on prevention table 13:

- Support and enhance the efforts of the Massachusetts Partnership for Healthy Weight.
- Increase access to areas where Massachusetts residents can walk and bike safely in all seasons.
- Advocate for public policy changes that establish daily physical education classes that are fun and non-competitive.
- Endorse programs that increase public knowledge of the decreased cancer risk for individuals who engage in regular moderate physical activity.
- Support workplace policy interventions that enable employees to incorporate physical activity into their lifestyle.

## Alcohol Use

According to the National Institute on Alcohol Abuse and Alcoholism, alcohol consumption directly and indirectly accounts for 2–4 percent of all cancer deaths.[50] There is convincing evidence that drinking alcohol increases the risk of cancers of the mouth, esophagus, pharynx, larynx, colon, and liver in men and women. Drinking alcohol also increases the risk of breast and ovarian cancer in women and prostate cancer in men. In general, these risks increase after about one daily drink for women and two daily drinks for men. (A drink is defined as 12 ounces of regular beer, 5 ounces of wine, or 1.5 ounces of 80-proof liquor).[51] There is also a dose-dependent relationship between alcohol and cancer: as alcohol consumption goes up, so does the risk for developing certain cancers. Alcohol has been identified as a co-carcinogen, which means that it enhances the effects of other chemicals. For example, when alcohol is combined with tobacco use, the cancer risk is higher than for either one alone. In fact, the use of tobacco and alcohol further increases the chances of getting cancers of the mouth, throat, and esophagus.[52] It is important that any recommendations about cancer prevention include information about the risks of drinking alcohol.

### Alcohol Use in Massachusetts

Approximately 8 percent of Massachusetts adults reported drinking more than the moderate level, also called heavy drinking (defined as consumption of more than 60 drinks in the past month for men and consumption of more than 30 drinks in the past month for women). Men were more likely than women were to report heavy drinking. Based on crude percentages, heavy drinking decreased as age increased. Persons 75 and older were less likely than those aged 18-24 to report heavy drinking. White non-Hispanic adults were more likely to report heavy drinking (8%) compared to Black non-Hispanic, Hispanic, and Asian non-Hispanic adults. Those with a high school education were more likely to report heavy drinking. Adults with a household income of $35,000 to $49,999 were more likely to report heavy drinking (prevention table 15).

**Prevention Table 15. Age-Adjusted Rates and 95% Confidence Limits for Heavy Drinking among Adults in Massachusetts, 2003**

| | Heavy Drinking |
|---|---|
| **Total Adults** | 7.7 (6.9–8.6) |
| **Gender** | |
| Male | 8.5 (7.2–9.9) |
| Female | 6.9 (5.9–7.9) |
| **Age**** | |
| 18–24 | 17.0 (12.8–21.1) |
| 25–34 | 8.5 (6.5–10.6) |
| 35–44 | 6.4 (4.9–7.9) |
| 45–54 | 6.9 (5.2–8.5) |
| 55–64 | 5.6 (3.9–7.3) |
| 65–74 | 4.9 (3.0–6.8) |
| 75 and Older | 3.3 (1.7–5.0) |
| **Race/Ethnicity** | |
| White non-Hispanic | 8.4 (7.4–9.4) |
| Black non-Hispanic | 5.0 (1.9–8.1) |
| Hispanic | 4.7 (2.4–7.0) |
| Asian non-Hispanic | 2.1 (0.6–7.2) |
| **Education** | |
| Less than High School | 6.7 (3.8–9.7) |
| High School | 8.9 (6.9–10.8) |
| One to three Years of College | 8.5 (6.7–10.2) |
| Four or More Years of College | 7.5 (6.0–9.0) |
| **Income** | |
| Less than $25,000 | 7.9 (6.0–9.7) |
| $25–34,999 | 6.6 (4.2–9.1) |
| $35–49,999 | 10.2 (7.6–12.8) |
| $50–74,999 | 8.7 (6.5–10.9) |
| $75,000 or More | 8.2 (6.3–10.1) |

* Rates are age-adjusted
** Rates and 95% Confidence Limits are based on crude age-specific rates
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.

According to the Massachusetts Triennial Prevalence Survey (1999), although alcohol remains the substance of choice among school-age students in Massachusetts, there have been declines in reported use. There were also significant declines in perceived availability and intention to use alcohol in the future. The average age that students reported first trying alcohol rose significantly in 1999, indicating that students are waiting longer to experiment with drinking. This is a positive outcome since many studies show that people who begin drinking in early adolescence are more likely to develop alcohol dependence in later life than are those adults who begin drinking at the legal age.[53]

**Highlights of Activities**

The Massachusetts Bureau of Substance Abuse Services (BSAS) at the Massachusetts Department of Public Health is working to reduce individual alcohol consumption in Massachusetts and to encourage physicians to incorporate issues related to alcohol consumption and abuse into their interventions with patients. The BSAS mission is to promote an integrated, consumer-based, culturally competent continuum of substance abuse and addiction prevention, intervention, and treatment and recovery support services that are (1) responsive to the needs of individuals, families, and communities, and (2) committed to quality, availability, and accessibility. The Prevention and Intervention Services Unit of the BSAS oversees Prevention Support Services and Youth Support Services, which provide statewide training and technical assistance to BSAS-funded prevention centers and youth programs. The unit supports 10 regional prevention centers, and 41 community-based BSAS Youth Programs that provide alcohol-, tobacco-, and other drug-prevention services. In addition, the unit coordinates early intervention initiatives and public media campaigns.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Over the past few years, access to treatment and services for substance abuse has decreased, but the rate at which children and young adults become addicted to alcohol has increased. Massachusetts must consider new and revised policies to reduce alcohol use. Possible strategies include increasing the state alcohol tax, prohibiting alcohol advertisements on MBTA subways and buses, and requiring labels on alcoholic beverages that communicate the connection between alcohol consumption and increased cancer risk. Early intervention methods for prevention and treatment of alcohol use among children and young adults need to increase, as well as awareness among parents that viewing alcohol as a rite of passage has negative consequences.

The connection between alcohol consumption and cancer risk needs to be communicated to the public, especially with new information about the association between excessive alcohol consumption and cancer. An important step in that direction would be to use existing prevention and treatment networks to get the word out, and to encourage health care providers to discuss the issue with their patients.

## Goal: Ensure that all Commonwealth residents limit their use of alcohol to a moderate level.

**Outcome Measure 16: By 2011, decrease the proportion of adults who drink more than the moderate level of alcohol (adult women one drink a day and adult men two drinks a day) 4 percent.**
Healthy People 2010: no objective
Baseline All: 7.7% Database: BRFSS 2003

| | | | |
|---|---|---|---|
| White non-Hispanic | 8.4% | Hispanic | 4.7% |
| Black non-Hispanic | 5.0% | Asian non-Hispanic | 2.1% |

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Promote programs that increase public knowledge of the increased cancer risk for individuals who engage in excessive alcohol consumption.
- Encourage primary care providers to counsel their patients on the negative health consequences of excessive drinking.

## Ultraviolet Rays

In the United States, skin cancer accounts for 2 percent of cancer deaths. There are three major types of skin cancer. Basal cell and squamous cell carcinomas are known as non-melanoma forms of skin cancer and are not life threatening. Melanoma is the most serious type of skin cancer because it has the ability to spread throughout the body and can lead to death.[54] While melanoma accounts for only 4 percent of skin cancer cases, it contributes to a majority of skin cancer deaths. The American Cancer Society estimates that melanoma will account for roughly 60,000 cases and 7,770 deaths due to skin cancer in 2005.[55] In the United States, the percentage of people who develop melanoma has doubled in the past 30 years.[56]

The incidence rates of both melanoma and non-melanoma skin cancers are on the rise. Much of this can be attributed to the popularity of tanning in the sun. Tanning beds can also contribute to the problem because they use UVA and UVB lamps. Both UVA and UVB can cause serious skin damage, and both contribute to skin cancer growth. The myth that tanning beds are harmless must be dispelled. Health experts in America and worldwide advise against tanning bed use. The World Health Organization (WHO) recommends that no person under 18 years of age should use a tanning bed. These recommendations were developed because it is known that young people who get burnt from exposure to UV will have a greater risk of developing melanoma later in life.[57]

The *Guide to Community Preventive Services* outlines several evidence-based interventions that have proven to be effective. Recommended interventions include educational/policy interventions in primary schools to improve children's sun-protective "covering up" behavior. In addition, educational/policy interventions in recreational/tourism settings are recommended to improve adult sun-protective "covering up" behavior (prevention table 16).

In addition, Cancer Control PLANET (Plan, Link, Act, Network with Evidence-based Tools) lists three sun-safety intervention programs that can be found on their Web site at http://cancercontrolplanet.cancer.gov/. These programs have been tested and all promote cover-up behavior. The site also lists specific policy and structural interventions that have been reviewed and have shown sufficient evidence to be recommended (table next page).

**Prevention Table 16. Preventing Skin Cancer by Reducing Exposure to Ultraviolet Light**

| Strategies | Level of Evidence |
|---|---|
| **Specific Interventions** | |
| 1. Educational/policy interventions in primary schools | Recommended (sufficient evidence) (to improve children's sun-protective "covering up" behavior) |
| 2. Educational/policy interventions in recreational/tourism settings | Recommended (sufficient evidence) (to improve adult sun-protective "covering up" behavior) |
| 3. Educational/policy interventions in recreational/tourism settings | Insufficient evidence to determine effectiveness (to improve children's sun-protective behavior) |
| 4. Educational/policy interventions in child care settings | Insufficient evidence to determine effectiveness |
| 5. Educational/policy interventions in secondary schools/colleges | Insufficient evidence to determine effectiveness |
| 6. Interventions oriented to health care settings and providers | Insufficient evidence to determine effectiveness |
| 7. Educational/policy approaches in occupational settings | Insufficient evidence to determine effectiveness |
| **Specific Interventions for Target Population** | |
| Interventions oriented to children's parents or caregivers | Insufficient evidence to determine effectiveness |
| **Community-wide interventions** | |
| Mass media and small media without other activities | Insufficient evidence to determine effectiveness |
| Community-wide multi-component interventions | Insufficient evidence to determine effectiveness |

Adapted from "Preventing Skin Cancer by Reducing Exposure to Ultraviolet Light." *Guide to Community Preventive Services*. Available from http://www.thecommunityguide.org/cancer/skin/default.htm.

## Melanoma in Massachusetts

As prevention table 17 shows, the incidence of melanoma in Massachusetts increased significantly from 1998 to 2002[58] with a rate of 19 cases for every 100,000 residents. The mortality rate for the same period was 3 cases for every 100,000 residents. The incidence of melanoma in Massachusetts males (23 cases per 100,000) was slightly higher than the incidence for males nationwide (19 cases per 100,000). The table also shows that male mortality rates from melanoma in Massachusetts and the nation were about equal, roughly four to five cases for every 100,000 men. For Massachusetts females, incidence rates of melanoma are also slightly higher when compared to the national numbers for females, with 16 cases for every 100,000 women in Massachusetts and 12 cases for every 100,000 women nationally. Mortality rates for melanoma among females for both Massachusetts and the nation are even, with two cases for every 100,000 women (table 17).

**Prevention Table 17. Age-adjusted Incidence and Mortality Rates for Melanoma by Gender, Massachusetts (1998-2002) and NAACCR Registries (1997-2001)**

| | Males | | Females | |
|---|---|---|---|---|
| | **Massachusetts** | **National** | **Massachusetts** | **National** |
| **Incidence** | 23.3 | 19.2 | 15.7 | 12.3 |
| **Mortality** | 4.4 | 4.5 | 2.0 | 2.1 |

*Per 100,000, age-adjusted to the 2000 U.S standard population.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report.* Boston, MA: 2005.

One of the major risk factors for melanoma is excessive and/or unprotected exposure to ultraviolet radiation, as well as having had severe sunburns as a child. [59] In the 2004 BRFSS survey, roughly 37 percent of Massachusetts adults reported that they had a sunburn in the past

12 months, with men (41%) reporting a higher frequency of sunburns compared to women (31%). Black non-Hispanic adults (5%) were less likely to report sunburn when compared to White non-Hispanic (42%), Hispanic (12%), and Asian non-Hispanic (19%) adults. As both education and income increased, adults were more likely to report having been sunburned in the past 12 months. Sunburns varied only slightly by geographic region, with adults in the South East region of the state (41%) reporting a higher frequency of having been sunburned in the past 12 months (prevention table 18).

**Prevention Table 18. Age-Adjusted Rates and 95% Confidence Limits of Adults Reporting a Sunburn in the Past 12 Months in Massachusetts, 2003**

| | Age-Adjusted Rates and 95% Confidence Limits |
|---|---|
| **Total Adults** | 36.6 (35.2–37.9) |
| **Gender** | |
| Male | 40.4 (38.2–42.5) |
| Female | 33.1 (31.4–34.9) |
| **Race/Ethnicity** | |
| White non-Hispanic | 42.3 (40.8–43.8) |
| Black non-Hispanic | 5.4 (3.1–7.7) |
| Hispanic | 11.8 (8.1–15.5) |
| Asian non-Hispanic | 18.9 (8.2–29.5) |
| **Education** | |
| Less than High School | 17.4 (13.2–21.6) |
| High School | 32.8 (30.0–35.5) |
| One to Three Years of College | 39.5 (36.7–42.2) |
| Four or More Years of College | 41.0 (38.7–43.2) |
| **Income** | |
| Less than $25,000 | 25.2 (22.2–28.2) |
| $25–34,999 | 26.9 (22.8–31.1) |
| $35–49,999 | 36.6 (33.0–40.1) |
| $50–74,999 | 43.8 (40.2–47.3) |
| $75,000 or More | 44.9 (42.0–47.8) |
| **Region** | |
| Western | 37.3 (33.7–40.8) |
| Central | 37.9 (34.3–41.5) |
| North East | 36.8 (33.7–39.9) |
| Metro West | 36.6 (33.7–39.9) |
| South East | 41.2 (38.0–44.4) |
| Boston | 26.8 (23.6–29.9) |

* Rates are age-adjusted

Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2003: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: 2004.

## Highlights of Activities

Massachusetts is actively engaged in skin cancer prevention. Many accomplishments to date can be attributed to the Massachusetts Skin Cancer Prevention Collaborative (the Collaborative), a statewide coalition committed to promoting the prevention, early detection, and treatment of all types of skin cancer. Established in June 2000, the Collaborative brings together survivors, family members, and representatives from a broad network of organizations including academic institutions, cancer centers, medical societies, schools, local public health commissions, businesses, and private foundations. Through shared concern, resources, and expertise, the Collaborative aims to educate the public about skin cancer and develop policies that support environmental action, shape social norms, and assure the sustainability of programs.

One of the lead organizations in the Collaborative is the Massachusetts Melanoma Foundation (MMF). The MMF redesigned its Web site to provide educational information and links to other organizations that provide sun-safety messages. It also created an online educational program for the Massachusetts Little League and co-sponsored an event at the Wellness Community of Greater Boston to discuss current melanoma treatment modalities. The organization developed an Educational Advisory Council of School Nurses and Administrators to introduce the SunWise curriculum to children in grades K–8 throughout the state. This year the MMF will collaborate with the Dana-Farber Blum Family Resource Van to deliver sun-safety education at local beaches.

The Sun Protection Foundation (SPF) has a program targeting children in grades Pre-K–12 called Real World Sun Safety. SPF uses its own interactive curriculum along with the Environmental Protection Agency's SunWise School Program to get children engaged. Twenty-two schools in nine towns participate in the program. SPF also provides professional development for school nurses and health educators.

Other activities by member organizations include a train-the-trainer program for school nurses, school nurse outreach during the prom season regarding tanning laws, and mini-grants to community organizations to provide sun-safety interventions for children at summer recreational and community centers.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Of concern in Massachusetts are a number of issues related to skin cancer. Tanning beds pose one risk of skin cancer among adolescents and adults. In Boston alone, there are approximately 60 tanning vendors with permits. Young women are the most likely users. Two ways to educate the public about the danger of tanning beds are to dispel the misconception that they are not harmful and to enforce regulations requiring visible warning signs at tanning salons.

Another concern is the public's insufficient understanding of the relationship between sun exposure and skin cancer. Public education should focus on communicating risk. Health educators should teach parents, teachers, and students how to identify and monitor abnormal skin markings. Schools and recreational facilities should establish policies and guidelines for sun protection, especially during peak sun hours. These should include availability and use of cover-ups, adequate shade areas, sunscreen tents, and other products that guard against excessive sun exposure.

## Goal: Reduce the incidence of malignant melanoma in Massachusetts.

**Outcome Measure 17: By 2011, decrease the proportion of adults who report having been sunburned within the last year to 20 percent.**
Healthy People 2010: no sunburn objective
Baseline All: 37% Database: BRFSS 2003

| | | | |
|---|---|---|---|
| Female | 33% | Male | 40% |

| | | | |
|---|---|---|---|
| White non-Hispanic | 40% | Hispanic | 13% |
| Black non-Hispanic | 6% | Asian non-Hispanic | 15% |

| | | | |
|---|---|---|---|
| <High School | 17% | College 1–3 yrs | 39.5% |
| High School | 33% | College 4+ | 41% |

| | | | | | |
|---|---|---|---|---|---|
| <$25,000 | 25% | $35–49,000 | 7% | $75,000 | 45% |
| $25–34,999 | 27% | $50–74,999 | 44% | | |

| | | | |
|---|---|---|---|
| Boston | 27% | Northeast | 37% |
| Central | 38% | Southeast | 41% |
| Metrowest | 37% | Western | 37% |

**Strategies to Achieve the Goal**

The work group selected the following strategies, based on prevention table 16:

- Encourage regulations warning consumers about tanning beds and the risk of skin cancer.
- Promote programs and activities in schools, daycare, and parks or other recreational areas that teach and encourage "covering up" behavior in adults and children.
- Encourage education of students on protection from UV exposure.
- Promote policy changes that encourage sun protection activities.
- Support the building of schools and recreational sites that have access to shade.
- Increase access to and use of sun protection materials such as hats and umbrellas.
- Teach children to identify abnormal markings on their skin.
- Increase education for adults to monitor changes on their skin.
- Establish and disseminate school guidelines for sun protection.

## Occupational and Environmental Carcinogens

According to the American Cancer Society, carcinogens are "substances that can cause changes that can lead to cancer. Substances classified as carcinogens may have different levels of cancer-causing potential. Some may cause cancer only after prolonged, high levels of exposure. And, for any particular person, the risk of developing cancer depends on many factors, including the length and intensity of exposure to the carcinogen and the person's genetic makeup."[60]

Tobacco smoke is a known environmental carcinogen, but cancer incidence caused by other environmental carcinogens is difficult to document. "There have been few studies which identify an increased cancer risk associated with exposure to environmental contaminants such as arsenic, radon, chromium, and nitrates, although a few specific substances found in the environment have been well established as carcinogenic, e.g., radon, solar radiation, and environmental tobacco smoke."[61] Nonetheless, the public is concerned about these contaminants.

Four known carcinogens dominate the national discussion: radon, arsenic, occupational exposure to asbestos, and Polychlorinated Biphenyls (PCBs).

Radon is an odorless, tasteless gas found in soil and water. It is the second leading cause of lung cancer in the United States. Each year 20,000 Americans die from lung cancer due to radon exposure. Radon exposure commonly occurs in homes where it enters through cracks in floors, walls, or foundations. It can also be released from building materials or from water obtained from wells that contain radon. Radon levels can be higher in homes that are well insulated, tightly sealed, and/or built on uranium-rich soil. The Environmental Protection Agency (EPA) recommends that people check their homes for high levels of radon. The threshold for radon is 4 pCi/L. However, the EPA advises homeowners with radon levels as low as 2pCi/L to 4pCi/L to have their homes fixed for this problem. It is important to note that there is no safe radon level in the home.[62]

Arsenic is a naturally occurring substance found in soil and bedrock. It is also a contaminant found in drinking water. Arsenic found in drinking water has been proven to cause cancer of the skin, lungs, urinary bladder, and kidney. A process called reverse osmosis is the most cost-effective way to reduce arsenic levels. This system costs between $88 and $1,500. Other methods for removing arsenic are anionic exchange and iron oxide filters.[63]

Asbestos is a naturally occurring mineral. Since asbestos is heat resistant, it has been used as an insulating agent and for fireproofing. Unfortunately, asbestos poses some health risks. Exposure to it can lead to development of lung cancer and mesothelioma, cancer of the chest and abdominal membranes. An overwhelming percentage of cases of mesothelioma occur in people who worked in jobs where they inhaled asbestos particles. Asbestos-related cancers usually develop within 10 to 40 years of exposure. According to the American Cancer Society, between 2,000 and 3,000 new cases of mesothelioma are diagnosed each year.[64]

Polychlorinated Biphenyls (PCBs) were widely used in chemical and industrial applications before 1977, when concern over their toxicity led Congress to prohibit their production and distribution. In 1996 a reassessment of PCBs by the Environmental Protection Agency (EPA) determined that "PCBs are probable human carcinogens."[65] The International Agency for Research on Cancer had drawn the same conclusion.[66] PCBs continue to be found in

many old industrial and commercial facilities. They are also the main contaminants of the many Superfund sites the EPA has proposed for cleanup.

Additional research on environmental carcinogens is required. The nation learned a difficult and tragic lesson from the tobacco industry's years of deception regarding the known hazards of tobacco use and exposure. Known and probable carcinogens used in any product must be carefully and objectively evaluated and their potential effect on human health fully disclosed. The evaluations by the *Guide to Community Preventive Services* of interventions to reduce exposure to occupational and environmental carcinogens are based on environmental tobacco exposure (prevention table 1).

**Occupational and Environmental Carcinogens in Massachusetts**

Exposure to environmental carcinogens is of great concern to residents of Massachusetts. At the Department of Public Health, the Bureau of Environmental Health Assessment fields more than 400 calls each year from residents concerned about potential cancer-causing chemicals in their communities.

One Massachusetts city, Woburn, received a great deal of public attention due to its history of chemical industries and a confirmed cancer cluster of childhood leukemia. A case-control study was conducted to investigate whether there was a relationship between the leukemia incidence and exposure to public drinking water from contaminated wells. The results of the study "imply an association between exposure to the contaminated wells and childhood leukemia during pregnancy but not for exposure after birth."[67]

As cancer incidence increases, industry's role in making our environment toxic will continue to be questioned. Massachusetts must continue to be watchful of local industry and to support research and monitoring of probable and known environmental carcinogens. Massachusetts must also apply proven interventions to eliminate the effect of environmental tobacco smoke, a known carcinogen.

**Highlights of Activities**

Several agencies in Massachusetts investigate potential links between environment and cancer. The Bureau of Environmental Health Assessment (BEHA) at the Massachusetts Department of Public Health, for example, has a broad mission of protecting the public health from a variety of environmental exposures. The BEHA responds to environmental health concerns and provides communities with epidemiological and toxicological health assessments. The Bureau comprises six programs and houses a field office located at the Massachusetts Military Reservation (MMR) on Cape Cod.

In addition, the federal Agency for Toxic Substances and Disease Registry (ATSDR) is responsible for helping state agencies identify hazardous exposures at Superfund sites. One example is the Shpack Landfill. Residents of Norton and Attleboro were concerned about potential cancer incidence related to this site, and ATSDR helped the MDPH conduct the site evaluation. ATSDR will also conduct written and oral health consultations regarding a specific site, chemical release, or hazardous material. They have worked with the MDPH and have provided consultation at more than 104 Massachusetts sites. ATSDR also conducts health studies

to investigate the relationships between exposures to hazardous substances and adverse health effects.[68]

**Highlights of Gaps, Issues, Barriers, and Concerns**

Massachusetts residents and public health workers are concerned about known and probable carcinogens affecting the rates of cancer throughout the state. Particular issues that need to be addressed include arsenic in drinking water, radon levels in homes, the cleanup of Superfund sites, and occupational exposure to asbestos.

Since 1979, approximately 1,355 people have died from asbestos exposure in Massachusetts. Currently, both the state and federal government regulate asbestos use, removal, and disposal. The Division of Occupational Safety is responsible for regulating occupational-related asbestos exposure in Massachusetts. This program provides site visits, analytical services, and technical services.[69,70]

The arsenic level in the Massachusetts public water supply is 1.2 parts per billion (ppm), significantly below the EPA's new standard of 10 ppm, which will take effect January 2006 (the current standard is 50 ppm).[71] However, there is concern regarding arsenic in private-well drinking water. Since private wells are not regulated, it is important for Massachusetts residents who use these wells as a source of water to test them regularly.[72,73]

Unfortunately there is no state or federal regulation regarding radon in Massachusetts. In 1988 the Massachusetts Department of Public Health Radiation Control Program and the EPA did a radon study. The results of the study were quite alarming, showing that one out of every four homes in Massachusetts may have radon levels above the 4 pCi/L action level. The only way to know if a home has radon is for the homeowner to voluntarily test for radon. The more common way to reduce the level of radon in homes is to increase the ventilation of the home and to install a mitigation system. Unfortunately for many homeowners, this kind of home improvement may be an expense they are unable to afford.[74]

Polychlorinated Biphenyls, or PCBs, are also of concern statewide. Fifteen Superfund sites in Massachusetts are identified on the EPA's National Priorities List, and many list PCBs as a main contaminant. These sites are in various stages of cleanup. Details can be found on the state government's waste site clean-up Web site.[75]

## Goal: Reduce the effect of occupational and environmental carcinogens on cancer incidence in Massachusetts

**Outcome Measure 18: By 2011, reduce the number of people who are drinking water contaminated with arsenic at levels above 10 parts per billion (ppb).**
Healthy People 2010: no objective
Baseline: to be determined Database: EPA 2004

**Outcome Measure 19: By 2011, increase the number of homes tested for radon in regions where radon levels are high.**
Healthy People 2010: no objective
Baseline: to be determined Database: to be determined

**Outcome Measure 20: By 2011, reduce the number of people who die of mesothelioma by 30 percent**.
Healthy People 2010: no objective
Baseline: 340 deaths Database: MCR 1979–2001

**Outcome Measure 21: By 2011, complete the cleanup of all PCB Superfund sites in Massachusetts.**
Healthy People 2010: no objective
Baseline: 15 Cleaned Database: EPA 2005

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Increase public knowledge of the effect of environmental factors on increased risk of cancer.
- Monitor and intervene early to reduce environmental cancers.
- Pay close attention to suspicious clusters of cancer even if numbers are less than statistically significant.
- Do more environmental testing in areas of increased cancer incidence rates.
- Support legislation that requires labeling of carcinogens on consumer products.
- Promote the use of non-carcinogenic materials in indoor air spaces.
- Consider system and regulatory interventions that will ensure the reduction of environmental pollutants.

## Infectious Agents

Infectious agents cause approximately 10 percent of cancers in the United States. These agents consist of viruses, bacteria, and parasites. The infectious agents of greatest concern in the U.S. for reducing the burden of cancer are Human Papillomaviruses (HPVs), Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV), Hepatitis C Virus (HCV), and Heliobacter pylori (H. pylori).[76]

### Human Papillomavirus (HPV)

HPV is "one of the most common causes of sexually transmitted diseases in the world."[77] It is estimated that more than 5 million new cases of HPV infections are reported in the United States every year, with approximately 20 million people in this country already infected.

There are approximately 100 types of HPV, with about 40 types that infect the human genitalia and are transmitted through sexual contact. HPVs that are classified as "low risk" are associated with benign lesions but not cancers. "High risk" types are associated with cervical cancer and other genital cancers. Of particular concern are HPV 16 and HPV 18, the most common types of high risk HPV. These two types of HPV are linked to cervical cancer. HPV is also linked to cancers of the penis, anus, cervix, vagina, and vulva.[78] Although most women who are sexually active will get HPV at some point in their lives, very few women with HPV will develop cervical cancer. Persistent infection is the most important risk factor for developing cervical cancer.

The Pap smear, or Pap test, is a screening test used to detect cervical cancer. The Pap test is done in order to gather cells from the cervix. These cells are smeared onto a slide and sent to a laboratory where they are examined for abnormalities. The lab will then search for dysphasia, cancer, or signs of infection with HPV. Pap test guidelines are covered in the early detection section of this document under cervical cancer.

An additional test, the HPV DNA test, can now be used to detect the presence of those HPVs associated with a higher risk of cervical cancer. Indication for use of this test is presence of atypical squamous cells of unknown significance (ASCUS) on Pap. Women with ASCUS are referred for further specialized testing (colposcopy). The HPV DNA test is used as an adjunct to cervical cancer screening for women age 30 or older.

An HPV vaccine has been developed and is expected to be released soon. Positive findings have been found so far for vaccines for HPV 16 and HPV 18. Researchers have found that they can control infection for two- to four-year periods.[79]

### Human Immunodeficiency Virus (HIV)

HIV has been linked to several cancers such as Kaposi's sarcoma, Hodgkin's disease, certain non-Hodgkin's lymphoma, and testicular cancer. Approximately 8 percent of HIV-infected individuals will develop non-Hodgkin's lymphoma. Another 20 to 30 percent will develop Kaposi's sarcoma. Kaposi's sarcoma is most common in men who have sex with men.[80]

Researchers are working hard to find an AIDS vaccine, and some HIV vaccine clinical trials are in process. Further study and evaluation are needed before anything is released to the public.[81]

**Hepatitis B Virus (HBV) and Hepatitis C Virus (HCV)**

HBV and HCV are both viruses that cause liver infection. It has been shown that HBV and HCV cause 25 to 50 percent of hepatocellular carcinomas. The good news is that vaccines are available to the public to prevent HBV infection. Many children and young adults are now required to have this vaccine before entering school. In addition, health care workers are mandated to get this vaccine. Currently no vaccines are available to prevent HCV infection.[82]

**Heliobacter pylori (H. pylori)**

H. pylori is the cause of most stomach cancers. Certain nitric substances may increase the risk of getting H. pylori, such as those found in cured meats, some drinking water, and certain vegetables. Fortunately, antibiotics and other medications are available to treat H. pylori. More research is needed to find out whether those who have the infection but do not have symptoms should be treated.[83]

Evidence-based interventions to prevent the spread of these infectious agents are currently under review by the *Guide to Community Preventive Services.* There are, however, concrete interventions that have been identified as effective. Preventing the spread of Hepatitis B and C has been assessed as a strong intervention in the fight to prevent cancer. Providing vaccinations and removing structural barriers, such as providing free needle exchange programs, decrease the spread of Hepatitis C. Vaccination and removing structural barriers are strongly recommended.

**Infectious Agents in Massachusetts**

The infectious agents that have the greatest effect on the burden of cancer in Massachusetts are the same as those nationwide: HPV, Hepatitis B and C, and HIV.

According to the 2004 BRFSS, 88 percent of Massachusetts women reported having had a Pap test in the past three years. Those 75 and older (65%) were less likely to report having had a Pap test, while those 35–44 (95%) were more likely to report having had a Pap test. Asian non-Hispanic women (65%) were less likely to report having had a Pap test, followed by Black non-Hispanic women (83%). White non-Hispanic (89%) and Hispanic (86%) women were more likely to report having had a Pap test. As both education and income increased, so did the number of women who reported having had a Pap test within the past three years. In all six regions of Massachusetts, the percentage of women who reported having had a Pap test was 85 percent or higher (prevention table 19, next page).

**Prevention Table 19. Age-Adjusted Rates and 95% Confidence Limits for Cervical Cancer Screening (Pap test within three years) among Women in Massachusetts, 2002**

| | Pap test within 3 years |
|---|---|
| **Total Women** | 87.7 (86.3–89.1) |
| **Age**** | |
| 18–24 | 80.8 (74.9–86.7) |
| 25–34 | 93.1 (90.8–95.4) |
| 35–44 | 94.5 (92.7–96.4) |
| 45–54 | 91.3 (88.6–93.9) |
| 55–64 | 88.8 (84.9–92.6) |
| 65–74 | 81.1 (75.7–86.5) |
| 75 and Older | 63.9 (56.9–70.9) |
| **Race/Ethnicity** | |
| White non-Hispanic | 88.9 (87.4–90.4) |
| Black non-Hispanic | 83.3 (75.2–91.5) |
| Hispanic | 86.3 (81.0–91.6) |
| Asian non-Hispanic | 65.2 (50.0–80.4) |
| **Education** | |
| Less than High School | 80.8 (75.7–86.0) |
| High School | 85.1 (82.1–88.2) |
| One to three Years of College | 88.3 (85.8–90.8) |
| Four or More Years of College | 90.7 (88.6–92.8) |
| **Income** | |
| Less than $25,000 | 81.7 (78.2–85.3) |
| $25–34,999 | 84.7 (79.9–89.6) |
| $35–49,999 | 86.6 (82.3–90.8) |
| $50–74,999 | 93.1 (89.8–96.4) |
| $75,000 or More | 93.6 (90.2–97.0) |
| **Region** | |
| Western | 88.3 (84.9–91.7) |
| Central | 84.7 (80.7–91.7) |
| North East | 89.9 (87.0–92.8) |
| Metro West | 87.7 (84.6–90.8) |
| South East | 87.9 (84.9–91.0) |
| Boston | 87.1 (83.4–90.7) |

* Rates are age-adjusted

** Rates and 95% Confidence Limits are based on crude age-specific rates, Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2002: Results from the Behavioral Risk Factor Surveillance System.* Boston, MA: April 2004.

It can be estimated from population-based data from 1999 that roughly 3,000 new cases of HPV will occur in Massachusetts this year, with roughly 11,000 individuals already infected with the HPV virus.[84]

HIV infection is a serious issue in this state. Between 1983 and July 1, 2004, 24,442 Massachusetts residents were diagnosed with HIV and/or AIDS. Forty-two percent of those died, and 58 percent are living with the disease. The statistical breakdown indicates that 47 percent were White non-Hispanic, 27 percent were Black non-Hispanic, 1 percent were Asian or Pacific Islander, and 1 percent were American Indian or Alaska Native. IV drug users and Men who Have Sex with Men accounted for 33 percent and 30 percent respectively.[85]

According to a May 1, 2005, report, 15,645 people are living with HIV/AIDS: 6,911 with HIV infection and 8,742 with full-blown AIDS.[86]

Approximately 100,000 people in Massachusetts are infected with Hepatitis C. Although incidence rates have decreased in the past 10 years due to a safer blood supply and safer IV drug use, about 10,000 new Hepatitis C cases have been reported annually since 2002.

**Highlights of Accomplishments**

Massachusetts has made great strides in combating infectious agents related to cancer. The Women's Health Network (WHN) conducts cervical cancer screenings for uninsured women. Because of the high percentage of Vietnamese women with cervical cancer, WHN is designing the Vietnamese Women Cervical Cancer Project. In addition, the STD/HIV Prevention Training Center conducts STD education for health care providers in Massachusetts and other New England states.

In Massachusetts, Hepatitis B vaccine is required for child care, kindergarten, and seventh grade attendance as well as for all health science students (full-time and part-time, undergraduate and graduate) and freshmen in college. The college requirement phased in gradually and applied to all sophomores in 2002, juniors in 2003, seniors in 2004, and graduate students in 2005. It is endorsed by the state chapters of both the American Academy of Pediatrics (AAP) and the American Academy of Family Practitioners (AAFP). [87]

Eight Viral Hepatitis Prevention Program screening sites counsel for Hepatitis C. Two sites are in Boston, and the rest are in Cape Cod, Fall River, Lynn, Somerville, Springfield, and Worcester. These sites vaccinate for Hepatitis A and B. Four needle-exchange programs are in place in community health centers in Boston, Cambridge, Northampton, and Provincetown. A Hepatitis C toll-free hotline is available and accessible statewide.

**Highlights of Gaps, Issues, Barriers, and Concerns**

The Prevention work group identified several barriers and issues related to infectious agents in Massachusetts. With regard to HPV and its link to cancer, they noted a lack of public and provider education and inconsistent messages to high school students. The availability of a new HPV vaccine in the next few years will provide an opportunity for accurate education and a potential for reducing HPV infection in the state.

There are several key issues, gaps, and barriers concerning Hepatitis C prevention in Massachusetts. The eight prevention sites mentioned above do not adequately cover the state. More sites need to be located in the western regions of the state as well as in Fitchburg, Lowell, and Gloucester.

The difficulty in establishing more needle-exchange programs is another barrier to reducing hepatitis transmission. Massachusetts is one of three states where it is unlawful to have possession of needles without a prescription. In addition, the Commonwealth is missing data on the immigrant population coming to Massachusetts with Hepatitis C infection. Fortunately, in May 2004 a statewide surveillance system was established for medical providers to fill out case history application forms. HCV is highly curable with a year of drug treatment. However, the cost-benefit analysis shows that this would cost between $18,000 and $20,000 per person per year. Many people with HCV are uninsured or underinsured.

Hepatitis vaccination targeting incarcerated individuals would help decrease incidence rates in this population. The Division of Viral Hepatitis, National Center for Infectious Disease issued a report, "Prevention and Control of Infections with Hepatitis Viruses in Correctional Settings."[88] Correctional facilities may find the HBV vaccine series difficult to introduce due to

the complicated dosing schedule. However, it is important to note that providing one dose is better than providing none at all.

## Goal: Reduce the effect of infectious agents on cancer incidence and mortality in Massachusetts.

**Outcome Measure 22: By 2011, increase public notification of the connection between cancer risk and specific sexual behaviors by including this information in 100 percent of relevant public health educational materials.**

Baseline: to be determined

Database: survey of public information materials used in MDPH 2005

**Outcome Measure 23: By 2011, decrease the number of children and adults who contract Hepatitis C by 30 percent**

Baseline: 10,000 cases (immigrants not included)

Database: Hepatitis C Surveillance System 2004

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Prevent the spread of Hepatitis C.
- Support a public awareness campaign, adding cancer risk from infectious agents to current materials used by existing programs.
- Promote access to and use of sexual health programs.
- Provide counseling about sexually transmitted infectious agents that increase the risk of cancer.
- Include infectious-agent cancer information in high school health classes.
- Increase the number of pediatric and adult Hepatitis vaccinations.
- Deregulate and decriminalize access to and use of syringes.

## Genetics and Cancer Prevention

Even though genetic risk factors account for a relatively small proportion of the total population risk of cancer, 5–10 percent of all cancers are estimated to have a hereditary component.[89]

Studies show that 5–10 percent of women with breast cancer have a mother or sister with the disease.[90, 91, 92, 93] Women who have a first-degree relative (mother, father, sister, or daughter) with breast cancer have approximately double the risk of developing this disease.[94] The greatest risk factor for developing ovarian cancer is having a family history of the disease. A woman with a first-degree relative with ovarian cancer has about three times more risk than a woman without this family history; women with two or three relatives with ovarian cancer have approximately 4.5 times the risk.[95] About 5 percent of patients with colorectal cancer have an inherited genetic abnormality that causes the cancer.[96]

Sometimes those at greatest risk for cancer will be referred to a genetic counselor. A genetic counselor helps patients understand their risk and its implications, helps them cope with the psychosocial aspects of that risk, and helps them make informed decisions about genetic testing and other issues.

Cancer genetics is still a new field, and much research needs to be done. To facilitate that effort, the National Cancer Institute has organized a research collaborative, the Cancer Genetics Network (CGN). The network supports research on the genetic basis of human cancer susceptibility; integration of the information into medical practice; and behavioral, ethical, and public health issues associated with human genetics. It has a database with genetic information on 24,000 individuals and seeks the participation of those from high risk and minority communities.[97]

The federal government has recognized the importance of knowing one's family history in relation to disease prevention. In 2002 Surgeon General Richard Carmona launched a national public health campaign in collaboration with other agencies within the U.S. Department of Health and Human Services. The U.S. Surgeon General's Family History Initiative was designed to encourage Americans to learn about their family history. The initiative includes a Web site with a link to a tool called "My Family Health Portrait."[98]

### Genetics in Massachusetts

The important link between genetics and public health and the need for research and education led to the creation of a genetics program within the Massachusetts Department of Public Health. The Massachusetts Genetics Program (MGP) developed a strategic plan with goals to address professional and public education around emerging issues and new technologies, to promote access and reduce barriers to genetics information and services, and to strengthen research and data collection. The MGP posts a statewide list of genetics resources on its Web site.[99]

Massachusetts residents also have access to a program called FIRSTLINK, a system that provides universal screening of all newborns and families at the time of birth for conditions that may place them at risk for adverse health or developmental outcomes. FIRSTLINK also links

identified families with needed services and support through referral to programs and resources in their own community.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Genetics is a new area of concern both in Massachusetts and nationwide. The best way to address genetics as a method of reducing the burden of cancer is still unclear. Barriers exist, even to tests that identify genetic predisposition to certain cancers. For example, the genetic test for women who are at higher risk for breast cancer has been available for several years, but most health insurance policies do not cover it. There is also concern over how the information about an individual's risk could be used. Many are worried about employment ramifications such as the likelihood of being laid off or being overlooked for employment opportunities. Clearly, this new area of research and opportunity for risk reduction requires careful consideration and monitoring as the science and subsequent policy issues evolve.

## Goal: Increase the early identification of people at risk for developing cancer due to genetic susceptibility or inherited predisposition.

**Outcome Measure 24: By 2011, increase the number of people who are aware of their family history of cancer.**
Baseline: to be determined Database: to be determined

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Promote programs that enhance public knowledge of the importance of knowing about family history of cancer and communicating that information to their health care provider.
- Educate providers regarding the importance of obtaining family history of cancer from their patients and encouraging early interventions.
- Support educating the public about genetics and chronic disease.
- Consider developing a Web site to communicate the full range of information about genetic issues.
- Incorporate new information about genetics into the cancer plan.
- Promote access to and use of genetic screening for high-risk populations.
- Ensure protection from discrimination for individuals who have had genetic testing.

# Early Detection Tab 3

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# EARLY DETECTION

Early detection is the application of a strategy or strategies to determine whether cancer or pre-cancerous cells are present in an asymptomatic person. Depending on the type of cancer, early detection strategies may employ clinical examination, X rays, laboratory analysis, endoscopic technologies, or a combination of those procedures. The goal is to find cancerous changes in early stages when the disease can be treated more effectively. The use of early detection strategies often leads to increased survival rates and can even prevent some cancers from developing.

Only some cancers can be detected early. For these cancers, recommendations may include widespread screening of the average-risk, asymptomatic population at certain time intervals. Depending on the type of cancer, this screening may begin at an age when the incidence rate is known to increase drastically. For individuals considered to be at high risk for developing a cancer that can be detected early, screening may be recommended starting at an earlier age and/or at more frequent time intervals. Some screening strategies recommended for average-risk individuals may be inappropriate for individuals at high risk.

There are other cancers for which no early detection strategy has proven effective. For these cancers, widespread screening is not recommended. However, for populations experiencing disparate rates of morbidity and mortality from any of these cancers, public health interventions that increase informed decision-making may be advised.

The United States Preventive Services Task Force and the National Cancer Institute have set best-practice standards for early detection of all cancers. In addition, the *Guide to Community Preventive Services* provides a review and assessment of evidence-based interventions for the promotion of breast, cervical, and colorectal cancer screening as well as for informed decision-making.

# Breast Cancer

The American Cancer Society's *Cancer Facts and Figures 2005* estimated that approximately 211,240 new cases of invasive breast cancer and 58,490 new cases of in situ breast cancer would occur among women in the United States in 2005. An estimated 40,410 women were expected to die from breast cancer in 2005. Breast cancer is the most frequently diagnosed cancer in women and, after lung cancer, is the second most common cause of cancer death in women in the United States. Breast cancer accounts for 32 percent of estimated new cases of cancer in females and 15 percent of estimated cancer deaths in females.[100]

**Early Detection Table 1. Breast Cancer (Female) Incidence[1] and Mortality Rates*[2] by Race and Ethnicity, U.S., 1998-2002**

| | White | African American | Asian American and Pacific Islander | American Indian and Alaska Native | Hispanic/Latino |
|---|---|---|---|---|---|
| **Incidence** | 141.1 (140.2–141.9) | 119.4 (117.1–121.6) | 96.6 (94.8–98.5) | 54.8 (50.2–59.7) | 89.9 (88.1–91.8) |
| **Mortality** | 25.9 (25.8–26.0) | 34.7 (34.3–35.1) | 12.7 (12.2–13.2) | 13.8 (12.7–14.9) | 17.7 (16.3–17.1) |

* Per 100,000, age-adjusted to the 2000 U.S. standard population. Hispanics and non-Hispanics are not mutually exclusive from whites, African Americans, Asian or Pacific Islanders, and American Indians and Alaska Natives.
[1]Statistics for Hispanics and Non-Hispanics do not include cases from the Detroit, Hawaii, Rural Georgia, and Alaska Natives registries.
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992-2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992-2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005, based on the November 2004 submission.
[2]Statistics for Hispanics and Non-Hispanics do not include cases from Connecticut, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, and Vermont
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992-2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992-2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005, based on the November 2004 submission.

Early detection of breast cancer can save lives and increases treatment options.[101] "The United States Preventive Services Task Force (USPSTF) recommends screening mammography, with or without clinical breast examination (CBE), every 1–2 years for women aged 40 and older. The USPSTF also concludes that the evidence is insufficient to recommend for or against either routine CBE alone or teaching or performing routine breast self-examination (BSE) to screen for breast cancer."[102] According to the National Cancer Institute, "screening by mammography, clinical breast examination, or both may decrease breast cancer mortality."[103]

The Guide to Community Preventive Services has outlined effective, evidence-based interventions to promote breast cancer screening. Recommended interventions consist of multi-component interventions using media, education, and enhanced access; client reminders; small media; removal of structural barriers (such as lack of insurance, or inaccessible facilities); reduction of out-of-pocket expenses; and incentives with client reminders (early detection table 2, next page).

**Early Detection Table 2. Interventions to Promote Breast Cancer Screening**

| Strategies | Level of Evidence |
|---|---|
| 1. Multi-component intervention using media, education, and enhanced access | Recommended (strong evidence) |
| 2. Client reminders | Recommended (strong evidence) |
| 3. Small media | Recommended (strong evidence) |
| 4. Removal of structural barriers | Recommended (sufficient evidence) |
| 5. Reduction of out-of-pocket expenses | Recommended (sufficient evidence) |
| 6. Incentives with client reminders | Recommended (sufficient evidence) |
| 7. Incentives alone | Insufficient evidence to determine effectiveness |
| 8. Group education | Insufficient evidence to determine effectiveness |
| 9. One-on-one education | Insufficient evidence to determine effectiveness |
| 10. Mass media alone | Insufficient evidence to determine effectiveness |

Adapted from "Improving the Use of Breast, Cervical and Colorectal Cancer Screening," *Guide to Community Preventive Services* (updated September 22, 2004); available from http://www.thecommunityguide.org/cancer/screening/default.htm.

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) supports the development of state-level systems to assure breast and cervical cancer screening for underinsured and uninsured women. In addition, the Breast and Cervical Cancer Prevention and Treatment Act of 2000 was signed into law on October 24, 2000. The law authorizes states to provide full Medicaid benefits to uninsured women who are screened and/or diagnosed with breast and/or cervical cancer through a state's breast and cervical cancer screening program.[104]

## Breast Cancer in Massachusetts

In Massachusetts, White non-Hispanic and Black non-Hispanic women have the highest incidence and mortality rates for breast cancer compared to Asian non-Hispanic and Hispanic women (early detection table 3).

**Early Detection Table 3. Breast Cancer (Female) Incidence and Mortality Rates* by Race and Ethnicity, MA, 1998-2002**

| | White non-Hispanic | Black non-Hispanic | Asian non-Hispanic | Hispanic |
|---|---|---|---|---|
| **Incidence** | 146.7 (144.8–148.5) | 116.3 (107.9–124.6) | 69.6 (61.1–78.2) | 90.1 (81.6–98.5) |
| **Mortality** | 27.7 (26.9–28.5) | 31.0 (26.6–35.4) | 15.3 (10.9–19.7) | 13.8 (10.5–17.2) |

* Per 100,000, age-adjusted to the U.S. standard population. Race/ethnicity categories are mutually exclusive.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report.* Boston, MA: 2005.

According to the most recent report of the Massachusetts Behavioral Risk Factor Surveillance System, "among women ages 40 years and older, 85% reported having had a mammogram in the past two years. The percentage of women reporting a mammogram increased with increasing age until age 79 years and then decreased. Black non-Hispanic women (90%) were more likely to have had a mammogram in the past two years than White non-Hispanic (85%), Hispanic (84%) or Asian (87%) women. Reports of having had a mammogram in the past two years increased with both increasing education and income. The trend in the percentage of women ages 40 years and older who report having a mammogram in the past 2 years has increased since 1992."[105]

"Over the past decade, programs such as the Women's Health Network (co funded by MDPH and the CDC's National Breast and Cervical Cancer Early Detection Program) have facilitated screening for uninsured and underinsured women who are disproportionately women

of color. Such programs may be successful in narrowing disparities in the future. Also, screening saves lives only when linked to timely diagnosis and treatment. The Boston REACH 2010 Breast and Cervical Cancer Coalition recently found that of African-American women enrolled in its breast cancer screening follow-up study, only 64% of those with abnormal screening results received timely and adequate follow-up."[106]

Between September 1993 and November 2004, the Women's Health Network (WHN) enrolled and screened more than 77,000 women and diagnosed 919 in situ/invasive breast cancers and 302 atypia breast disorders. In FY 2004 the WHN served 11,001 clients, 8,000 of whom received mammograms. Of the Women's Health Network clients in 2004, 55.9 percent were identified as White non-Hispanic, 31.5 percent as Hispanic, 8.5 percent Black non-Hispanic, 2.1 percent Asian non-Hispanic, and 1.7 percent other. In terms of client age in 2004, 43 percent of clients were between 50 and 64, 40 percent were between 40 and 49, 14 percent were under 40, and 3 percent were 65 and older.[107]

The Massachusetts Cancer Registry (MCR) recently assessed social disparities in breast cancer diagnosis and treatment by comparing the stage at diagnosis and the treatment patterns of women diagnosed with breast cancer through the Women's Health Network to Massachusetts breast cancer patients diagnosed elsewhere. The MCR concluded that women diagnosed with breast cancer through the Women's Health Network had similar stage and treatment patterns as other breast cancer patients in Massachusetts, with the exception that the women enrolled in the WHN were less likely to receive radiation therapy, particularly after partial mastectomy.[108]

**Highlights of Activities**

Massachusetts has accomplished a great deal in improving access to and use of breast cancer screening services by women across the state. Much of the success can be attributed to the Women's Health Network (WHN) at the Massachusetts Department of Public Health (MDPH). The WHN provides breast and cervical cancer screening for low-income, underserved, uninsured women with special emphasis on reaching those who are geographically or culturally isolated, older, or members of racial/ethnic minorities. There are 29 medical service sites statewide. These sites also subcontract with mammography facilities. The Women's Health Network provides such services as surveillance, partnership development, screening, referral and follow-up, quality assurance, public and provider education, and outreach and evaluation. WHN staff includes community outreach specialists who work in conjunction with regional coalitions, community groups, and other Massachusetts Department of Public Health programs. Their goal is to improve statewide outreach and education on breast cancer, cervical cancer, and cardiovascular disease and to identify underserved women who may be eligible to receive WHN screening services.

A task force and an expert panel are evaluating the Women's Health Network. One of the goals of this evaluation is the restructuring of the WHN to provide wider access to screening services.

In January 2004, the WHN began administering the Massachusetts Breast and Cervical Cancer Treatment Program (MBCCTP). The program builds on existing screening services by providing MassHealth Standard (Medicaid) medical care coverage for eligible women throughout their cancer treatment. From January 1, 2004, through June 1, 2004, 161 clients were enrolled in the MBCCTP. The WHN also expanded its outreach to underserved communities

through its collaboration with the MDPH Division for Special Health Needs and its publication of *A Directory of Accessible Mammography Sites.*[109]

The American Cancer Society is also engaged in efforts to improve breast cancer screening rates in the Commonwealth. Current ACS outreach programs include a pilot project with WHN, an effort to target Latina and African American women through a grant from Bay State Medical Center in Springfield.

Another active group in Massachusetts is Boston's REACH (Racial and Ethnic Approach to Community Health) 2010 Coalition, a grassroots effort led by women who want to eliminate inequalities in health care and to provide greater access to better care. REACH 2010 Coalition seeks to create a culturally competent system that promotes screening, education, prevention, treatment, and access to care for Black women and women of African descent in Boston. REACH 2010 connects, empowers, supports, and helps women and their families understand and manage personal health care issues, particularly breast and cervical cancer.[110]

**Highlights of Gaps, Issues, Barriers, and Concerns**

In Massachusetts a number of issues affect residents' access to mammography and prevention services. Geography can be a major barrier, with limited service availability and long drives for residents living in certain parts of the state. Also at issue are the decline in WHN sites and a decrease in mobile mammography statewide. These barriers may particularly affect those in lower socioeconomic levels or with less education, and are reflected in BRFSS statistics for the state. Other issues include inaccessibility to some mammography sites by women with disabilities and the inability of WHN to manage wait times at contracted sites.

## Goal: Reduce the mortality rate of all women from breast cancer.

**Outcome Measure 25: By 2011, increase the percentage of women ages 40+ who have had a mammogram in the previous two years to 90 percent.** (
Healthy People 2010: 70% mammogram in preceding 2 years (women 40+)
Baseline All: 85% Database: BRFSS 2003

| | | | |
|---|---|---|---|
| White non-Hispanic | 85% | Asian non-Hispanic | 86% |
| Black non-Hispanic | 92% | Less than high school diploma | 77% |
| Hispanic | 81% | Less than $25,000 household income | 74% |

(Regional percentages are similar)

**Outcome Measure 26: By 2011, decrease the proportion of White non-Hispanic and Black non-Hispanic women diagnosed with late stage (regional and distant) breast cancer to 35 per 100,000.**
Baseline: late diagnosis: 45.7 White non-Hispanic and 45.7 Black non-Hispanic
Database: MCR 1998–2002

| | |
|---|---|
| White non-Hispanic | 45.7 per 100,000 (44.6–46.8) |
| Black non-Hispanic | 45.4 per 100,000 (40.3–50.6) |
| Asian non-Hispanic | 25.1 per 100,000 (20.1–30.1) |
| Hispanic | 30.9 per 100,000 (26.3–35.6) |

**Strategies Selected by Work Group**

The work group based the following strategies on early detection table 2:

- Continue to promote and advocate for early detection health insurance coverage for all women, monitoring and reducing health disparities.
- Protect and support the statewide Women's Health Network Breast and Cervical Health Programs.
- Support restructuring of the Women's Health Network to provide for increased access to screening.
- Support increased state funding for screening and treatment.
- Ensure that screening mammography is available and accessible throughout the state.
- Encourage provider-based reminder, follow-up, and case management systems.
- Introduce combined mass- and small-media campaigns along with other communication strategies to remind and educate women about the importance of early detection.
- Encourage partnering with other programs so women can take care of many health needs simultaneously.
- Ensure that women with disabilities have access to information and early detection services.

# Cervical Cancer

The American Cancer Society's *Cancer Facts and Figures 2005* estimated that 10,370 cases of invasive cervical cancer would be diagnosed in America during 2005. An estimated 3,710 women were expected to die from cervical cancer in 2005.[111] Since most cervical pre-cancers develop slowly, nearly all cases of cervical cancer can be prevented through regular screening.[112]

**Early Detection Table 4. Cervical Cancer Incidence[1] and Mortality Rates*[2] by Race and Ethnicity, U.S., 1998-2002**

| | White | African American | Asian American and Pacific Islander | American Indian and Alaska Native | Hispanic/Latino |
|---|---|---|---|---|---|
| **Incidence** | 8.7 (8.5-9.0) | 11.1 (10.5-11.8) | 8.9 (8.3-9.5) | 4.9 (3.7-6.5) | 15.8 (15.1-16.6) |
| **Mortality** | 2.5 (2.4-2.5) | 5.3 (5.1-5.5) | 2.7 (2.5-2.9) | 2.6 (2.2-3.1) | 3.5 (3.3-3.7) |

*Per 100,000, age-adjusted to the 2000 U.S. standard population. Hispanics and non-Hispanics are not mutually exclusive from whites, African Americans, Asian or Pacific Islanders, and American Indians and Alaska Natives.
[1]Statistics for Hispanics and Non-Hispanics do not include cases from the Detroit, Hawaii, Rural Georgia, and Alaska Natives registries.
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992-2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992-2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005, based on the November 2004 submission.
[2]Statistics for Hispanics and Non-Hispanics do not include cases from Connecticut, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, and Vermont
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992-2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992-2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

The United States Preventive Services Task Force (USPSTF) strongly recommends screening for cervical cancer in women who have been sexually active and have a cervix. It recommends against routinely screening women older than age 65 for cervical cancer if they have had adequate recent screening with normal Pap smears and are not otherwise at high risk for cervical cancer. The Task Force also recommends against routine Pap smear screening in women who have had a total hysterectomy for benign disease. The USPSTF concludes that the evidence is insufficient to recommend for or against the routine use of new technologies to screen for cervical cancer or the routine use of human papillomavirus (HPV) testing as a primary screening test for cervical cancer.[113] According to the National Cancer Institute, "regular screening of appropriate women for cervical cancer with the Papanicolaou (Pap) test reduces mortality from cervical cancer. Screening is effective when started within 3 years after beginning vaginal intercourse and becomes much less effective in women ages 65 years and older who have recent negative Pap tests."[114]

The *Guide to Community Preventive Services* outlines effective, evidence-based interventions to promote cervical cancer screening. The two recommended interventions consist of multi-component interventions using media, education, and enhanced access, and client reminders (early detection table 5, next page).

**Early Detection Table 5. Interventions to Promote Cervical Cancer Screening**

| Strategies | Level of Evidence |
|---|---|
| 1. Multi-component interventions using media, education, and enhanced access | Recommended (strong evidence) |
| 2. Client reminders | Recommended (strong evidence) |
| 3. Small media | Insufficient evidence to determine effectiveness |
| 4. Removal of structural barriers | Insufficient evidence to determine effectiveness |
| 5. Reducing out-of-pocket expenses | Insufficient evidence to determine effectiveness |
| 6. Incentives with client reminders | Insufficient evidence to determine effectiveness |
| 7. Incentives alone | Insufficient evidence to determine effectiveness |
| 8. Group education | Insufficient evidence to determine effectiveness |
| 9. One-on-one education | Insufficient evidence to determine effectiveness |
| 10. Mass media alone | Insufficient evidence to determine effectiveness |

Adapted from "Improving the Use of Breast, Cervical and Colorectal Cancer Screening," *Guide to Community Preventive Services* (updated September 22, 2004); available from http://www.thecommunityguide.org/cancer/screening/default.htm.

The National Breast and Cervical Cancer Detection Program (NBCCEDP) supports the development of state-level systems to assure breast and cervical cancer screening for underinsured and uninsured women. In addition, the Breast and Cervical Cancer Prevention and Treatment Act of 2000 was signed into law on October 24, 2000. The law authorizes states to provide full Medicaid benefits to uninsured women who are screened and/or diagnosed with breast and/or cervical cancer through a state's breast and cervical cancer screening program.

## Cervical Cancer in Massachusetts

In Massachusetts, Hispanic and Black non-Hispanic women have the highest incidence rates for cervical cancer, followed by Asian non-Hispanic and White non-Hispanic women. Black non-Hispanic women also have the highest mortality rates for cervical cancer (early detection table 6).

**Early Detection Table 6. Cervical Cancer Incidence and Mortality Rates* by Race and Ethnicity, MA, 1998–2002**

| | White non-Hispanic | Black non-Hispanic | Asian non-Hispanic | Hispanic |
|---|---|---|---|---|
| **Incidence** | 6.2 (5.8–6.6) | 13.5 (10.7–16.2) | 8.9 (5.8–12.1) | 16.4 (12.9–19.8) |
| **Mortality** | 1.8 (1.5–2.0) | 4.5 (2.8–6.1) | † | † |

*Per 100,000, age-adjusted to the U.S. standard population. Race/ethnicity categories are mutually exclusive.
†Age-adjusted incidence rate not calculated when number of cases or deaths is less than 20.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health, *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report* (Boston, MA: 2005).

According to the most recent report of the Massachusetts Behavioral Risk Factor Surveillance System, "88% of Massachusetts women reported having had a pap smear in the past 3 years. The percent of women having had a pap smear in the past 3 years was lowest in the youngest (18–24) and oldest (75+) age groups. Asian women were less likely to have had a pap smear in the past 3 years than women in other race-ethnicity groups. The percentage of women having had a pap smear in the past 3 years improved with increasing education and income. Since 1997, the trend in the percentage of women reporting that they had a pap smear in the past 3 years has remained relatively stable."[115]

Between September 1993 and November 2004, WHN enrolled and screened more than 77,000 women and diagnosed 1,396 cervical disorders and 258 in situ/invasive cervical cancers. In FY 2004, the Women's Health Network served 11,001 clients, 6,000 of whom received Pap

tests. Of the Women's Health Network clients in 2004, 55.9 percent identified themselves as White non-Hispanic, 31.5 percent Hispanic, 8.5 percent Black non-Hispanic, 2.1 percent Asian non-Hispanic, and 1.7 percent other. In terms of client age in 2004, 43 percent were between 50 and 64, 40 percent were between 40 and 49, 14 percent were under 40, and 3 percent were 65 and older.[116]

**Highlights of Activities**

Massachusetts has achieved a great deal concerning improved access to and use of cervical cancer screening services by women across the state. Much of the success can be attributed to the Women's Health Network (WHN) at the Massachusetts Department of Public Health (MDPH). The WHN provides breast and cervical cancer screening for low-income, underserved, uninsured women with special emphasis on reaching those who are geographically or culturally isolated, older, or members of racial/ethnic minorities. There are 29 medical service sites statewide. These sites also subcontract with mammography facilities. The Women's Health Network provides such services as surveillance, partnership development, screening, referral and follow-up, quality assurance, public and provider education, and outreach and evaluation. WHN staff includes community outreach specialists who work in conjunction with regional coalitions, community groups, and other Massachusetts Department of Public Health programs. Their goal is to improve statewide outreach and education on breast cancer, cervical cancer, and cardiovascular disease, and to identify underserved women who may be eligible to receive WHN screening services.

A task force and an expert panel are evaluating the Women's Health Network. One of the goals of this evaluation is the restructuring of the WHN to provide broader access to screening services.

In January 2004, the WHN began administering the Massachusetts Breast and Cervical Cancer Treatment Program (MBCCTP). The program builds on existing screening services by providing MassHealth Standard (Medicaid) medical care coverage for eligible women throughout their cancer treatment. From January 1, 2004, through June 1, 2004, 161 clients were enrolled in the MBCCTP.

The American Cancer Society is also engaged in efforts to improve cervical cancer screening rates in the Commonwealth. Current ACS outreach programs include a pilot project with WHN, an effort to target Latina and African American women through a grant from Bay State Medical Center in Springfield.

Another active group in Massachusetts is Boston's REACH (Racial and Ethnic Approach to Community Health) 2010 Coalition, a grassroots effort led by women who want to eliminate inequalities in health care and provide greater access to better care. REACH 2010 Coalition seeks to create a culturally competent system that promotes screening, education, prevention, treatment, and access to care for Black women and women of African descent in Boston. REACH 2010 connects, empowers, and supports women and their families and helps them understand and manage personal health care issues, particularly breast and cervical cancer.117

In June 2004 the state legislature mandated the formation of a Special Legislative Commission Relative to Eliminating Cervical Cancer in the Commonwealth. The duties of this commission consist of "undertaking a statistical and qualitative examination of the prevalence

and burden of cervical cancer; raising public awareness on the causes and capture of cervical cancer, personal risk factors, value of prevention, early detection, option for testing, treatment costs, new technology, medical care reimbursement, and physician education; identifying priority strategies, new technologies, or newly introduced vaccines which are effective in preventing and controlling the risk of cervical cancer; and identifying and examining the limitations of existing laws, regulations, programs and services with regard to coverage and awareness issues for cervical cancer. The Commission will also receive and consider reports and testimony from individuals, local health departments, community-based organizations, voluntary health organizations, and other public and private organizations statewide to learn more about contributions to cervical cancer diagnosis, prevention, and treatment and more about improving cervical cancer prevention, diagnosis, and treatment in the Commonwealth."118

**Highlights of Gaps, Issues, Barriers, and Concerns**

Notable disparities in screening for cervical cancer exist in Massachusetts. As mentioned above, the BRFSS results illustrate that the screening rates for cervical cancer are drastically lower among Asian non-Hispanic women compared to other racial and ethnic groups. Screening rates are also lowest among Massachusetts' youngest (18–24) and oldest (75+) women. There is a slight disparity in screening rates across the six regions of Massachusetts, with Central Massachusetts having the lowest screening rates.[119]

National data highlight that Vietnamese women have the highest cervical cancer rates in the nation (43 per 100,000).[120] According to U.S. Census Data from 2000, Massachusetts has the fifth highest Vietnamese population in the country with nearly 34,000 Vietnamese men and women living in the Commonwealth.[121] .

## Goal: Reduce the mortality rate of all women from invasive cervical cancer.

**Outcome Measure 27: By 2011, increase the percentage of women ages 18–69 with an intact cervix who report having had a Pap test in the previous three years to 90 percent.**
Healthy People 2010: 90%, Pap test within the last three years
Baseline All: 88.2% Database: BRFSS 2002

| | | | |
|---|---|---|---|
| White non-Hispanic | 89.4% | Hispanic | 87.0% |
| Black non-Hispanic | 84.8% | Asian non-Hispanic | 66.5% |

| | | | |
|---|---|---|---|
| Boston | 86.7% | Northeast | 90.0% |
| Central | 85.6% | Southeast | 87.9% |
| Metrowest | 88.7% | Western | 89.0% |

**Outcome Measure 28: By 2011, decrease the proportion of Black non-Hispanic women diagnosed with late stage (regional and distant) cervical cancer to 2 per 100,000.**
Baseline late diagnosis (regional + distant): 7.1 Database: MCR 1998-2002

| | |
|---|---|
| White non-Hispanic | 2.4 per 100,000 (2.1–2.6) |
| Black non-Hispanic | 2.4 per 100,000 (2.1–2.6) |
| Asian non-Hispanic | too few cases to calculate age-adjusted incidence rate |
| Hispanic | 5.2 per 100,000 (3.3–7.1) |

**Strategies Selected by Work Group**

The work group based the following strategies on early detection table 5:

- Promote programs that increase access to cervical cancer screening with follow-up and case management reminder systems for all women and targeting health disparities in particular.
- Provide professional education regarding screening guidelines for women age 65 and older.
- Use small-media interventions that match the unique needs of each region.
- Encourage partnering with other programs so women can take care of many health needs simultaneously.

# Colorectal Cancer

The American Cancer Society's *Colorectal Cancer Facts and Figures 2005* estimated that in 2005, 145,290 people in the United States would be diagnosed with colorectal cancer and 56,290 people would die of colorectal cancer. Combined, cancers of the colon and rectum are the third most common type of cancer and the second most common cause of cancer death in the United States. In males, colorectal cancer accounts for 10 percent of estimated new cases of cancer and 10 percent of estimated cancer deaths. In females, colorectal cancer accounts for 11 percent of estimated new cases of cancer respectively and 10 percent of estimated cancer deaths.[122]

**Early Detection Table 7. Colorectal Cancer Incidence[1] and Mortality Rates*[2] by Race and Ethnicity, U.S., 1998-2002**

| | White | African American | Asian American and Pacific Islander | American Indian and Alaska Native | Hispanic/Latino |
|---|---|---|---|---|---|
| **Incidence (Males)** | 61.7 (61.0–62.3) | 72.5 (70.2–74.8) | 56.0 (54.3–57.7) | 36.7 (31.9–42.0) | 48.3 (46.5–50.1) |
| **Incidence (Females)** | 45.3 (44.9–45.8) | 56.0 (54.4–57.6) | 39.7 (38.4–40.9) | 32.2 (28.4–36.4) | 32.3 (31.1–33.6) |
| **Mortality (Males)** | 24.3 (24.1–24.4) | 34.0 (33.4–34.5) | 15.8 (15.1–16.5) | 16.2 (14.7–17.9) | 17.7 (17.2–18.2) |
| **Mortality (Females)** | 16.8 (16.7–16.9) | 24.1 (23.7–24.4) | 10.6 (10.2–11.1) | 11.8 (10.7–13.0) | 11.6 (11.1–11.9) |

*Per 100,000, age-adjusted to the 2000 U.S. standard population. Hispanics and non-Hispanics are not mutually exclusive from whites, African Americans, Asian or Pacific Islanders, and American Indians and Alaska Natives.
[1]Statistics for Hispanics and Non-Hispanics do not include cases from the Detroit, Hawaii, Rural Georgia, and Alaska Natives registries.
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992-2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992-2002), National Cancer Institute, DCCPS,
Surveillance Research Program, Cancer Statistics Branch, released April 2005, based on the November 2004 submission.
[2]Statistics for Hispanics and Non-Hispanics do not include cases from Connecticut, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, and Vermont
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992-2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992-2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

In the United States, less than 50 percent of adults 50 or older have been screened for colorectal cancer as recommended by the American Cancer Society, United States Preventive Services Task Force, the GI Consortium, and other health organizations. Screening for colorectal cancer can actually prevent colorectal cancer through the detection and removal of precancerous polyps before they have the opportunity to develop into cancer. Screening can also detect colorectal cancer at an earlier stage when it is more treatable.

"The United States Preventive Services Task Force (USPSTF) strongly recommends that clinicians screen men and women 50 years of age or older for colorectal cancer. The USPSTF found good evidence that periodic fecal occult blood testing (FOBT) reduced mortality from colorectal cancer and fair evidence that sigmoidoscopy alone or in combination with FOBT reduces mortality. The USPSTF did not find direct evidence that screening colonoscopy is effective in reducing colorectal cancer mortality; efficacy of colonoscopy is supported by its integral role in trials of FOBT, extrapolation from sigmoidoscopy studies, limited case-control evidence, and the ability of colonoscopy to inspect the proximal colon. Double-contrast barium enema offers an alternative means of whole-bowel examination, but is less sensitive than colonoscopy, and there is no direct evidence that it is effective in reducing mortality rates. The

USPSTF found insufficient evidence that newer screening technologies (for example, computed tomographic colography) are effective in improving health outcomes. There are insufficient data to determine which strategy is best in terms of the balance of benefits and potential harms or cost-effectiveness. Studies reviewed by the USPSTF indicate that colorectal cancer screening is likely to be cost-effective (less than $30,000 per additional year of life gained) regardless of the strategy chosen."[123] According to the National Cancer Institute, "Guaiac-based fecal occult blood testing either annually or biennially using rehydrated or nonrehydrated stool specimens in people aged 50 to 80 decreases mortality from colorectal cancer and regular screening by sigmoidoscopy in people older than 50 years may decrease mortality from colorectal cancer."[124]

The *Guide to Community Preventive Services* outlines effective, evidence-based interventions to promote colorectal cancer screening. Recommended interventions consist of removal of structural barriers and client reminders (early detection table 8).

**Early Detection Table 8. Interventions to Promote Colorectal Cancer Screening**

| Strategies | Level of Evidence |
|---|---|
| 1. Removal of structural barriers | Recommended (strong evidence) |
| 2. Client reminders | Recommended (sufficient evidence) |
| 3. Multi-component interventions using media, education, and enhanced access | Insufficient evidence to determine effectiveness |
| 4. Small media | Insufficient evidence to determine effectiveness |
| 5. Reducing out-of-pocket expenses | Insufficient evidence to determine effectiveness |
| 6. Incentives with client reminders | Insufficient evidence to determine effectiveness |
| 7. Incentives alone | Insufficient evidence to determine effectiveness |
| 8. Group education | Insufficient evidence to determine effectiveness |
| 9. One-on-one education | Insufficient evidence to determine effectiveness |
| 10. Mass media alone | Insufficient evidence to determine effectiveness |

Adapted from "Improving the Use of Breast, Cervical and Colorectal Cancer Screening." *Guide to Community Preventive Services* (updated September 22, 2004). Available from http://www.thecommunityguide.org/cancer/screening/default.htm.

Medicare began covering colorectal cancer screening tests on January 1, 1998, as a result of the Balanced Budget Act of 1997. The Screen for Life media campaign was developed shortly after as a joint effort by The Centers for Medicare & Medicaid Services (CMS) and the Centers for Disease Control and Prevention (CDC) with technical support from the National Cancer Institute. The multimedia campaign had three goals: (1) to inform men and women 50 and older of the importance of having regular CRC screening tests; (2) to motivate the target audience to talk with their health care practitioners about establishing a colorectal screening program; and (3) to promote Medicare's CRC screening benefits. The Screen for Life campaign is repeated each year.[125]

The American Cancer Society has launched a nationwide colorectal cancer awareness campaign for 2005. The campaign has two objectives. The first objective, targeted to men and women age 50 and older, with an emphasis on women, is to raise awareness of the personal need to get tested for colon cancer. The second objective, for health care providers (including those in primary care, internal medicine, family practice, and OB/GYN), is to increase emphasis on the importance of colon cancer testing among patients 50 and older. The campaign includes paid advertising, earned media (public relations), and interactive/online outreach. It will be evaluated using the results of a baseline study to track colon cancer awareness that will be conducted before the campaign starts and two follow-up studies to be conducted after it ends.[126]

The Cancer Research and Prevention Foundation (CRPF) founded the National Colorectal Cancer Awareness Month (NCRCAM) campaign in 2000. The campaign has grown to include 54 collaborating partners. CRPF has also hosted eight annual National Dialogues for Action on Colorectal Cancer and has recently begun to provide technical assistance to states that choose to host state-level Dialogues for Action on colorectal cancer.[127]

## Colorectal Cancer in Massachusetts

In Massachusetts, men have higher incidence of and mortality rates for colorectal cancer compared to women. White non-Hispanic and Black non-Hispanic men have the highest incidence and mortality rates for colorectal cancer compared to Asian non-Hispanic and Hispanic men. White non-Hispanic women and Black non-Hispanic women have higher incidence and mortality rates for colorectal cancer compared to Asian non-Hispanic and Hispanic women (early detection table 9).

**Early Detection Table 9. Colorectal Cancer Incidence and Mortality Rates* by Race and Ethnicity, MA, 1998–2002**

| | White non-Hispanic | Black non-Hispanic | Asian non-Hispanic | Hispanic |
|---|---|---|---|---|
| **Incidence (Males)** | 72.5 (71.0–74.0) | 67.1 (59.0–75.3) | 47.0 (37.9–56.1) | 51.6 (43.1–60.1) |
| **Incidence (Females)** | 51.0 (49.9–52.0) | 49.7 (44.0–55.4) | 39.9 (32.4–47.5) | 35.2 (29.5–40.9) |
| **Mortality (males)** | 28.2 (27.3–29.2) | 37.0 (30.6–43.5) | 11.2 (6.7–15.8) | 13.3 (8.7–18.0) |
| **Mortality (females)** | 18.7 (18.0–19.3) | 24.4 (20.3–28.5) | 13.8 (9.1–18.5) | 11.5 (8.0–14.9) |

*Per 100,000, age-adjusted to the U.S. standard population. Race/ethnicity categories are mutually exclusive.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report.* Boston, MA: 2005.

According to the most recent report of the Massachusetts Behavioral Risk Factor Surveillance System, approximately 67 percent of Massachusetts adults age 50 and older reported that they had a sigmoidoscopy/colonoscopy in the past five years or fecal occult blood test in the past two years. Reports of these tests were higher among males (71.5%) and adults 65 and older (74.6%) and lower among females (64.1%) and adults age 50 to 64 (60.9%). White non-Hispanic (68.0%) and Black non-Hispanic (63.9%) adults were more likely than Hispanic adults (48.9%) were to report a sigmoidoscopy/colonoscopy or fecal occult blood test. Adults with an annual household income between $35,000 and $49,999 (64.2%) and above $75,000 (64.8%) were least likely to have had a sigmoidoscopy/colonoscopy or a fecal occult blood test. Adults from the Metro West region (70.9%), Boston (70.0%), and the South East region (69.2%) were more likely to report these tests than adults in the Central (66.7%), North East (65.1%) and Western (62.0%) regions.[128]

## Highlights of Activities

Massachusetts has many accomplishments related to improving colorectal cancer screening rates across the state. Much of that success can be attributed to the Massachusetts Colorectal Cancer Working Group, a statewide coalition of individuals and organizations that was established in 1997 to reduce the incidence, morbidity, and mortality of colorectal cancer. The Massachusetts Colorectal Cancer Working Group (the Working Group) focuses on education, prevention, early detection, advocacy, policy, and research.

The Working Group's public education efforts have included colorectal cancer community outreach projects in Worcester, Berkshire, and Barnstable counties, as well as in the City of Springfield. A media campaign, "If You Remember the First Color TV, Get Tested for Colorectal Cancer," was conducted as part of the Berkshire County community outreach project, and the resulting print products continue to be distributed statewide. In addition, two brochures, *You Can Prevent Colorectal Cancer* and *Take Control: Get Tested for Colorectal Cancer,* have been produced on behalf of the Working Group through a collaboration between Harvard Center for Cancer Prevention and the Massachusetts Department of Public Health. These brochures are available in the languages most commonly spoken in Massachusetts, including English, Chinese, French, Spanish, Portuguese, Vietnamese, Russian, and Khmer. The Massachusetts Department of Public Health has also participated in local tagging of CDC's annual "Screen for Life" television public service announcements.

Professional education efforts by the Working Group and its member organizations have included several print and online publications. These include the following:

- The Working Group's production and distribution of Colorectal Cancer: A Risk Management Guide for Health Care Professionals
- The Risk Management Foundation's production and distribution of the *RMF Colorectal Cancer Screening Algorithm: A Decision Support Tool for Primary Care Providers*
- Harvard Center for Cancer Prevention and the American Cancer Society's launch of the online manual *Tools and Strategies to Increase Colorectal Cancer Screening Rates: A Practical Guide for Health Insurance Plans*
- Harvard Center for Cancer Prevention and the Massachusetts Cancer Registry's release of a *Data Report on Colorectal Cancer in Massachusetts*

The *Data Report* was sent to approximately 7,000 primary care providers and gastroenterologists in Massachusetts through collaboration with the Dana-Farber Cancer Institute and Massachusetts Colorectal Cancer Working Group.

The Working Group has also developed a slide set aimed at primary care providers. Most recently the Working Group, with an unrestricted educational grant from EXACT Sciences Corporation, used this slide set to conduct a breakfast symposium Continuing Medical Education (CME) event, "Enhancing Colorectal Cancer Screening in the Primary Care Setting," at the Pri-Med East Conference and Exhibition in Boston.

In terms of research, Harvard Center for Cancer Prevention received a Targeted Intervention Opportunity Grant (TIOG) from the American Cancer Society. The results of the research conducted with this grant, "Improving Colorectal Cancer Screening by Targeting Office Systems in Primary Care Practices: Disseminating Research Results Into Clinical Practice," were recently published in the *Archives of Internal Medicine*.[129]

Massachusetts' capacity to screen the over-50 population using flexible sigmoidoscopy or colonoscopy was assessed as part of CDC's National/State Study of the Capacity for Colorectal Cancer Screening and Follow-up Tests. Information about the study and the state-level survey of endoscopic capacity sites (SECAP) is available at www.cdc.gov/cancer/colorctl/secap.htm.

The Massachusetts Colorectal Cancer Working Group has formed a planning committee for a state-level Dialogue for Action conference on colorectal cancer in 2006. The state Dialogue for Action conferences are based on the national model developed by the Cancer Research and Prevention Foundation and are designed to help states move their comprehensive cancer control plans forward. Information is available at www.preventcancer.org/Programs/dialogue_state.cfm.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Massachusetts faces a challenge in its efforts to increase colorectal cancer screening rates. Approximately 67 percent of the asymptomatic, average-risk Massachusetts population, men and women age 50 and older, has been screened for colorectal cancer as recommended by existing guidelines.[130] According to the results of an American Cancer Society Awareness survey conducted in Massachusetts in 2001, "continuing to build awareness of the importance of screening for colorectal cancer may be valuable. Just half (50%) of those who had heard of colorectal cancer thought it was extremely important that they themselves be tested."[131]

Removal of structural barriers is a key step to increasing the rate of colorectal screening. As noted earlier in the Prevention section of this document, many residents of Massachusetts are without health insurance or have minimal insurance plans that do not cover colorectal screening. Increasing the rate of health insurance coverage for colorectal screening would decrease the incidence rate of colorectal cancer and ultimately save lives. Another structural barrier identified among the rural regions of the state is transportation. Many regions do not have public transportation or even taxi services. Individuals opting for colonoscopy cannot drive to and from their appointments. A strategy that addresses this barrier would increase colorectal cancer screening rates.

Improving colorectal cancer screening rates by increasing doctor recommendations is a strategy that has been supported by recent research. A medical record review of 145 primary care providers in Massachusetts, New Hampshire, and Connecticut, conducted through an American Cancer Society Targeted Intervention Opportunity Grant (TIOG), "suggested that clinicians give CRC screening recommendations to approximately 40% of their asymptomatic average-risk patients 50 years or older. Clinicians potentially miss opportunities to provide screening recommendations because of their perception of efficacy." These same primary care providers were supplied with patient education methods, CRC screening guidelines, and simple tools to track and monitor patient compliance, the results of which illustrated that simple office interventions are feasible in the real world and can help clinicians increase colorectal cancer screening rates.[132]

The state budget line item for the Massachusetts Colorectal Cancer Awareness Program was eliminated in Fiscal Year 2003.

## Goal: Reduce the mortality rate from colorectal cancer.

**Outcome Measure 29: By 2011, increase the percentage of adults ages 50+ who have had FOBT or endoscopy to 85 percent.**
Healthy People 2010: 50% colorectal screening 50+
Baseline All: 67.4% Database: BRFSS 2003

| | | | |
|---|---|---|---|
| Females: | 64.1% | Males: | 71.5% |

| | | | |
|---|---|---|---|
| White non-Hispanic | 68.0% | Asian non-Hispanic | no data |
| Black non-Hispanic | 63.9% | Hispanic | 48.9% |

| | | | |
|---|---|---|---|
| Boston | 70.0% | Northeast | 65.1% |
| Central | 66.7% | Southeast | 69.2% |
| Metrowest | 70.9% | Western | 62.0% |

**Outcome Measure 30**: **By 2011, decrease the proportion of White non-Hispanic and Black non-Hispanic men and women diagnosed with late stage (regional and distant) colorectal cancer to 25 per 100,000.**
Baseline late diagnosis: men and women as listed below Database: MCR 1998–2002

| | |
|---|---|
| White non-Hispanic males | 41.6 per 100,000 |
| White non-Hispanic females | 30.4 per 100,000 |
| Black non-Hispanic males | 42.3 per 100,000 |
| Black non-Hispanic female | 30.1 per 100,000 |

**Strategies to Achieve the Goal**

The work group based the following strategies on early detection table 8:

- Remove structural barriers such as health insurance coverage and lack of transportation.
- Devise, test, implement, and evaluate a mass- and small-media campaign for colorectal early detection cancer screening.
- Provide education that will enable the general public and providers to understand the current early detection options and where to get the appropriate screening.
- Encourage providers to establish case management and patient reminder systems.
- Help private groups and associations communicate with their constituency about the vital importance of colorectal cancer early detection.
- Work with community health clinics to introduce a system for ensuring early detection screenings, case management, and patient reminders systems.
- Encourage advocacy efforts specifically for colorectal cancer.

# Prostate Cancer

The American Cancer Society's *Cancer Facts and Figures* estimated that 232,090 new cases of prostate cancer would occur among men in the United States during 2005. An estimated 30,350 men were expected to die from prostate cancer in 2005. Prostate cancer is the second most common cause of cancer death in men in the United States. Prostate cancer accounts for 33 percent of estimated new cases of cancer in males and 10 percent of estimated cancer deaths in males.[133]

**Early Detection Table 10. Prostate Cancer Incidence[1] and Mortality Rates*[2] by Race and Ethnicity, U.S., 1998–2002**

| | White | African American | Asian American and Pacific Islander | American Indian and Alaska Native | Hispanic/Latino |
|---|---|---|---|---|---|
| **Incidence** | 169.0 (167.9–170.0) | 272.0 (267.7–276.4) | 101.4 (99.1–103.7) | 50.3 (44.7–56.6) | 141.9 (138.9–144.9) |
| **Mortality** | 27.7 (27.6–27.9) | 68.1 (67.3–69.0) | 12.1 (11.5–12.8) | 18.3 (16.5–20.4) | 23.0 (22.3–23.6) |

*Per 100,000, age-adjusted to the 2000 U.S. standard population. Hispanics and non-Hispanics are not mutually exclusive from whites, African Americans, Asian or Pacific Islanders, and American Indians and Alaska Natives.
[1]Statistics for Hispanics and Non-Hispanics do not include cases from the Detroit, Hawaii, Rural Georgia, and Alaska Natives registries.
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992-2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992-2002), National Cancer Institute, DCCPS,
Surveillance Research Program, Cancer Statistics Branch, released April 2005, based on the November 2004 submission.
[2]Statistics for Hispanics and Non-Hispanics do not include cases from Connecticut, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, and Vermont
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992-2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992-2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

The United States Preventive Services Task Force (USPSTF) found that there is insufficient evidence to recommend for or against routine screening for prostate cancer using prostate specific antigen (PSA) testing or digital rectal examination (DRE).[134] According to the National Cancer Institute, there is good evidence that screening with PSA and/or DRE detects some prostate cancers that never would have caused important clinical problems. This has led to overtreatment. The evidence reveals that current prostate cancer treatments, including radical prostatectomy and radiation therapy, can result in permanent side effects in many men. These side effects commonly include erectile dysfunction and urinary incontinence, both of which permanently affect the individual's quality of life.[135]

The Task Force on Community Preventive Services conducted a systematic review of the scientific literature regarding the effectiveness of population-based interventions that increase informed decision-making (IDM) for cancer screening. The review included prostate cancer risk assessment. The Task Force review found that these approaches can improve knowledge about screening tests and the risks and benefits associated with screening. However, there was insufficient evidence to show the extent to which these interventions (1) helped patients participate in decision making at the level they desire, (2) resulted in decisions that are consistent with patient values and preferences, or (3) improved actual screening rates to allow the Task Force to recommend them for implementation.[136] Peer education models showed effectiveness in other venues attempting to reach specific at-risk populations. This type of intervention may be applicable to reaching the male Black non-Hispanic population.

## Prostate Cancer in Massachusetts

In Massachusetts, incidence rates for prostate cancer are approximately twice as high in Black non-Hispanic men compared to White non-Hispanic men and Hispanic men and nearly four times higher than the rate in Asian non-Hispanic men. Mortality rates for prostate cancer are also twice as high in Black non-Hispanic men compared to White non-Hispanic men and three times as high compared to Hispanic men (early detection table 11).

**Early Detection Table 11. Prostate Cancer Incidence and Mortality Rates* by Race and Ethnicity, MA, 1998–2002**

| | White non-Hispanic | Black non-Hispanic | Asian non-Hispanic | Hispanic |
|---|---|---|---|---|
| **Incidence** | 179.9 (177.6–182.2) | 312.7 (295.4–330.0) | 78.4 (66.6–90.2) | 177.5 (162.1–192.9) |
| **Mortality** | 30.8 (29.8–31.9) | 60.0 (51.0–68.9) | † | 22.3 (15.8–28.8) |

*Per 100,000, age-adjusted to the U.S. standard population. Race/ethnicity categories are mutually exclusive.
† Age-adjusted incidence rate not calculated when number of cases or deaths is less than 20.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998-2002: Statewide Report.* Boston, MA: 2005.

## Highlights of Activities

The accomplishments by Massachusetts toward increasing awareness and reducing prostate cancer disparities can be attributed to the efforts of a number of committed state and non-profit organizations. The Men's Health Partnership (MHP), for example, is a state-funded and statewide program for the reduction of prostate cancer and heart disease. The program is available to uninsured and underinsured men across the state through local health centers and provides education, screening, counseling, and medical referrals. There are thirteen MHP sites statewide. Prostate cancer screenings are available to all underinsured and uninsured men who are age 50 and older, under- and uninsured African American men age 40 and older, and under- and uninsured men age 40 and older with a family history of prostate cancer. Massachusetts also has a network of 70 men's cancer support groups throughout the state. More than one-third of these groups is situated in portions of the state where individuals at higher risk for health disparities reside. Local MHP community-based clinics will partner with six of these groups to sponsor small educational forums in African American communities. Each clinic site is uniquely equipped to address the diverse cultural and social economic needs of the communities it serves. Each of the clinics has an outreach educator who will help market these forums.

The Foundation for Informed Medical Decision Making created a video, "Shared Decision Making: Treatment Choices for Prostate Cancer," to encourage patients to ask questions about prostate cancer treatment options and to encourage shared decision-making in their prostate cancer care. The Massachusetts Department of Public Health is involved in the testing and editing of this video and has conducted two focus groups in the regions of the state with a high population of the target group: Boston and Springfield. The focus groups confirmed that the video is an informative and appropriate tool for Black non-Hispanic men making decisions about their prostate cancer treatment. The focus groups also pointed out a few areas that could be improved. The Foundation will recommend changes that are supported by scientific evidence.

The video is distributed by Health Dialog Services Corporation and is provided to enrolled members of Blue Cross and Blue Shield. This membership includes a high percentage of Medicare beneficiaries in the target population: Black non-Hispanic men who are disabled or over the age of 65. The video is also available to patients of Dana-Farber Cancer Institute and the

Massachusetts General Hospital. This shared-decision-making video was used at the 2005 Prostate Cancer Symposium as the focus for a workshop led by a Black non-Hispanic survivor of prostate cancer and will also be made available to the two men's health clinics that participated in the focus groups. The video is currently being tested with family members of survivors to assess whether the video is an appropriate tool to use with family members as they support their loved ones through the difficult decision-making process.

The Massachusetts Prostate Cancer Coalition (MPCC) is a statewide, non-profit organization providing information and education on prostate cancer to newly diagnosed individuals, survivors, and their families, and health care professionals. The MPCC sponsors research on prostate cancer in collaboration with local hospitals and various health care providers and engages people across the Commonwealth in outreach to increase funding for prostate cancer education and research. The MPCC publishes a periodic online E-newsletter, *Conquer & Cure*, which provides current news, regional information, research, and Web-based resources about prostate cancer. In addition, for the past seven years the MPCC has organized an annual Prostate Cancer Symposium to increase understanding and knowledge of prostate cancer screening, treatment, and quality-of-life issues faced by survivors.[137]

The Prostate Health Education Network, Inc. (PHEN) is another non-profit organization founded by a local prostate cancer survivor. PHEN was established to increase prostate health education and awareness among men at high risk for prostate cancer. African American men and their families are a primary focus for PHEN.

PHEN initiatives include the following:

- Public events to heighten prostate health awareness
- Outreach efforts alerting men to their prostate cancer risk
- Education about early detection guidelines, seminars and workshops to educate families, and education about prostate cancer treatment options
- Emphasis on the efforts and works of other individuals and organizations, identifying practices that can be emulated
- Support of screening and testing programs
- Fundraising to support PHEN programs[138]

**Highlights of Gaps, Issues, Barriers, and Concerns**

One of the greatest challenges for Massachusetts is reaching those residents who are at greatest risk. Current prostate cancer interventions in the state do not adequately address informed decision-making, and no interventions are geared specifically to Black non-Hispanic men, the group at highest risk for developing and dying from prostate cancer. Limited interventions are targeted at health care providers or family members of men at risk.

In addition, there is no measure of the number of Massachusetts men who have discussed prostate cancer early detection with their health care providers.

## Goal: Reduce the mortality rate of all men from prostate cancer.

**Outcome Measure 31: By 2011, decrease the proportion of Black non-Hispanic men diagnosed with late stage (regional and distant) prostate cancer to 20 per 100,000.**
Baseline late diagnosis: 45.3 Database: MCR 1998–2002

| | |
|---|---|
| White non-Hispanic | 21.3 per 100,000 (20.5–22.1) |
| Black non-Hispanic | 45.3 per 100,000 (38.7–52.0) |
| Asian non-Hispanic | 11.2 per 100,000 (6.7–15.7) |
| Hispanic | 26.5 per 100,000 (20.6–32.3) |

**Outcome Measure 32: By 2011, increase the number of men who have discussed prostate cancer early detection with their providers.**
Healthy People 2010: currently no measure
Baseline: to be determined Database: to be determined

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Develop, test, and evaluate the effect and reach of a full range of interventions targeting Black non-Hispanic men and shared and informed decision making about prostate cancer screening.
- Support prostate health education and early detection options, which includes best practice standards, to the full range of health practitioners, and men and their families.
- Assess how many men are receiving education about prostate cancer early detection and ways to increase effectiveness and/or efficiency of the process.

# Ovarian Cancer

The American Cancer Society's *Cancer Facts and Figures* estimated that 22,220 new cases of ovarian cancer would occur among women during 2005. An estimated 16,210 women were expected to die from ovarian cancer in 2005. Ovarian cancer accounts for 3 percent of estimated new cases of cancer in females and 6 percent of estimated cancer deaths in females, more than any other cancer of the female reproductive system.[139]

**Early Detection Table 12. Ovarian Cancer Incidence[1] and Mortality Rates*[2] by Race and Ethnicity, U.S., 1998–2002**

| | White | Black | Asian American or Pacific Islander | American Indian/ Alaska Native | Hispanic |
|---|---|---|---|---|---|
| **Incidence (Females)** | 14.8 (14.5–15.1) | 9.9 (9.3–10.6) | 10.4 (9.8–11.0) | 7.8 (6.1–9.9) | 11.9 (11.1–12.6) |
| **Mortality (Females)** | 9.2 (9.1–9.3) | 7.4 (7.2–7.6) | 4.7 (4.5–5.0) | 4.9 (4.2–5.6) | 6.2 (6.0–6.5) |

*Per 100,000, age-adjusted to the 2000 U.S. standard population. Hispanics and non-Hispanics are not mutually exclusive from whites, African Americans, Asian or Pacific Islanders, and American Indians and Alaska Natives.
[1]Statistics for Hispanics and Non-Hispanics do not include cases from the Detroit, Hawaii, Rural Georgia, and Alaska Natives registries.
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992–2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992–2002), National Cancer Institute, DCCPS,
Surveillance Research Program, Cancer Statistics Branch, released April 2005, based on the November 2004 submission.
[2]Statistics for Hispanics and Non-Hispanics do not include cases from Connecticut, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, and Vermont
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992–2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992–2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

The United States Preventive Services Task Force (USPSTF) recommends against routine screening for ovarian cancer.[140] According to the National Cancer Institute, there is insufficient evidence to establish that screening for ovarian cancer with a serum marker such as CA125, transvaginal ultrasound, or pelvic examinations would result in a decrease in mortality from ovarian cancer. The potential for a false-positive test result can be a serious problem leading to anxiety and invasive diagnostic procedures. There is good evidence that screening for ovarian cancer with the tests above would result in more diagnostic laparoscopies and laparotomies than new ovarian cancers found. Unnecessary oophorectomies may also result.[141]

In 2000, as part of a workshop titled "Identifying Public Health Opportunities to Reduce the Burden of Ovarian Cancer," the Centers for Disease Control and Prevention (CDC) convened work groups focusing on ovarian cancer surveillance and prevention, early detection, and treatment. The Early Detection Work Group recommended the following four priorities:

- Identify potential early symptoms of ovarian cancer and evaluate sources of delay from the appearance of these symptoms to diagnosis.
- Develop best practice guidelines for primary care providers on the recommended cascade of diagnostic tests necessary for optimal management of women who present with symptoms suspicious for ovarian cancer.
- Develop a method for clinicians to collect more accurate information on family history of cancer.
- Develop methods or standards to improve the quality of ultrasound examinations.

Evidence-based activities for ovarian cancer have not been specifically evaluated in Cancer Control PLANET or by the *Guide to Community Preventive Services.* The *Community Guide* did find sufficient evidence that providing information, specifically to individuals making decisions about health screening and personal risk, can improve knowledge. At this time there is insufficient evidence that this knowledge changes behavior. The National Women's Health Network and the Gynecologic Cancer Foundation both support public awareness and education campaigns on ovarian cancer including print media and small educational forums such as speakers' bureaus.

## Ovarian Cancer in Massachusetts

In Massachusetts, White non-Hispanic women have the highest incidence rates for ovarian cancer, followed by Asian non-Hispanic, Hispanic, and Black non-Hispanic women. White non-Hispanic women also have the highest mortality rates for ovarian cancer (early detection table 13).

**Early Detection Table 13. Ovarian Cancer Incidence Mortality Rates 1998–2002* by Race and Ethnicity, MA**

| | White non-Hispanic | Black non-Hispanic | Asian non-Hispanic | Hispanic |
|---|---|---|---|---|
| **Incidence** | 14.9 (14.3–15.5) | 6.6 (4.6–8.7) | 9.1 (6.0–12.2) | 8.7 (6.2–11.3) |
| **Mortality** | 9.3 (8.8–9.7) | 6.0 (4.0–8.0) | † | 5.1 (3.0–7.2) |

*Per 100,000, age-adjusted to the U.S. standard population. Race/ethnicity categories are mutually exclusive.
† Age-adjusted incidence rate not calculated when number of cases or deaths is less than 20.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998–2002: Statewide Report.* Boston, MA: 2005.

## Highlights of Activities

Many accomplishments in Massachusetts related to increased ovarian cancer awareness can be attributed to the Massachusetts Division of the National Ovarian Cancer Coalition (MA-NOCC). MA-NOCC's efforts have included professional and peer education training. Over the last two years, the organization collaborated with the Massachusetts Medical Society to conduct two small continuing medical education (CME) ovarian cancer forums that received high ratings from participating physicians.

The MA-NOCC has trained 14 ovarian cancer survivors representing all the high-risk groups—women 50 and older, and lesbian, Ashkenazi Jewish, and minority women—to use the Gillette Foundation–sponsored educational CD presentation on ovarian cancer awareness. As members of the speakers' bureau, these women provided 15 well-received forums. The content of the CD corresponds to the National Cancer Institute's Physician Data Query (PDQ.)

## Highlights of Gaps, Issues, Barriers, and Concerns

Women age 50 and older, and lesbian, Ashkenazi Jewish, and minority women are at highest risk for developing ovarian cancer. Informed decision making interventions geared toward this high-risk population are needed. The efforts by MA-NOCC to educate health care providers and women at risk must be expanded and much more accomplished to reduce the mortality rate of Massachusetts women from ovarian cancer.

## Goal: Increase informed decision making about ovarian cancer screening for women in high-risk groups.

**Outcome Measure 33: By 2011, increase the number of women in high-risk groups who have discussed their personal risk for ovarian cancer with their provider.**
Baseline: to be determined Database: to be determined

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Develop, test, and evaluate the effect and reach of a full range of interventions targeting women in high-risk groups regarding informed decision making about ovarian cancer screening.
- Support ovarian cancer education and options for best practice considerations on early detection to the full range of health practitioners and women and their families.
- Assess how many women are receiving education and/or information about their personal risk of ovarian cancer.
- Advocate for national funding of public health interventions.

# Oral Cancer

The American Cancer Society's *Cancer Facts and Figures* estimated that 29,370 new cases of cancer of the oral cavity and pharynx would occur among men and women in America during 2005. An estimated 7,320 men and women were expected to die from oral cancer in 2005. Oral cancer accounts for 3 percent of estimated new cases of cancer in males. "Incidence rates are more than twice as high in men as in women, and are greatest in men who are older than 50."[142] In addition, "over 75 percent of oral cancers are now related to tobacco use."[143]

**Early Detection Table 14. Oral Cavity and Pharynx Cancer Incidence[1] and Mortality Rates*[2] by Race and Ethnicity, U.S., 1998–2002**

| | White | Black | Asian American or Pacific Islander | American Indian/ Alaska Native | Hispanic |
|---|---|---|---|---|---|
| **Incidence (Males)** | 15.4 (15.1–15.8) | 19.0 (18.0–20.1) | 11.9 (11.1–12.6) | 8.9 (6.8–11.6) | 9.2 (8.5–10.0) |
| **Incidence (Females)** | 6.4 (6.2–6.6) | 6.1 (5.6–6,6) | 5.8 (5.3–6.2) | 3.8 (2.7–5.4) | 3.9 (3.5–4.3) |
| **Mortality (Males)** | 3.9 (3.8–3.9) | 7.1 (6.9–7.3) | 3.5 (3.3–3.8) | 3.6 (2.9–4.4) | 2.9 (2.7–3.1) |
| **Mortality (Females)** | 1.6 (1.5–1.6) | 1.9 (1.8–2.0) | 1.4 (1.2–1.6) | 1.2 (0.9–1.6) | 0.8 (0.8–0.9) |

*Per 100,000, age-adjusted to the 2000 U.S. standard population. Hispanics and non-Hispanics are not mutually exclusive from whites, African Americans, Asian or Pacific Islanders, and American Indians and Alaska Natives.
[1]Statistics for Hispanics and Non-Hispanics do not include cases from the Detroit, Hawaii, Rural Georgia, and Alaska Natives registries.
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992–2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992–2002), National Cancer Institute, DCCPS,
Surveillance Research Program, Cancer Statistics Branch, released April 2005, based on the November 2004 submission.
[2]Statistics for Hispanics and Non-Hispanics do not include cases from Connecticut, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, and Vermont
Source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Databases: Incidence - SEER 13 Regs Public-Use, Nov 2004 Sub for Expanded Races (1992–2002) and Incidence - SEER 13 Regs excluding AK Public-Use, Nov 2004 Sub for Hispanics (1992–2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2005. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

"Dentists and primary care physicians can detect cancer at an early, curable stage by identifying abnormal changes in oral tissues."[144] However, the United States Preventive Services Task Force (USPSTF) and the National Cancer Institute have determined that evidence is insufficient to recommend for or against routinely screening adults for oral cancer and that the evidence does not demonstrate that screening would result in a decrease in mortality from oral cancer.[145]

In August 1996, the CDC convened a national conference to develop strategies for preventing and controlling oral and pharyngeal cancer in the United States. A follow-up meeting resulted in the prioritization of recommendations, some of which pertain to early detection. These recommendations include:

- Requiring instruction in preventing and controlling tobacco and alcohol use at all levels of training in dental, medical, nursing, and other related health-care disciplines.
- Encouraging Medicaid, Medicare, traditional insurance plans, and managed-care entities to consider making oral cancer examinations an integral part of comprehensive physical and oral examinations.
- Designating federal funding for a national program of oral cancer prevention, early detection, and control.
- Developing health-care curricula that require competency in prevention, diagnosis, and multidisciplinary management of oral and pharyngeal cancer.[146]

The *Guide to Community Preventive Services* outlines effective, evidence-based interventions to promote oral health. In terms of intervention strategies for preventing oral and pharyngeal cancers, there is insufficient evidence to recommend a population-based intervention for early detection.[147] As mentioned in the prevention section of this document, a significant barrier to cancer prevention and early detection is lack of health insurance or inadequate health insurance. This includes coverage of dental care. Increasing dental coverage could have a considerable effect on detection of oral cancers at early stages.

## Oral Cancer in Massachusetts

In Massachusetts, men have higher incidence and mortality rates for oral cancer compared to women. Hispanic men have the highest incidence rates, followed by Black non-Hispanic, White non-Hispanic, and Asian non-Hispanic men. Asian non-Hispanic men have the highest mortality rates, however, followed by Black non-Hispanic, Hispanic, and White non-Hispanic men. Asian non-Hispanic women have the highest incidence rates compared to women of other races and ethnicities; however, mortality rates are nearly identical among women in all racial and ethnic groups (early detection table 15).

**Early Detection Table 15. Oral Cancer Incidence and Mortality Rates* by Race and Ethnicity, MA, 1998–2002**

| | White non-Hispanic | Black non-Hispanic | Asian non-Hispanic | Hispanic |
|---|---|---|---|---|
| **Incidence (Males)** | 16.7 (16.0–17.4) | 21.0 (16.7–25.2) | 12.8 (8.6–16.9) | 23.2 (18.1–28.4) |
| **Incidence (Females)** | 6.7 (6.3–7.1) | 6.6 (4.6–8.6) | 9.1 (5.9–12.4) | 5.1 (3.0–7.1) |
| **Mortality (Males)** | 4.3 (3.9–4.6) | 5.8 (3.5–8.1) | † | † |
| **Mortality (Females)** | 1.7 (1.5–1.9) | † | † | † |

*Per 100,000, age-adjusted to the U.S. standard population. Race/ethnicity categories are mutually exclusive.
† Age-adjusted incidence rate not calculated when number of cases or deaths is less than 20.
Source: Center for Health Information, Statistics, Research, and Evaluation and the Massachusetts Department of Public Health. *Cancer Incidence and Mortality in Massachusetts 1998–2002: Statewide Report.* Boston, MA: 2005.

## Highlights of Activities

Accomplishments by Massachusetts related to oral cancer prevention can be attributed to a variety of dedicated collaborative and non-profit organizations. Massachusetts Oral Cancer Partnership, for example, is a collaborative made up of Delta Dental Plan of Massachusetts and educational institutions related to oral health. These institutions include Tufts University School of Dental Medicine, the Harvard School of Dental Medicine, Boston University School of Dental Medicine, The Forsyth Institute, the Forsyth Hygiene School at Massachusetts College of Pharmacy, and the Massachusetts Dental Society. The partnership provides community-based oral cancer prevention information and screening to neighborhoods.[148]

The Massachusetts Oral Health Collaborative was established in response to the findings and recommendations of the February 2000 report of the Special Legislative Commission on Oral Health. In November 1998 the governor and the Massachusetts Legislature appointed this commission, the first of its kind in more than thirty years. The commission was authorized by Chapter 170, section 42, of the Acts of 1997 to investigate oral health status, community prevention programs, and access to dental care services for residents of the Commonwealth.[149]

Health Care For All, a state consumer health organization, also coordinates a statewide Oral Health Advocacy Taskforce, a coalition comprising consumers, advocates, health care

professionals, academics, and insurers. This task force works to expand access to oral health care education, prevention, and treatment services for all Massachusetts residents. This includes increasing dental coverage.[150]

**Highlights of Gaps, Issues, Barriers, and Concerns**

Dental insurance is a major issue for Massachusetts residents. According to Health Care For All, approximately 2.3 million Massachusetts residents lack dental insurance. Only 41 percent of them received a dental visit in 2004 compared with 82 percent of insured adults. In 2002 the Commonwealth of Massachusetts eliminated comprehensive dental care for adult MassHealth (Medicaid) enrollees over age 21; only extractions are covered. There is an exception for adult enrollees with "special circumstances" defined as those MassHealth "members with severe, chronic disabilities who are unable to maintain oral hygiene and those for whom oral disease may be life threatening."[151]

Those who use tobacco and alcohol are at high risk for developing oral cancer, so oral health messages should be integrated with public education campaigns on tobacco and alcohol. Unfortunately, in Massachusetts there has been no funding for tobacco mass-media education since 2002.

## Goal: Raise awareness about the cause and risk factors for oral cancer.

**Outcome Measure 34: By 2011, increase the number of oral health providers who counsel patients about the causal link between alcohol, smoking, and cancer.**
Healthy People 2010: currently no measure
Baseline: to be determined Database: oral health provider survey 2005

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Increase access to comprehensive oral health care.
- Include oral cancer information in all public education campaigns on tobacco and alcohol.
- Promote the role of dentists and other oral health providers in counseling patients on tobacco and alcohol and their links to oral cancer.
- Encourage community clinics to provide general oral health screenings.
- Encourage oral health insurance coverage and screening by dental and non-dental health providers for adults 65 and older.

# EMERGING SCIENCE

New research is constantly emerging relative to cancer prevention, early detection, treatment, palliation, survivorship, and end-of-life care. As data becomes available, organizations such as the National Cancer Institute and the United States Preventive Services Task Force are poised to amend their recommendations and guidelines to reflect this latest evidence in best practices standards.

The National Cancer Institute's Physician Data Query (PDQ) has editorial boards comprising experts in cancer and related specialties who are responsible for producing and maintaining evidence-based, peer-reviewed cancer information summaries. The editorial boards meet regularly to review and update the cancer information summaries on the basis of newly published research results. Corresponding editorial advisory boards review the PDQ cancer information summaries on a regular basis and make recommendations for changes to these editorial boards.[152] The United States Preventive Services Task Force decides how often recommendations are updated, depending on the topic priority and availability of new evidence.[153]

In addition, the Task Force on Community Preventive Services meets three times a year to evaluate evidence from population-based interventions. These interventions include those relative to promoting cancer screening or informed decision making. Up-to-date recommendations are then made available through the *Guide to Community Preventive Services*.[154]

**Emerging Science in Massachusetts**

Massachusetts is fortunate to have both an NCI-designated comprehensive cancer center, the Dana-Farber/Harvard Cancer Center, and a cancer center at the Massachusetts Institute of Technology, The MIT Center for Cancer Research. The Dana-Farber/Harvard Cancer Center has several research programs in process or in development including the following:

- Angiogenesis, Invasion and Metastasis
- Biostatistics
- Breast Cancer
- Cancer and Developmental Biology
- Cancer and Gene Expression
- Cancer Cell Biology
- Cancer Disparities
- Cancer Epidemiology
- Cancer Genetics
- Cancer Imaging
- Cancer Immunology
- Cancer Nursing Research
- Cancer Risk Reduction
- Childhood Cancer Survivorship
- Gastrointestinal Malignancies
- Gynecologic Cancer
- Head and Neck Malignancies
- Leukemia
- Lung Cancer
- Lymphoma and Myeloma
- Melanoma and Cutaneous Oncology
- Neuro-Oncology
- Outcomes Research
- Palliative Care and Psychosocial Oncology
- Prostate Cancer
- Radiation Biology/DNA Repair
- Renal Cancer
- Sarcoma
- Translation Pharmacology and Early Therapeutic Trials [155]

The MIT Center for Cancer Research focuses on three research areas including molecular genetics and immunology**;** tumor suppressors, cell cycle, and check points**;** and cell biology, development, and differentiation.[156]

**Highlights of Activities**

For this cancer control plan, the Massachusetts Comprehensive Cancer Control Coalition evaluated trends and new research in cancer prevention, early detection, treatment, palliation, survivorship, and end of life care. One of the major pieces of new information that became available during the development of the Plan was a series of papers related to addressing social disparities in cancer, which appeared in the February 2005 Special Issue of *Cancer Causes and Control.*

During development of the Plan, interest in the *Massachusetts Comprehensive Cancer Control Coalition* (MCCCC) *Newsletter* increased substantially, as evidenced by requests from individuals to be added to the e-mail distribution list and an increase in the number of submissions received for publication. The *MCCCC Newsletter* is a free quarterly publication, distributed electronically to every coalition member as well as to interested parties. The goal of the newsletter is to allow the coalition members to communicate with fellow coalition members across the state and to learn about one another's current projects, upcoming events, accomplishments, and publications. The *MCCCC Newsletter* also allows members to communicate their research about emerging science. Interest in the *MCCCC Newsletter* has grown, and a review board is now being established to decide which submissions are appropriate for publication, to provide editorial assistance, and to guide the layout and design of future issues.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Currently no system is in place for monitoring emerging science and communicating new directives and/or recommendations statewide.

## Goal: Monitor emerging science and include new breakthroughs and updates in Massachusetts' cancer control efforts.

**Outcome Measure 35: By 2011, formally review emerging science in cancer at least twice a year.**
Baseline: once a year Database: CCCP research 2005

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Monitor NCI, the U.S. Preventive Task Force, and peer-reviewed scientific journals for updates and changes in cancer prevention, early detection, treatment, palliation, survivorship, and end-of-life-care.
- Communicate updates to the Coalition; determine whether the Comprehensive Cancer Control Plan should be modified, and how.

# TAB 4

# Survivorship

## Survivorship/Treatment/Palliation Work Group

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Administrative Director
Mercy Medical Center
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**Arlene Lowney, RN, MBA**
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**Dana Palit, MSW, LCSW**
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## SURVIVORSHIP

The term "cancer survivors" refers to those people who have been diagnosed with cancer and the people in their lives who are affected by the diagnosis, including family members, friends, and caregivers. Due to advancements in cancer treatment and technology, more people are living with and surviving cancer each year. These cancer survivors face many compelling challenges that directly affect the quality of their lives. In "A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies, 2004" (National Action Plan), experts described the need for action:

> Although many public health initiatives address early detection, prevention, and control of cancer, public health efforts to address cancer survivorship are relatively new. Survivors face numerous physical, psychological, social, spiritual, and financial issues at diagnosis, during treatment, and for the remaining years of their lives. Many of these issues could be successfully addressed through coordinated public health initiatives.[157]

The National Action Plan is the framework developed by 100 experts in cancer survivorship and public health from the Centers for Disease Control and the Lance Armstrong Foundation. The plan identifies and prioritizes cancer survivorship needs and proposes strategies for addressing them. These include physical symptoms such as pain, fatigue, and nausea that require progressive, survivor-centered, quality, palliative care. Also included are psychological issues such as fear, stress, depression, anger, and anxiety. Survivors may experience many losses and stressors due to their cancer, such as job loss due to an inability to work, changes in self-image, and feelings of helplessness. Many of these issues are related. For example, job loss may lead to loss of health insurance, of one's social support system, and of financial stability. For those on the bottom rung of the socio-economic ladder, the challenges and needs can multiply. Individuals may be facing cancer while simultaneously struggling to maintain housing, food, and other basic needs.

Using patient navigators is one strategy to address the burden that cancer imposes on individuals with low social and economic status. The patient navigator is a person who assists patients throughout their cancer care, guiding them through the medical system as well as helping them with financial support, transportation to appointments, and childcare. The National Institute of Cancer has funded research to identify the most effective patient navigator models, and the American Cancer Society has established patient navigator programs. It is too soon, however, to determine the effect of these interventions.

Specific data on the issues survivors must face is not captured by current public surveillance systems. New systems must be devised to collect that data and use it to inform program fulfillment for survivors.

Strategies at the national level to address the many survivorship gaps include creating surveillance system(s), conducting research on the multitude of issues survivors face, improving access to quality care and services, and determining evidence-based methods to address the needs of all cancer survivors. General evidence-based interventions currently rely on shared and informed decision making literature. For example, increasing the knowledge level among cancer survivors, loved ones, and providers can have a positive outcome on the cancer survivors' quality of life. Making sure policy makers understand the issues that survivors face can also have a

positive effect. With expanded surveillance and research, experts can gather the data needed to understand the major gaps, issues, concerns, and barriers that cancer survivors face. Findings, however, must be shared and must loop back to influence interventions and strategies.

**Survivorship in Massachusetts**

The number of cancer survivors in Massachusetts is unknown. There are, however, networks of survivor support groups and services throughout the state. The New England Coalition for Cancer Survivorship (NECCS) is one such coalition, comprising survivors, family members, friends, caregivers, and cancer-related organizations from all over New England. NECCS focuses on three areas of activity: advocacy, information provision, and public education. The organization publishes topical newsletters on survivorship issues such as pain management and complementary and alternative medicine, provides speakers for panels, conferences, and legislative advocacy, and collaborates with organizations on conferences and events dealing with survivorship.[158]

The Wellness Community (TWC) has two offices in Massachusetts: one in Newton and a satellite location at the Dimock Community Health Center in Boston. TWC is an international non-profit organization dedicated to helping people with cancer fight for their recovery by providing free psychological and emotional support as an adjunct to conventional medical treatment. Today TWC has 22 locations across the United States. This mission-driven agency helps hundreds of cancer survivors, caregivers, and their loved ones, including children. Specially trained mental health professionals lead all of the services.[159]

The Massachusetts Prostate Cancer Coalition (MPCC) is a statewide non-profit organization devoted to providing information and education on prostate cancer to newly diagnosed individuals, survivors, and their families as well as to health care professionals. MCPP presents an annual prostate cancer symposium for prostate cancer survivors, their loved ones, and providers to network and increase their knowledge on survivorship, treatment, and early detection.[160]

These are just a few of the many organizations and coalitions in the Commonwealth who are working diligently to improve the quality of life for cancer survivors and their loved ones.

**Highlights of Gaps, Issues, Barriers, and Concerns**

The Survivorship Work Group identified many gaps, issues, barriers and concerns that are consistent with the national survivor assessments. The lack of survivorship data, for example, is a concern for the Commonwealth. The number of survivors and the issues they face are now anecdotal. These accounts are deeply troubling and include job loss, health access issues, and in some instances, inability to meet basic needs such as housing and food. Systematic collection of information that can be evaluated and applied programmatically is needed. In Massachusetts, as in the nation at large, the challenges faced by cancer survivors of low economic status are magnified and multiplied. There is an urgent need to understand the range of issues and to begin providing linkages or strategies to address them. For example, patient navigator programs are now available in some parts of the state. They must be evaluated to determine which ones best meet the many needs of cancer survivors. Also, there is a concern about whether cancer survivors are taking an active role in their treatment decisions and a need to provide patients and their loved ones with guidance on self-advocacy. Addressing the long-term needs and lifestyle

changes of children who live through and beyond cancer is a concern requiring special consideration.

## Goal: Ensure that all cancer survivors in the Commonwealth have equal access to information and to follow-up medical, rehabilitative, and psychosocial services.

**Outcome Measure 36: By 2011, improve the overall experience and quality of life of all Commonwealth residents who are living with, through, and beyond cancer.**
Healthy People 2010: no objective listed
Baseline: to be determined Database: to be determined

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Add a question (or questions) to the BRFSS that specifically addresses the number of people diagnosed with cancer in Massachusetts.
- Design, administer, publish, and disseminate a study that presents insight into the experiences of cancer survivors in Massachusetts. Include work, economic, and psychosocial issues.
- Support the development of interventions, such as patient navigator programs, to ensure that all Commonwealth residents—especially those in low socio-economic groups—get the assistance they require.
- Develop and maintain patient navigation systems that can facilitate optimum care for cancer survivors.
- Develop an infrastructure for a comprehensive database on cancer survivorship.
- Support the development and dissemination of clinical practice guidelines for each phase of cancer survivorship.
- Encourage the development and dissemination of public education programs that empower cancer survivors to make informed and shared decisions.
- Conduct research on interventions that improve the quality of life for cancer survivors.
- Educate policy makers and decision makers about issues that affect the quality of life for cancer survivors.
- Empower survivors with advocacy skills.
- Support efforts to educate survivors about the importance of nutrition and physical activity.

# TAB 5

# Cancer Treatment

# CANCER TREATMENT

The American Cancer Society estimated that 1,372,910 people would be diagnosed with new cases of cancer in 2005.[161] The survival of these Americans depends on access to quality care that meets best practice standards.

There is ample evidence, however, that not everyone has the same access to quality treatment and care. Disparities in access are particularly evident among racial/ethnic minorities, people of lower socioeconomic status, residents of rural areas, and other underserved populations for whom the unequal burden of cancer continues to be documented through the nation's cancer surveillance networks. These population groups often experience unacceptable delays in follow-up of abnormal findings, definitive diagnoses, and subsequent treatments.

The National Cancer Institute (NCI) understands that if it is to reach its goal of eliminating suffering and death due to cancer by 2015, it must eliminate this unequal access to quality treatment and palliation services. NCI researchers are studying access issues and are identifying outcome measures that indicate whether a patient is receiving quality cancer treatment. One indicator, for example, is treatment at a facility approved by the American College of Surgeons (ACOS) Commission on Cancer (CoC). CoC-approved cancer centers must meet specific best practice standards.[162] These standards, which are updated by NCI work groups, are devised to aid cancer treatment facilities in establishing internal systems that ensure every patient receives treatment of the highest quality.

In its 2001 report, "Voice of a Broken System: Real People, Real Problems," the President's Cancer Panel spoke of the many barriers that contribute to the disconnect between development and delivery of quality cancer services for all. Some barriers that the panel identified are systemic. For example, patients may face a fragmented medical delivery system, going to a variety of facilities and providers instead of a single provider who can provide consistent, coordinated, and continuous care. The system may also fail to provide medical tests and laboratory results to the patient in a timely fashion. The President's Cancer Panel also identified financial barriers including inadequate health insurance, and employment situations that do not allow for time off from work for screenings. Other issues raised by the panel include physical barriers to care such as inadequate transportation assistance for patients who live far from treatment facilities, and educational and informational gaps where not all providers are informed of the best practices and not all patients receive necessary and comprehensible information.[163]

The President's Cancer Panel of 2001 also noted that cultural and linguistic differences can impede patient understanding and acceptance of standard biomedical cancer care. It is highly likely, the panel concluded, that members of underserved populations experience multiple barriers. This can result in delays in detection, diagnosis, and quality treatment. Panel participants noted that people facing these multiple challenges may give up and drop out of cancer services.

The National Cancer Institute is examining other ways to reduce some of these barriers to care. The Patient Navigation Research Program is one such effort being conducted nationwide. As previously mentioned, the patient navigator is a person who assists patients throughout their cancer care, guiding them through the medical system as well as helping them with financial

support, transportation to appointments, and childcare. The purpose of the Patient Navigator Research Program is to develop interventions to reduce the time of delivery of standard cancer services, cancer diagnosis, and treatment after identifying an abnormal finding.[164]

Another aspect of quality cancer care is access to and informed choice about clinical trials. Only 4 percent of individuals diagnosed with cancer currently participate in clinical trials.[165] The barriers to participation occur on several levels. With many cancers, the focus is on treating both the disease and subsequent acute episodes. In addition, many cancer sufferers do not know the benefits of participating in clinical trials and may be reluctant to become part of an experiment if they do not see a direct benefit. Nationally, many efforts are under way to educate providers and cancer sufferers about clinical trials.

There are evidence-based interventions to address the gaps, issues, barriers, and concerns outlined above. The evaluation of efforts to increase the knowledge level of cancer survivors and providers has shown a positive effect on shared and informed decision making. There is sufficient evidence to support patient navigator programs. The specific characteristics required for an effective navigator program are being researched. Research on improving participation in clinical trails has also yielded several evidence-based interventions, although more understanding of the barriers to participation is required.

**Highlights of Activities**

Massachusetts can claim many assets and accomplishments in the area of quality cancer treatment. An effort of major importance, for example, is the consideration by the state's legislature and governor of options for health insurance coverage for all Commonwealth residents. As outlined in the prevention section of this document, lack of health insurance is a significant barrier to timely and quality cancer care. Massachusetts' efforts to ensure health insurance for all residents of the Commonwealth is an important policy step that will affect the burden of cancer in this state in a positive way.

The Commonwealth is also fortunate to have an NCI-designated major cancer center, the Dana-Farber Cancer Institute (DFCI). Since its founding in 1947, DFCI has been committed to providing cancer patients with the best treatment available while developing tomorrow's cures through cutting-edge research. The institute employs about 3,000 people, supports more than 150,000 patient visits a year, is involved in some 200 clinical trials, and is internationally renowned for its blending of research and clinical excellence. The institute's expertise in these two arms of the fight to eradicate cancer uniquely positions it to bring into clinical use novel therapies that prove beneficial and safe in the laboratory setting.

Massachusetts is home to 48 Commission on Cancer-approved (CoC) cancer centers. Since timely access to cancer treatment that meets best practice standards affects the quality and length of life, these CoC-approved centers are important state assets. In Massachusetts, CoC-approved facilities provide 80 percent of cancer care. This utilization data mirrors the national data.[166]

Health disparities have become an important focus for cancer providers, advocates, and policy makers throughout the state. Agencies such as the American Cancer Society have developed an array of new initiatives under the broad rubric of "navigation" to increase survivors' access to care and support. There is a specific focus on reaching out and meeting the

needs of historically underserved populations. One new initiative, the Patient Navigation Service, primarily serves cancer survivors who are facing multiple and complex barriers to care. The majority of survivors in this program do not have insurance or are on state/federal entitlement programs. The program also seeks to reach cancer survivors who are experiencing heightened levels of emotional distress and are without supportive services. One recent study done in affiliation with John Hopkins University found that only 5 percent of severely distressed cancer survivors got the support they needed. This level of heightened distress is experienced by approximately 30 percent of all cancer survivors.[167]

Research shows that unmet emotional needs can have a significant effect on multiple aspects of treatment that include missed appointments, delays in making treatment decisions and starting treatment, and decreased compliance with treatment plans. In the Patient Navigation Service, clinical licensed social workers provide supportive counseling, information, resource linkage, and direct advocacy by telephone when needed to increase survivors' access to care and support. Translation services are available through this program to serve non-English-speaking survivors.

Another key initiative being developed to reduce barriers to care is the Boston Hope Lodge, which will offer free accommodations for cancer patients who are actively receiving cancer treatment. ACS also maintains a hotline 24 hours a day, seven days a week (National Cancer Information Center at 1-800-ACS-2345), where trained cancer information specialists provide information and resource linkage. (Translation services are available to accommodate non-English speakers and TTY 1-800-439-2370 services available to serve the deaf community.) ACS provides other free services to cancer survivors in Massachusetts to increase access to care. These include transportation to medical appointments, education, and clinical trials matching service. ACS offers a variety of quality-of-life programs as well. The ACS Web site (www.cancer.org) provides topical information, decision-making tools, and local resource information

The Massachusetts Cancer Registry has begun using its data to monitor health disparities. In a recent report, "The Effects of a National Breast and Cervical Cancer Early Detection Program on Social Disparities in Breast Cancer Diagnosis and Treatment in Massachusetts," the Registry compared the stage of breast cancer at diagnosis and first course of treatment for women enrolled in a program for low-income or uninsured women (the Women's Health Network, or WHN) to other women diagnosed with breast cancer. This important study reveals that women enrolled in WHN were diagnosed at similar stage and treatment patterns as other women. The study noted that the only difference between the groups was that those enrolled in WHN were less likely to receive radiation therapy, particularly after partial mastectomy.[168] Using Registry data to identify disparities in cancer treatment is an important step.

The formation of a Special Legislative Commission on Health Disparities was mandated in Massachusetts by language included in Section 53 of Chapter 65 of the Acts of the Fiscal Year 2004 supplemental appropriations bill, which was approved April 5, 2004. This commission will address the racial, ethnic, and linguistic disparities in access to health care and prevention services and quality care, and the disparities in medical outcomes in the Commonwealth, including disparities in breast, cervical, prostate, and colorectal cancers. The commission will also address diversity in the health care workforce, including but not limited to, doctors, nurses, and physician assistants. A report by the commission is expected by the end of 2005, and will

include recommendations for designing, implementing, and improving programs and services, and proposing appropriate statutory and regulatory changes.[169]

Also in Massachusetts, specific efforts have been made to increase participation of cancer patients in clinical trials. The Dana-Farber/Partners Cancer Care Affiliates Network and the clinical trial network at the National Cancer Institute have reached out to community oncologists to conduct clinical trials and/or refer a patient to the comprehensive cancer center for consideration. These efforts have directly lead to 170 more patients having access to a clinical trial.

**Highlights of Gaps, Issues, Barriers, and Concerns**

In Massachusetts, as on the national level, the lack of access to accurate information by providers, patients, and their loved ones has been identified as a barrier to quality care. There is a need for accurate, accessible, culturally sensitive information in many languages about specific cancers, the related range of treatment options, risks, and side effects. Information must be available in a variety of formats and delivered through multiple channels to meet different population needs. Formats and channels include print, mass media, the Internet, and telephone helplines.

While two major national information sources are available for information specific to Massachusetts, either they are not well known or they are underused by cancer survivors and their loved ones in the state. One information source is the National Cancer Institute's (NCI) Cancer Information Service (CIS). Both NCI and CIS offer online evidence-based information for health professionals and other individuals. CIS also provides a toll-free telephone information line, 1-800-4-CANCER, staffed with specially trained cancer information specialists. This number is available anywhere in the country from 9 a.m. to 5 p.m. For the year 2004, the CIS call center received 1,322 calls from Massachusetts residents seeking cancer information. The American Cancer Society (ACS) also maintains a toll-free help line. As mentioned earlier, the help line is staffed 24 hours a day year-round. Callers can get general information on cancer and can be connected with local support and services. The ACS received 1,781 calls in 2004. These calls included requests for cancer information, financial assistance, lodging, patient programs, prevention and early detection, and transportation. While most of the CoC-approved centers provide cancer information resources on site, these resources are underused.

The Coalition Treatment Work Group identified a lack of understanding among patients about the benefits of obtaining treatment and services from a CoC-approved cancer center. Increasing awareness about these centers could produce successful treatment outcomes for more cancer survivors. Another barrier identified on both a national and state level is health disparities in cancer treatment. This was a strong concern for the work group due to the number of under- and uninsured people living in the Commonwealth, the barriers individuals face due to social and economic status, and cultural barriers between providers and survivors. Based on the research pertaining to shared and informed decision making, many evidence-based interventions are possible to address these barriers, gaps, issues, and concerns. The initial research on limited clinical trial participation has also revealed evidence-based strategies. Patient Navigation systems are supported in the literature as an important way to address health disparities. However, the specific models that are the most effective are being evaluated.

**Goal: Ensure that all Commonwealth residents have equal and immediate access to cancer information, treatment, and clinical trials that are based on nationally recognized best practice standards.**

**Outcome Measure 37: By 2011, increase the number of people in Massachusetts who call the toll-free numbers for the Cancer Information Service (CIS) or the American Cancer Society (ACS).**
Healthy People 2010: no objective listed
Baseline: 1,322 cancer information calls to CIS Database: CIS 2004
Baseline: 17,813 cancer information calls to ACS Database: ACS 2004

**Outcome Measure 38: By 2011, increase the number of individuals who receive their cancer treatment from Commission on Cancer-approved cancer centers to 90 percent.**
Healthy People 2010: no objective listed
Baseline All: 80% Database: ACOS 2004

**Outcome Measure 39: By 2011, increase participation in cancer clinical trials to 10 percent**
Healthy People 2010: no objective listed
Baseline: 4% Database: NCI 2004

**Outcome Measure 40: By 2011, increase the number of evidence-based educational forums or initiatives on informed and shared decision making.**
Healthy People 2010: no objective listed
Baseline Data: to be determined Database: to be determined

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Identify and support efforts to eliminate barriers to equitable access to high-quality cancer care.
- Evaluate first course of treatment to determine health disparities. Distribute this information with recommendations to CoC-approved providers throughout the state.
- Educate survivors about the benefits of CoC-approved facilities.
- Encourage use of CoC-approved cancer treatment facilities.
- Encourage hospitals to become CoC-approved and to maintain that status.
- Increase public awareness and access to credible cancer and clinical trial information using ACS or CIS toll-free numbers, the NCI interactive Web site, and patient resource centers at CoC-approved hospitals and treatment facilities throughout the state.
- Teach primary-care practitioners to tell their patients where to obtain credible cancer information.
- Support the development of comprehensive patient navigator systems and support the evaluation of navigator interventions, identifying best practice standards.
- Encourage navigation programs to collaborate and share information to promote best practices, reduce redundancies, and increase effectiveness of programs.
- Encourage cancer survivors (in-kind) to volunteer as navigators to other survivors.

- Encourage use of distress screening tools in all navigation programs to more effectively identify and meet the emotional needs of cancer survivors.
- Promote and support the development and distribution of individualized patient educational and resource kits.
- Evaluate practitioner and provider education on informed and shared decision making to determine effect on practice.
- Support activities that ensure evidence-based informed and shared decision making education for patients and their families.
- Ensure evidence-based informed and shared decision making education for practitioners and providers.
- Determine the best way to educate providers about the benefits of clinical trials.
- Support programs that increase information about and access to clinical trials.
- Educate patients and loved ones early in the disease process about the benefits of clinical trials.

# TAB 6

# Palliative

# PALLIATIVE CARE

Tremendous medical advancements in cancer treatment are evident in many parts of the world, and today many people diagnosed with cancer are living longer with the disease. However, the focus on curing the disease can jeopardize the quality of the cancer survivor's life unless attention is paid to his or her palliative care needs as well. The World Health Organization defines palliative care as "an approach that improves the quality of life for patients and their families facing the problems associated with a life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual."[170]

In 2001 the Institute of Medicine (IOM) called upon the National Cancer Institute (NCI) to make palliative care a central focus at all of the nation's cancer centers. IOM authors agreed that palliative care should begin at the time of diagnosis and remain a central focus until death, but they noted the existence of many barriers to making that happen.[171]

Barriers to palliative care have been identified by the Institute of Medicine, the National Cancer Advisory Board, and most recently in *A National Action Plan for Survivorship: Advancing Public Health Strategies,* completed jointly by the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation.[172] These barriers fall into several main categories: attitudinal, behavioral, economic, educational, and legal. Many strategies have emerged on a national level to address these barriers. They include but are not limited to (1) having the NCI-designated cancer centers become centers of excellence in palliative care, (2) formal evaluation and testing of best practice standards for palliative care for both adults and children, (3) ensuring patient access to the best information using currently existing resources such as the Cancer Information Service, and (4) ensuring that a sufficient number of providers become certified in palliative care.

One of the most common palliative care issues for cancer patients is pain management. Over the past 25 years, scientific advances in molecular biology, neuroscience, pharmacology, and anesthesiology have led to a better understanding of the anatomy and physiology of pain. Pain receptors and mediators have been identified and duplicated in the laboratory, and medications and methods of treatment have been improved. The International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage."[173] Pain is a highly subjective experience. The same physical stimulus may cause greater or lesser amounts of pain in different people and even in the same person in different situations. Nonphysical stressors, such as emotional, financial, and spiritual difficulties, can influence the patient's experience of pain.

Cancer care centers across the country are establishing palliative care services. A major priority of a pain and palliative care service is incorporation of the principles of palliative care into the care of all patients with cancer from the time of diagnosis, not only in the setting of advanced or terminal disease.

Palliative care treatment:

- Affirms life and regards death as a normal process.
- Neither hastens nor postpones death.
- Provides relief from pain and other distressing symptoms.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their bereavement.

Cancer patients may not have access to hospice services. It is important that hospitals and nursing homes have the ability to provide quality palliative care at the time of diagnosis through the end of life.

Under the topic of shared and informed decision making, the literature reveals that increased knowledge can have a positive effect on provider and cancer survivor care and treatment. Increasing the knowledge level of cancer survivors, loved ones, and providers can have a positive effect on receiving quality and timely palliative care services. Removing structural barriers is another evidence-based intervention that has a positive effect on obtaining access to palliative care. This includes health insurance coverage of pain and symptom management from the time of diagnosis to the end of life. It also includes increasing the availability of certified palliative care providers and changing cultural barriers in facilities and communities to facilitate access to palliative care for all. There are many effective interventions that can address the barriers, issues, gaps, and concerns regarding the cancer survivor's access to timely palliative care.

**Palliative Care in Massachusetts**

There is a growing recognition in the Commonwealth of the importance of integrating palliative care into cancer care from the day of diagnosis throughout disease progression. To meet this goal, each of the 48 Commissions on Cancer (CoC)-approved facilities and the comprehensive cancer centers are working to institute palliative care systems. There is also an increased effort to certify the full range of health care providers in palliative and end-of-life care. Currently there are 52 certified physicians, 6 certified nurse practitioners, 178 certified registered nurses, 2 certified LPN/VNs, and 76 certified nursing assistants in palliative and end of life care.

The Center for Palliative Care at Harvard University Medical School has established a specialized program to train both physicians and nurses to become leaders in palliative care. The program offers intensive learning experiences for physicians and nurse educators who wish to become experts in the clinical practice and teaching of comprehensive, interdisciplinary palliative care. The program helps participants gain expertise in leading and managing improvements in palliative care education and practice at their own institutions.

Several major medical centers in the state are taking a progressive role in establishing palliative services within their facilities. For example, in 2003 Massachusetts General Hospital (MGH) and Harvard Medical School received a three-year, $375,000 grant from the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care program. The funds are being used to merge MGH's well-established palliative care program with its medical intensive

care unit (ICU). The MGH Palliative Care Service (PCS) is one of the most experienced palliative care programs in the country. The program provides training and consultation in palliative care practice to all health professionals as well as health profession students. According to principal investigators for the grant, "We will identify, pilot and evaluate a series of practical, transferable and measurable interventions that will assure greater attention to the physical, psychosocial and spiritual suffering of all patients admitted to the Medical Intensive Care Unit and their families." Cross training between PCS and ICU will assure that palliative care staff are experienced in the culture and practice of critical care medicine.[174]

Several key statewide organizations are devoted to improving palliative care for all Commonwealth residents. For example, the Massachusetts Compassionate Care Coalition (MCCC), a 501(c)3 charitable organization, is committed to improving care for people with life-threatening illness and their loved ones. MCCC's mission is to promote informed choice, dignity, comfort, and compassionate care at the end of life through community-based initiatives. Its vision is a culture in which the physical, emotional, social, and spiritual needs of all seriously ill people are met through advocacy, committed care, education, and community support.

These are the Massachusetts Compassionate Care Coalition's guiding strategies:

- Contribution to lasting cultural and social change that honors informed choice
- Collaboration with others who share MCCC values and vision
- Access to optimal end of life care across all settings
- Respect for diverse cultural and spiritual values and beliefs
- Awareness among health policy leaders, providers, and the public about the importance of advance care planning and better end-of-life care
- Empowered communities taking action at the local level

The Massachusetts Pain Initiative (MassPI), in partnership with the American Cancer Society, is a statewide, non-profit, voluntary organization dedicated to ending needless suffering from persistent and acute pain and improving quality of life for all those affected by pain. Its vision is that every person will have knowledge of and access to appropriate pain management. MassPI has three active working councils: Professional Education, Public Awareness, and Legislative Issues and Access to Care.

MassPI's overall strategic goals are as follows:

- Provide public education and increase awareness of pain and pain management.
- Provide basic pain management education for all health care providers.
- Convince public policy makers to create effective pain management laws and programs.
- Provide equal access to excellent pain management for people with pain.
- Develop a media communications plan for MassPI.

MassPI is achieving these goals through such vehicles as the Pain Management Pocket Tool for Professionals, Power Over Pain (grassroots public awareness project), numerous collaborative educational offerings, legislative outreach, and the MassPI Web site at www.masspaininitiative.org.

The Catastrophic Illness in Children Relief Fund (CICRF) is developing best practice guidelines for pediatric palliative care. These efforts will then be disseminated to the organizations providing care to children with life-threatening illnesses.

**Highlights of Gaps, Issues, Barriers, and Concerns**

Although Massachusetts has made important progress in palliative care, those involved in the work group for this statewide plan identified some fundamental gaps, issues, barriers, and concerns. Many of these issues are the same as those on the national level. One of the major areas requiring attention is public, provider, and policy maker education on how palliative care affects the quality of life and medical status for cancer survivors. Public education is needed on pain-related topics such as the prevalence of pain, the consequences of unrelieved pain, the elements of appropriate pain management, and self-advocacy for pain relief. Providers need better training in palliative care. Basic competencies in pain and symptom management should be part of health provider education, and schools should certify more palliative care providers. Provider training should include cultural competency to address the palliative care needs of diverse populations throughout Massachusetts. Providers should know how to respond, for example, to individuals from cultures that may not express a need for pain relief.

The multidisciplinary palliative care teams at cancer centers need to be better utilized. Work group members expressed concern that providers may be so focused on treatment that they do not consult with the palliative care experts.

Access is a barrier in palliative care as much as it is in other cancer-related areas. For example, after burglaries in several major pharmacies, many pharmacies stopped carrying some pain medications. While mail order is an option, the lack of available pain medication in local pharmacies is a concern for many cancer patients. Insurer restrictions on reimbursement for some palliative care services present another barrier to access. The lack of access to palliative care guidance for patients at home is also a concern. For example, unmitigated pain between medical appointments can have an adverse effect on the cancer survivor's medical and functional status.

Access to a variety of appropriately trained providers and resources for palliative care is limited for many patients. This includes access to specialists in complementary and alternative medicine (CAM). In addition, CAM interventions should be integrated into the person's overall treatment plan, but cancer survivors may be reluctant to let their provider know they are using them.

## Goal: Ensure that all Commonwealth residents have access to quality palliative care.

**Outcome Measure 41: By 2011, increase the number of certified palliative care providers by 15 percent.**
Healthy People 2010: no objective listed
Baseline: 52 certified physicians, 6 certified nurse practitioners, 178 certified registered nurses, 2 certified LPN/VNs, 76 certified nursing assistants
Physician Database: American Board of Hospice & Palliative Medicine, June 2005
Nursing Database: Hospice & Palliative Nurses, June 2005

**Outcome Measure 42: By 2011, increase the number of NCI Cancer Centers and CoC-approved hospitals with palliative care programs to 50 percent.**
Healthy People 2010: no objective listed

Baseline: 20% (10 out of 50) Database: Massachusetts Telephone Survey, NCI Cancer Centers, and CoC-approved hospitals, June 2005

Strategies to Achieve the Goal

The work group selected the following strategies:

- Provide statewide education about quality palliative care to policy makers, health professionals, patients, and family.
- Support efforts to educate the public about the prevalence of pain, the consequences of unrelieved pain, what appropriate pain management is, and how to speak up to get effective pain relief.
- Encourage strong advocacy of pain management public policy interventions.
- Ensure equal access to excellent pain management.
- Support efforts that ensure basic pain management competency for all health care providers.
- Support and encourage participation in CEU opportunities for providers on symptom management. Collaborate with the many agencies providing palliative care education.
- Encourage reimbursement for palliative care (case management and follow-up).
- Support efforts to increase information to patients and their loved ones about disease progression and symptom management.
- Increase the number of certified practitioners in palliative care.
- Ensure that patients have access to complementary alternative medicine (CAM) and that these interventions are coordinated with the person's overall treatment plan.
- Encourage providers to consult with or refer patients to palliative care experts.
- Increase availability of and access to support at home after treatment.
- Provide opportunities to increase cultural competency of all providers.

# TAB 7

# End of Life

## End of Life Work Group

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# END OF LIFE CARE

In 2004 the National Institutes of Health held the State-of-the-Science Conference on Improving End of Life Care. What is meant by "end of life?" Conference participants found existing definitions ambiguous and set out to clarify the term. They agreed that while in most cases it is not possible to accurately predict an individual's death, it is possible to identify the components that mark the transition to the final stage of life. They found evidence to support the existence of two such components: (1) the presence of a chronic disease(s) or symptoms, or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require paid professional or unpaid care and can lead to death.[175]

The conferees also identified a number of subjects in need of further research. These include (1) bereavement for special populations, including children; (2) the effect of advance directives on the quality of end of life care; (3) advance care planning, a process for preparing for the end of life, including discussion of death; and (4) the burden of end of life care on caregivers. More research is also needed on interventions that will improve outcomes for patients and their caregivers.[176]

Finally, those participating in the conference made the following recommendations: (1) use what is known about pain management; (2) consistently train health care professionals on symptom management and evaluate the [medical and health profession] curricula to determine its ultimate effect on the quality of end of life care; and (3) improve communication between health care providers (physicians and nurses). The last recommendation is based on studies conducted outside the U.S. demonstrating that better communication between health care providers improved quality of care.[177]

There are many barriers to improved end of life care. Inadequate pain management, for example, has been identified as a significant barrier to quality of life at the end of life by many researchers. In 2001 The National Cancer Policy Board (NCPB) of the Institute of Medicine, in its report "Improving Palliative Care for Cancer," declared, "Patients, their families and caregivers all suffer from inadequate care available to patients in pain and distress."[178] The NCPB report highlights the medical, research, and regulatory impediments to adequate pain management and proposes recommendations for their improvement.

Other obstacles to adequate end of life care include payment, systemic, and legal matters as well as attitudinal, behavioral, and educational challenges. One payment issue, for example, is the federal Medicare hospice benefit that limits the availability of the full range of interventions needed at the end of life. The benefit requires that death be predicted six months in advance. It also requires beneficiaries to choose between skilled care and hospice care when entering a nursing home after a hospital stay. Some state-specific Medicaid programs contain similar barriers to the highest quality of care for cancer patients at the end of life.

Advance care planning is another issue where gaps prevail. In addition to the need for more research, as mentioned earlier, palliative care and hospice organizations emphasize the value of discussion between patients and family members that advance care planning requires.

One tool that professionals working on end of life care have designed is Five Wishes, an advance directive that offers a framework for discussions.[179]

The Agency for Healthcare Research and Quality (AHRQ) has furthered research on advance care planning. AHRQ has funded a number of studies on this topic and describes them in "Research in Action Report, Advance Care Planning: Preferences for Care at the End of Life." According to that report, physicians can and should help patients make their wishes known. The AHRQ-funded studies revealed that "less than 50 percent of the severely or terminally ill patients studied had an advance care directive in their medical records;…between 65 to 76 percent of physicians whose patients had advance care directives were not aware that it existed;…physicians were only about 65 percent accurate in predicting patient preferences and tended to make errors of undertreatment, even after reviewing the patient's advance directive." The results of the studies also indicated that language in advance directives was often too general to provide clear instructions and surrogates named were often not available or were too emotional to offer assistance.[180] There are many areas of possible intervention and research that could improve end of life care for cancer patients and their loved ones.

Another area requiring attention concerns the unique needs of child cancer patients at the end of life. Resources and systems of care designed for adults do not fit children. According to a study published in the New England Journal of Medicine, 80 percent of children dying from cancer in this country are suffering, and their symptoms are not being adequately palliated.[181] An Institute of Medicine report, "End of Life Care: Special Issues in Pediatric Oncology,"[182] outlines the challenges and introduces possible strategies to improve end of life care for children. Some of these strategies include the following:

- Investigate the barriers to optimal symptom control in pediatric oncology.
- Develop ways to teach providers how to communicate bad news.
- Incorporate palliative and curative therapies simultaneously.
- Evaluate models of informed and shared decision making that are family centered.
- Evaluate the needs of siblings.
- Address barriers to reimbursement for palliative care.

Another issue of concern is the disparate use of palliative and hospice care across the nation. Despite higher incidence and death rates from cancer, African Americans and other racial and ethnic groups use palliative and hospice care at a remarkably lower rate than the White non-Hispanic population.[183] Based on 2003 national data, only 4 percent of the hospice care population includes Hispanic people and only 9 percent are African American.[184] Explanations for this underutilization include access and cultural issues as well as information deficits by providers and others about the services and their benefits.

The scientific literature reveals evidence-based interventions to address the gaps, issues, barriers, and concerns pertaining to end of life care. For example, providing cancer survivors with information about end of life and helping them make their wishes known early on will help them make important decisions. Also, as noted in the palliative care section of this document, if cancer symptoms can be managed, then cancer survivors can focus on their loved ones and finalize their affairs. Removing structural barriers such as inadequate heath care coverage of hospice care is another evidence-based intervention. Finally, children who lose a loved one to cancer require specialized interventions. Although not enough is known about the long-term

effects of early losses in a child's life, bereavement interventions are valuable. These and other interventions can be brought about today to improve the quality of end of life for cancer survivors while more study and investigation is completed to enhance and refine approaches.

**End of Life Care in Massachusetts**

Massachusetts has made important inroads into improved end of life care. These accomplishments can be attributed to the efforts of a number of local organizations, including the Massachusetts Commission on End of Life Care, the Hospice and Palliative Care Federation of Massachusetts, and the Massachusetts Compassionate Care Coalition.

The Massachusetts Commission on End of Life Care was established in 2001. The commission pursues its mission to improve the quality of life at the end of life by promoting public, professional, and institutional awareness, education and engagement, and by advocating for changes in public policies and health care systems. The commission collaborates with organizations throughout the state on projects that include statewide planning, improved pain management policy, education of clergy, end of life care for veterans, financial implications of improved end of life care, and the multicultural needs of older adults at end of life.

The commission has also developed the *Resource Guide for End of Life Services in Massachusetts.* Despite the inevitability of death, many Massachusetts residents are not aware of the health care and other options available to them as they approach the end of life. The *Resource Guide* helps individuals and their loved ones find these options and better address the difficult subjects around end of life. The *Resource Guide* includes a searchable database of end of life providers, organizations, and agencies throughout the state. It is available online and in print.[185]

The Hospice & Palliative Care Federation of Massachusetts (Federation) was founded in 1980. Its mission is to advance and promote excellence in end of life care by advocating for members, patients, families, and the end of life caregiving community, providing education, enhancing awareness, and fostering innovation in end of life services. It provides technical support to hospice programs, advocacy for legislation that benefits hospice patients and their families, educational materials, and best practice white papers, or protocols, on clinical and access issues.[186]

Another statewide organization, the Massachusetts Compassionate Care Coalition (MCCC) is a statewide coalition of consumers and caregivers, providers, clergy, elder lawyers, institutions, organizations, and communities committed to improving end of life care in the Commonwealth. Founded in 1999, MCCC has developed creative partnerships and networking forums to make positive changes in cultural attitudes, expectations, and practices surrounding death, dying, and bereavement.[187] For example, the MCCC partnered with the Federation to create an end of life training curriculum for nursing educators. Ninety registered nurses were trained as End of Life Nursing Education Consortium trainers (ELNEC). This nationally recognized curriculum was initially funded by the Robert Wood Johnson Foundation.

Massachusetts has begun a number of endeavors to address the end of life needs of pediatric cancer patients. The Catastrophic Illness in Children Relief Fund (CICRF) is one such effort. It provides financial assistance to families with children who have medical needs beyond what their health insurance plan covers. The fund enables families to request assistance for a full range of services that could reduce suffering and improve the quality of their child's life. Although there are general guidelines for use of the funds, each request is reviewed individually

and decisions are based on the needs of each child. Currently the CICRF program is drafting best practice guidelines for pediatric palliative care.[188] Another effort by the Commonwealth for terminally ill children was the 2004 Guidelines for school doctors and nurses, issued by the Massachusetts Department of Public Health, "for the care of students with Comfort Care/Do Not Resuscitate orders."[189] This provides guidance for schools so children can continue to attend and stay in contact with their support and social network.

Another Massachusetts accomplishment in the end of life arena is the Comfort Care/Do Not Resuscitate (CC/DNR) Order Verification Protocol. A Do Not Resuscitate order demands that emergency service (EMS) personnel not revive an individual in the event of cardiac or respiratory arrest. Until this order, EMS personnel were obligated to perform full resuscitative measures when encountering a patient unable to convey directions regarding medical treatment.[190] However, more patients, when it is medically appropriate, are choosing not to be resuscitated. This protocol is approved by the Department of Public Health (DPH) and allows EMS personnel, in an out-of-hospital setting, to honor a patient's request not to resuscitate and to provide the patient with palliative care in conformance with the Comfort Care protocol.

**Highlights of Gaps, Issues, Barriers, and Concerns**

The gaps, issues, barriers, and concerns about end of life care in Massachusetts mirror those existing nationwide. This includes the problems with advance directives already described as well as the fact that health care proxies are the only advance directives that are legal in the Commonwealth. In other states, living wills offer individuals an opportunity to communicate more detail about their wishes for medical treatment, the withholding of treatment, and end of life care. In Massachusetts, as elsewhere in the nation, physicians and other health care providers need to initiate early discussions with their patients about advance care planning. Providers who know the cancer patient's wishes are better able to help the individual and his or her family make choices. Introducing proven, standardized curriculum for health care providers is also important and has the potential of improving the quality of end of life care.

There is also a gap in the general public's understanding of advance care planning, and Massachusetts professionals have been discussing the most opportune age for initiating educational programs on the topic. One suggestion, for example, is to conduct education about advance care planning as early as high school.

The need to improve pediatric end of life care in Massachusetts reflects the same need at the national level. The state has fifteen hospice organizations with specific expertise in pediatric end of life care. Staffing and financial barriers impede efforts to further the skills of hospice providers to meet the needs of dying children.

Another topic of concern in this state as well as across the nation is the disparity in utilizing hospice care. The National Hospice and Palliative Care Organization's 2003 National Data Set Report reveals that 94 percent of the individuals who use hospice services in the Commonwealth are White non-Hispanic, 2.1 percent are Black non-Hispanic, and 6 percent are Asian non-Hispanic. The barriers to using hospice services in this state are the same as those expressed nationally, and include information deficits by providers and others about the services and their benefits.

Finally, the financial barriers to better end of life care in the Commonwealth include limitations in Medicare coverage for hospice. For example, Medicare hospice benefits will not cover medical interventions that may be considered "curative treatment" as opposed to palliation. This means Medicare will not cover patient participation in clinical trials even if the clinical trials address palliative care, since clinical trials are categorized as "treatment." Another Medicare issue is for patients who choose not to enroll in hospice. They are excluded from coverage of the psychosocial services that a hospice enrollment provides.[191] Many of these services are necessary for adequate end of life care.

## Goal: Ensure that all Commonwealth residents have access to quality end of life care.

**Outcome Measure 43: By 2011, increase the number of people who use hospice care in the last year of life 30 percent.** (
Healthy People 2010: no objective listed
Baseline: 28% Database: Hospice and Palliative Care Federation of Massachusetts, 2004

**Outcome Measure 44: By 2011, increase the medium number of days in hospice care to 20.**
Healthy People 2010: no objective listed
Baseline: 15.4 days Database: Hospice & Palliative Care Federation of Massachusetts, 2003

**Strategies to Achieve the Goal**

The work group selected the following strategies to achieve the goal:

- Support efforts to educate survivors and loved ones about available services, resources, and quality care options for end of life care for children and adults to enhance informed and shared decision making.
- Study and then devise strategies to decrease health disparities in utilization of hospice care.
- Ensure that pediatric and adult palliative and hospice care, and particularly symptom management, are a central part of end of life care in all settings.
- Support systems that ensure advance care planning and advance care directives are discussed, written, and disseminated.
- Educate survivors and their loved ones about the availability and importance of advanced care planning, including health care proxies, wills, and financial planning.
- Encourage education of all health care providers on end of life care.
- Support education of all health care professionals on how to address and discuss strategies for end of life care with survivors and their loved ones in a timely manner.
- Determine the feasibility of tracking the number of people who have health care proxies.
- Encourage reform in hospice coverage by Medicare and all third party payers.
- Ensure bereavement support is available to loved ones, including children and adults.
- Encourage research on best practice standards in culturally competent end of life care.
- Support efforts to enhance the capacity for quality end of life care for all children and their families.

# TAB 8

## Surveillance, Evaluation, and Research Work Group

## Surveillance, Evaluation, and Research Work Group

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# SURVEILLANCE, EVALUATION, AND RESEARCH INTO PRACTICE

Surveillance, evaluation, and putting research into practice are essential components of effective, comprehensive cancer control. Surveillance is the process of collecting and measuring important data on cancer trends and patterns. The two main surveillance systems are the cancer registries and the Behavioral Risk Factor Surveillance System (BRFSS).

The Center for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR) supports central cancer registries and the use of registry data in nearly every state, the District of Columbia, and some U.S. territories. Cancer registries collect data about cancer incidence by type of cancer, stage at diagnosis, and treatment received. As required by law, hospitals, physicians' offices, surgical centers, therapeutic radiation facilities, and pathology laboratories report this data to the statewide cancer registry corresponding to the residence of the individual diagnosed with cancer. Some registries also collect survival data. Public health professionals use cancer registry data to assess and address the burden of cancer and to guide and monitor cancer prevention, control, treatment, and research.[192] Registry data also has the potential to be used to determine disparities in cancer incidence, mortality, and treatment based on socioeconomic status; to develop prevalence estimates for cancer control planning; to describe patterns of care; and to determine disparities in early detection and first course of treatment. Although cancer registry data has multiple uses, it is not used in the same manner or to the same extent by every state-level registry.

The Behavioral Risk Factor Surveillance System (BRFSS) is a telephone survey established by the CDC in 1984 "to monitor state-level prevalence of the major behavioral risks among adults associated with premature morbidity and mortality…. CDC developed a standard core questionnaire for states to use to provide data that could be compared across states. The BRFSS, administered and supported by the Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, CDC, is an ongoing data collection program. By 1994 all states, the District of Columbia, and three territories were participating in the BRFSS."[193]

Evaluation is a critical component of comprehensive cancer control efforts. A five-step evaluation process has been recommended by Cancer Control PLANET (Plan, Link, Act, Network with Evidence-based Tools), a Web-based tool that aids in the design, implementation, and evaluation of evidence-based cancer control programs. Cancer Control PLANET is a collaborative effort of the National Cancer Institute, Centers for Disease Control and Prevention, American Cancer Society, the Substance Abuse and Mental Health Services Administration, and the Agency for Healthcare Research and Quality. The five recommended evaluation steps are (1) assess cancer control program priorities, (2) identify potential partners, (3) determine effectiveness of different intervention approaches, (4) find research-tested intervention programs and products, and (5) plan and evaluate cancer control programs.[194]

Research and evaluation are of no use unless they are put into practice. Two major national organizations focus on translating research into practice: the National Cancer Institute's Quality of Cancer Care Initiative and the Agency for Healthcare Research and Quality's "Put Prevention Into Practice" program.

NCI's Quality of Cancer Care Initiative was established in response to the lack of consensus on what constitutes "quality care" as well as to the need to ensure that best practices, once defined, are accomplished equitably to prevent disparities in care. The organizational core of the Initiative is the Quality of Cancer Care Committee (QCCC), whose members come from the U.S. Department of Health and Human Services as well as other federal agencies.

The QCCC supports the following three collaborative projects:

- The Health Resources and Services Administration and Centers for Disease Control and Prevention Collaborative, to improve screening, referral, and follow-up for breast, cervical, and colorectal cancers among underserved populations.
- The Centers for Medicare and Medicaid Services Collaborative, to increase awareness and improve delivery of the Medicare colorectal cancer screening benefit.
- The Department of Veterans Affairs Collaborative, to improve utilization of evidence-based colorectal cancer screening, surveillance, treatment, and end of life care practices in the VA Health Care System.[195]

In response to clinician, office, and patient barriers to the effective delivery of clinical preventive services, "Put Prevention Into Practice" (PPIP) is a program designed for health care providers to "improve the delivery of clinical preventive services, such as those based on USPSTF (U.S. Preventive Services Task Force) recommendations." The program includes research-tested interventions that can be accessed in print or online and include clinical guides as well as consumer information.[196]

There is sufficient and strong evidence that specific interventions could have a positive effect on the gaps, issues, barriers, and concerns listed above. As noted in other sections of this document, there is sufficient evidence that interventions that increase consumer and provider knowledge level can have a positive effect. Use of surveillance systems to make decisions about strategies and initiative has strong evidence in the literature and is clearly documented in Cancer Control PLANET.

## Surveillance in Massachusetts

In Massachusetts, as nationally, the two main surveillance systems are the cancer registry and the Behavioral Risk Factor Surveillance System.

### Massachusetts Cancer Registry

The Massachusetts Cancer Registry (MCR) was established by the Massachusetts Legislature in 1980 and has been collecting data on malignant disease since 1982. The MCR collects data on all newly diagnosed cases of cancer in Massachusetts. This data, in aggregate form, is available through consultation, technical assistance, presentations, and various publications and reports, including the annual report *Cancer Incidence and Mortality in Massachusetts* and the *City/Town Supplement* series. MCR also prepares publications focused on certain cancer types or certain populations, such as the *Data Report on Colorectal Cancer in Massachusetts, Cancer in Massachusetts Women, Childhood Cancers in Massachusetts,* and *Cancer in Massachusetts Men.* The registry collects and analyzes data on stage of diagnosis of different cancers to monitor success and racial/ethnic disparities of screening interventions. They

use geographic information systems (GIS) to map clusters of late-stage diagnoses to identify underserved populations and communities. For each of the six years from 1997 to 2002, the Massachusetts Cancer Registry received Gold recognition certificates from the North American Association of Central Cancer Registries for meeting the highest standard of incidence data quality (awarded for completeness, accuracy, and timeliness).[197,198]

**Massachusetts Behavioral Risk Factor Surveillance System**

The Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) is a random-digit-dial telephone health survey of Massachusetts adults conducted in English, Spanish, and Portuguese. The survey involves only non-institutionalized adults residing in households with telephones. The number of adults completing the survey has grown from 1,825 adults in 1992 to 8,149 adults in 2000. The cities of Boston, Worcester, Springfield, Lawrence, Lowell, Fall River, and New Bedford are over-sampled. BRFSS does have some limitations, including inability to reach households that are without a telephone, increasing replacement of home phones with cell phones, non-completion of the survey by contacted households, inability to reach the randomly selected adult in a household, and adults refusing to participate in the survey. An additional limitation is that the data gathered through BRFSS is entirely self-report.[199] Other surveillance systems and data sources must be considered when monitoring cancer prevention and early detection.

**Youth Surveillance Systems**

Data on Massachusetts youth are collected through two survey instruments, the Youth Risk Behavior Survey and the Youth Health Survey, which are administered biannually in alternating years.

The Youth Risk Behavior Survey (YRBS) is administered by the Massachusetts Department of Education and measures the prevalence of tobacco use, alcohol and other drug use, and sexual behaviors that might lead to unintended pregnancy or sexually transmitted disease. It also measures dietary behaviors, physical activity, and behaviors associated with intentional or unintentional injuries. Participants include students in randomly selected high schools. YRBS data is available only in aggregate and not by individual schools or communities.[200]

The Youth Health Survey (YHS) is administered by the Massachusetts Department of Public Health's Bureau of Substance Abuse Services and measures the prevalence of substance abuse among Massachusetts youth. In addition to prevalence and risk, the YHS includes measures of protection. Participants include a sample of school classrooms within school districts. Like the YRBS data, YHS data is available only in aggregate and not by individual schools or communities.[201]

**Highlights of Activities**

Massachusetts is home to multiple collaborative efforts, with several efforts created to address cancer disparities in particular. For instance, the Massachusetts Cancer Registry and the Women's Health Network at the Massachusetts Department of Public Health recently assessed social disparities in breast cancer diagnosis and treatment. They did so by comparing the stage at diagnosis and treatment of women diagnosed with breast cancer through the Women's Health

Network (WHN), a National Breast and Cervical Cancer Early Detection Program (NBCCEDP) for low-income and uninsured women in Massachusetts, to other breast cancer patients in the state.[202]

The Center for Community-Based Research at Dana-Farber Cancer Institute seeks to promote behaviors that reduce cancer risk, reduce potential exposures that increase cancer risk, modify social policies to reduce cancer risk, and increase access to and comprehension of cancer risk information. The mission of the Center for Community-Based Research is accomplished with community partnerships and collaborations through the following: intervention research, health communication research, research on the social context of cancer risk, disparities research, and research dissemination and knowledge transfer.[203]

Harvard School of Public Health, Dana-Farber/Harvard Cancer Center, and Brigham and Women's Hospital recently received a grant from the National Cancer Institute to establish MASS CONECT (Massachusetts Community Networks to Eliminate Cancer Disparities through Education, Research and Training). The purpose of MASS CONECT is to improve prospects for eliminating socioeconomic and racial/ethnic cancer disparities. The project will involve the following four cores: community-level cancer disparities data, media and communication, leadership and research training, and prevention and clinical services. The grant will span five years and will involve the cities of Boston, Worcester, and Lawrence.

The national Cancer Prevention and Control Research Network (CPCRN) is a federally funded, national network of academic, public health, and community partnerships working together to reduce cancer burden and disparities by disseminating and translating proven interventions into practice.[204] The CPCRN comprises five sites, one of which is the Massachusetts Cancer Prevention Community Research Network (MCPCRN). Established in 2002, the MCPCRN is a collaborative effort between the Harvard Prevention Research Center (HPRC), the Boston University Prevention Research Center (BU-PRC), the Dana-Farber/Harvard Cancer Center (DF/HCC), and a steering committee of community and academic representatives. The MCPCRN focuses on low-income and ethnically diverse populations with the aim of engaging community sectors not traditionally involved in cancer prevention and control efforts, including but not limited to work sites, labor unions, and health care providers.[205]

The Massachusetts Comprehensive Cancer Control Coalition has identified outcome measures to monitor the burden of cancer in the Commonwealth and ultimately evaluate the efficacy of the Coalition and its comprehensive cancer control plan. Progress toward each outcome will be reported regularly to the Coalition members as well as any interested parties. The outcome measures mirror the continuum covered in the Plan and are listed in surveillance table 1 (next page).

**Surveillance Table 1. Outcome Measures for Massachusetts Comprehensive Cancer Control Statewide Plan 2006-2011**

| PREVENTION OUTCOME MEASURES | |
|---|---|
| **1.** | **By 2011, reduce the percentage of all adult smokers to 12 percent**.<br>Healthy People 2010: 12%<br>Baseline All: 19% Database: BRFSS 2003 |
| **2.** | **By 2011, reduce cigarette smoking among pregnant women during their last three months of pregnancy to 1 percent.**<br>Healthy People 2010: 1%<br>Baseline All: 7.7% Database: Vital Statistics 6/30/2005 |
| **3.** | **By 2011, reduce the proportion of high school students who are current smokers (smoked at least one cigarette in the last 30 days) to 16 percent.**<br>Healthy People 2010: 16%<br>Baseline All: 21% (26% in 2000) Database: YRBS 2003 |
| **4.** | **By 2011, reduce the proportion of high school students who are daily smokers to 6 percent.**<br>Healthy People 2010: 16%<br>Baseline All: 7% (10% in 2001) Database: YRBS 2003 |
| **5.** | **By 2011, reduce the proportion of high school students who report using smokeless tobacco in the past 30 days to 1 percent.**<br>Healthy People 2010: 1%<br>Baseline All: 4% Database: YRBS 2003 |
| **6.** | **By 2011, reduce the proportion of high school students who report smoking cigars in the past 30 days to 8 percent.**<br>Healthy People 2010: 8%<br>Baseline All: 12% Database: YRBS 2003 |
| **7.** | **By 2011, reduce the proportion of high school students who report having their first cigarette before the age of thirteen to 12 percent.**<br>Healthy People 2010: no objective<br>Baseline All: 15% (19% in 2001) Database: YRBS 2003 |
| **8.** | **By 2011, decrease the percentage of public middle school students, grades 6–8, who have smoked in the last thirty days to 5 percent.**<br>Healthy People 2010: no objective<br>Baseline All: 7.1% Database: MA Youth Health Survey 2004 |
| **9.** | **By 2011, increase the number of adults living in households where smoking is not allowed to 80 percent.**<br>Healthy People 2010: no objective<br>Baseline All: 71% Database: BRFSS 2003 |
| **10.** | **By 2011, increase the percentage of Commonwealth residents who report having a usual source of primary care to 100 percent.**<br>Healthy People 2010 Target: 96%<br>Baseline All: 87% Database: BRFSS 2003 |
| **11.** | **By 2011, increase the percentage of Commonwealth residents who have health insurance to 100 percent.**<br>Healthy People 2010 Target: 100%<br>Baseline All: 92% Database: BRFSS 2003 |
| **12.** | **By 2011, reduce the adult prevalence of obesity to 15 percent and overweight to 40 percent.**<br>Healthy People 2010: 15 % for obese, none for overweight<br>Baseline All: 70% Database: BRFSS 2003 |
| **13.** | **By 2011, decrease the percentage of students ages 12–19 who are at risk or are currently overweight to 5 percent.**<br>Healthy People 2010: 5%<br>Baseline All: 24% Database: YRBS 2003 |
| **14.** | **By 2011, increase the proportion of adults who report regular moderate physical activity (physical activity five or more sessions per week for 30 minutes or more per session regardless of intensity) to 70 percent.**<br>Healthy People 2010: 70%<br>Baseline All: 53% Database: BRFSS 2003 |
| **15.** | **By 2011, increase the proportion of high school students who report regular vigorous physical activity to 85 percent and those who report regular moderate physical activity to 35 percent.**<br>Healthy People 2010: vigorous 85%, moderate 35%<br>Baseline All: vigorous 61%, moderate 24%, total 85%<br>Database: YRBS 2003 |

| | |
|---|---|
| **16.** | **By 2011, decrease the proportion of adults who drink more than the moderate level of alcohol (adult women one drink a day and adult men two drinks a day) 4 percent.**<br>Healthy People 2010: no objective<br>Baseline All: 7.7% Database: BRFSS 2003 |
| **17.** | **By 2011, decrease the proportion of adults who report having been sunburned within the last year to 20 percent.**<br>Healthy People 2010: no sunburn objective<br>Baseline All: 37% Database: BRFSS 2003 |
| **18.** | **By 2011, reduce the number of people who are drinking water contaminated with arsenic at levels above 10 parts per billion (ppb).**<br>Healthy People 2010: no objective<br>Baseline: to be determined Database: EPA 2004 |
| **19.** | **By 2011, increase the number of homes tested for radon in regions where radon levels are high.**<br>Healthy People 2010: no objective<br>Baseline: to be determined Database: to be determined |
| **20.** | **By 2011, reduce the number of people who die of mesothelioma by 30 percent**.<br>Healthy People 2010: no objective<br>Baseline: 1,355 deaths Database: MCR 1979–2001 |
| **21.** | **By 2011, complete the cleanup of all PCB Superfund sites in Massachusetts.**<br>Healthy People 2010: no objective<br>Baseline: 0 of 15 Database: EPA 2005 |
| **22.** | **By 2011, increase public notification of the connection between cancer risk and specific sexual behaviors by including this information in 100 percent of relevant public health educational materials.**<br>Baseline: to be determined<br>Database: survey of public information materials used in MDPH 2005 |
| **23.** | **By 2011, decrease the number of children and adults who contract Hepatitis C 30 percent.**<br>Baseline: 10,000 cases (immigrants not included)<br>Database: Hepatitis C Surveillance System 2004 |
| **24.** | **By 2011, increase the number of people who are aware of their family history of cancer.**<br>Baseline: to be determined Database: to be determined |
| | **EARLY DETECTION OUTCOME MEASURES** |
| **25.** | **By 2011, increase the percentage of women ages 40+ who have had a mammogram in the previous two years to 90 percent.**<br>Healthy People 2010: 70% mammogram in preceding two years (women 40+)<br>Baseline All: 85% Database: BRFSS 2003 |
| **26.** | **By 2011, decrease the proportion of White non-Hispanic and Black non-Hispanic women diagnosed with late stage (regional and distant) breast cancer to 35 per 100,000.**<br>Baseline late diagnosis: 45.7 White non-Hispanic and 45.7 Black non-Hispanic<br>Database: MCR 1998–2002 |
| **27.** | **By 2011, increase the percentage of women ages 18–69 with an intact cervix who report having had a Pap test in the previous three years to 90 percent.**<br>Healthy People 2010: 90% (Pap test within the last three years)<br>Baseline All: 88.2% Database: BRFSS 2002 |
| **28.** | **By 2011, decrease the proportion of Black non-Hispanic women diagnosed with late stage (regional and distant) cervical cancer to 2 per 100,000**.<br>Baseline late diagnosis: 7.1 Database: MCR 1998–2002 |
| **29.** | **By 2011, increase the percentage of adults ages 50+ who have had FOBT or endoscopy to 85 percent.**<br>Healthy People 2010: 50% (colorectal screening 50+)<br>Baseline All: 67.4% Database: BRFSS 2003 |
| **30.** | **By 2011, decrease the proportion of White non-Hispanic and Black non-Hispanic men and women diagnosed with late stage (regional and distant) colorectal cancer to 25 per 100,000.**<br>Baseline late diagnosis: White non-Hispanic males 41.6, females 30.4<br>Black non-Hispanic males 42.3, females 30.1<br>Database: MCR 1998–2002 |
| **31.** | **By 2011, decrease the proportion of Black non-Hispanic men diagnosed with late stage (regional and distant) prostate cancer to 20 per 100,000.**<br>Baseline late diagnosis: 45.3 Database: MCR 1998–2002 |
| **32.** | **By 2011, increase the number of men who have discussed prostate cancer early detection with their providers.**<br>Healthy People 2010: currently no measure<br>Baseline: to be determined Database: to be determined |
| **33.** | **By 2011, increase the number of women in high-risk groups who have discussed their personal** |

| | |
|---|---|
| | **risk for ovarian cancer with their provider.**<br>Baseline: to be determined Database: to be determined |
| **34.** | **By 2011, increase the number of oral health providers who counsel patients on the causal link between alcohol, smoking, and cancer**.<br>Healthy People 2010: currently no measure<br>Baseline: to be determined Database: Oral health provider survey 2005 |
| **35.** | **By 2011, formally review emerging science in cancer at least twice a year.**<br>Baseline: once a year Database: CCCP research 2005 |
| | **TREATMENT, PALLIATION, AND SURVIVORSHIP OUTCOME MEASURES** |
| **36.** | **By 2011, improve the overall experience and quality of life of all Commonwealth residents who are living with, through, and beyond cancer.**<br>Healthy People 2010: no objective<br>Baseline: to be determined Database: to be determined |
| **37.** | **By 2011, increase the number of people in Massachusetts who call the toll-free numbers for the Cancer Information Service (CIS) or the American Cancer Society (ACS).**<br>Healthy People 2010: no objective<br>Baseline: 1,322 cancer information calls to CIS Database: CIS 2004<br>Baseline: 17,813 cancer information calls to ACS Database: ACS 2004 |
| **38.** | **By 2011, increase the number of individuals who receive their cancer treatment from Commission on Cancer-approved cancer centers to 90 percent.**<br>Healthy People 2010: no objective<br>Baseline All: 80% Database: ACOS 2004 |
| **39.** | **By 2011, increase participation in cancer clinical trials to 10 percent.**<br>Healthy People 2010: no objective<br>Baseline: 4% Database: NCI 2004 |
| **40.** | **By 2011, increase the number of evidence-based educational forums or initiatives on informed and shared decision making.**<br>Healthy People 2010: no objective<br>Baseline: to be determined Database: to be determined |
| **41.** | **By 2011, increase the number of certified palliative care providers by 15 percent.**<br>Healthy People 2010: no objective<br>Baseline: 52 certified physicians; 6 certified nurse practitioners; 178 certified registered nurses; 2 certified LPN/VN; 76 certified nursing assistants<br>Physician Database: American Board of Hospice & Palliative Medicine, June 2005<br>Nursing Database: Hospice & Palliative Nurses, June 2005 |
| **42.** | **By 2011, increase the number of NCI Cancer Centers and CoC-approved hospitals with palliative care programs to 50 percent.**<br>Healthy People 2010: no objective<br>Baseline: 20% (10 of 50)<br>Database: Massachusetts Telephone Survey, NCI Cancer Centers, and CoC-approved hospitals, June 2005. |
| | **END OF LIFE CARE OUTCOME MEASURES** |
| **43.** | **By 2011, increase the number of people who use hospice care in the last year of life 30 percent.**<br>Healthy People 2010: no objective<br>Baseline: 28%<br>Database: Hospice and Palliative Care Federation of Massachusetts, 2004 |
| **44.** | **By 2011, increase the medium number of days in hospice care to 20.**<br>Healthy People 2010: no objective<br>Baseline: 15.4 days<br>Database: Hospice & Palliative Care Federation of Massachusetts 2003 |
| | **SURVEILLANCE, RESEARCH, AND EVALUATION OUTCOME MEASURES** |
| **45.** | **By 2011, expand first course of treatment studies on breast and other cancers.**<br>Baseline: Breast Cancer First Course of Treatment 2005<br>Database: MCR 2005 |
| **46.** | **By 2011, disseminate progress on outcome measures listed in this plan.**<br>Baseline: 0<br>Database: Review 2005 Massachusetts Comprehensive Cancer Control Plan 2001 |
| **47.** | **By 2011, devise a system that ensures routine communication and dissemination of program activity evaluations.**<br>Baseline: 70% of Comprehensive Cancer Control activities evaluated<br>Database: program specific 2005 |
| **48.** | **By 2011, increase communication by way of the *Coalition Newsletter* of research that can be put into practice throughout the cancer continuum.**<br>Baseline: to be determined Database: Review of Newsletters 2004–2005 |

**Highlights of Gaps, Issues, Barriers, and Concerns**

There are significant gaps in terms of surveillance, evaluation, and translation of research into practice. Current surveillance systems lack data on survivorship issues, social disparities, and the prevalence of cancer in Massachusetts.

In terms of evaluation, there are two major gaps. The first is that the 1998–2001 Massachusetts Comprehensive Cancer Control Plan did not have outcome measures. Although this current plan includes outcome measures, there are no corresponding baseline measures for some of them. Determining these baseline measures will be an important part of the evaluation.

The second gap is insufficient communication and consistency among cancer stakeholders in Massachusetts with regard to evaluation practices and results. Several organizations throughout the state have conducted their own interventions; however, some of these interventions have been evaluated while others have not. Among those that have been evaluated, this information is not centralized, nor is it routinely disseminated to Cancer Control Coalition partners. It is essential that ongoing and new programs and interventions be evaluated to ensure that interventions are linked to the current scientific evidence and that high-risk populations are targeted. In addition, it is essential that this information be accessible or disseminated to all coalition members so that current and future cancer prevention and control efforts are well informed.

Finally, although several impressive collaborative efforts are underway in Massachusetts, there is still a need for increased communication, integration, and collaboration to facilitate research into practice. There is especially a need for collaborations that extend beyond the medical and academic center of Greater Boston. There is also a need for additional research on issues faced by survivors and late and long-term effects of cancer treatment. Dialogues about research into practice should be expanded to include survivors, health care providers, community outreach workers, policymakers, and advocacy groups.

The Massachusetts Cancer Control Coalition will take the lead in the following efforts:

- Using and introducing surveillance systems
- Making data-driven decisions about cancer prevention and control efforts
- Following the five steps outlined in Cancer Control PLANET
- Facilitating a process for putting research into practice

**Goal: The Massachusetts Cancer Control Coalition will use surveillance, evaluation, and research to make decisions about cancer control interventions.**

**Outcome Measurement 45: By 2011, expand first course of treatment studies on breast and other cancers.**
Baseline: Breast Cancer First Course of Treatment 2005
Database: MCR 2005

**Outcome Measurement 46**: **By 2011, disseminate progress on outcome measures listed in this plan.**
Baseline: 0
Database: Review 2005 Massachusetts Comprehensive Cancer Control Plan 2001

**Outcome Measurement 47**: **By 2011, devise a system that ensures routine communication and dissemination of program activity evaluations.**
Baseline: 70% of Comprehensive Cancer Control activities evaluated
Database: program specific 2005

**Outcome Measurement 48: By 2011, increase communication by way of the *Coalition Newsletter* of research that can be put into practice throughout the cancer continuum.**
Baseline: to be determined Database: Review of newsletters 2004–2005

**Strategies to Achieve the Goal**

The work group selected the following strategies:

- Report to the Coalition membership and other interested parties the progress made on each of the outcome measurements listed in this plan.
- Seek opportunities to educate health systems and policy makers about cancer health disparities and the importance of collecting socioeconomic demographic data.
- Collaborate with person or groups conducting research to communicate these findings to practitioners.
- Use BRFSS, MCR, YRBS, YHS, and other data sets to make decisions about intervention specific to cancer prevention and control.
- Use incidence, mortality, and stage at diagnosis data to monitor and report trends.
- Encourage regular evaluation of program activities for reach and effect, and incorporate these findings into future activities.
- Review, communicate, and disseminate program activity and evaluations through the Coalition network.
- Encourage communication, integration, and collaboration that will facilitate putting research into practice.
- Collaborate and coordinate with outcome researchers and cancer survivors in Massachusetts on opportunities and topics for research on long-term and late effects of cancer treatment.
- Coordinate and facilitate public and private partnerships as needed to secure funding to support community based participatory cancer prevention research.
- Advocate for support of prevention, early detection, and treatment research.
- Feature research-into-practice meeting themes for coalition meetings that include community, practitioners, policy makers, and advocacy groups.

# Appendix A: Healthy People 2010

Healthy People 2010 is a comprehensive set of disease prevention and health promotion objectives for the nation to achieve over the first decade of the new century. Created by scientists both inside and outside the government, it identifies a wide range of public health priorities and specific, measurable objectives.

**The Central Goals of Healthy People 2010**
Healthy People 2010 is designed to achieve two overarching goals:

- Increase quality and years of healthy life.
- Eliminate health disparities.

These two goals are supported by specific objectives in 28 focus areas. Each objective includes a target to be achieved by the year 2010.

**Focus Area 3: Cancer**
Co-Lead Agencies: Centers for Disease Control and Prevention, National Cancer Institute

Goal: Reduce the number of new cancer cases as well as the illness, disability, and death caused by cancer.

Objectives (short title):

3-1 Cancer deaths
3-2 Lung cancer deaths
3-3 Breast cancer deaths
3-4 Cervical cancer deaths
3-5 Colorectal cancer deaths
3-6 Oropharyngeal cancer deaths
3-7 Prostate cancer deaths
3-8 Melanoma deaths
3-9 Sun exposure
3-10 Provider counseling about preventive measures
3-11 Pap tests
3-12 Colorectal cancer screening
3-13 Mammograms
3-14 Statewide cancer registries
3-15 Cancer survival

More information about Healthy People 2010 can be found at http://www.healthypeople.gov.

Source: U.S. Department of Health and Human Services, *Healthy People 2010: Understanding and Improving Health.* Washington, DC: U.S. Department of Health and Human Services, Government Printing Office, 2000.

# Appendix B: Massachusetts Cancer Registry (MCR)

**Purpose**

The Massachusetts Cancer Registry (MCR) is responsible for collecting information about all newly diagnosed cases of cancer in Massachusetts. These data provide crucial information for monitoring the effect of environmental and occupational hazards as well as for designing and evaluating cancer prevention and control programs.

**Coverage**

All cases of malignant disease and benign brain-related tumor disease diagnosed, evaluated, treated, medically supported, or palliated among residents of the Commonwealth of Massachusetts.

**Years**

The Massachusetts legislature authorized the establishment of the MCR in 1980, and it has been collecting malignant disease data since 1982. Generally, Massachusetts cancer incidence data are released about two years after a diagnosis year; for example, data for 2002 diagnoses were released for the first time in early 2005.

**Key Data Elements**

Key data elements include age, city/town or region of residence, gender, race/ethnicity, year of diagnosis, type of cancer (site), stage at diagnosis, first course of treatment, and detailed clinical information such as histology, nodal involvement, and tumor size.

**Reporting System**

Reporting to the MCR follows rules 105 CMR 301.000. The MCR collects reports of newly diagnosed cancer cases from all Massachusetts acute care hospitals and one medical practice association. In 2001 the MCR started to collect reports from dermatologists' offices and dermatopathology laboratories, particularly on cases of melanoma. In 2002 the MCR started to collect reports from urologists' offices and a general laboratory. The MCR also works with 15 other state cancer registries to obtain information on Massachusetts residents who are diagnosed or treated for cancer in these states.

**Classification and Coding**

The MCR collects information on *in situ* and invasive cancers and benign tumors of the brain and associated tissues. The MCR does not collect information on basal and squamous cell carcinomas of the skin. The International Classification of Diseases for Oncology, Third Edition (ICD-O-3) codes are used to report primary site, histology, and behavior. Stage at diagnosis is typically reported using Summary Stage from the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute.

**Data Quality Procedures**

The MCR staff perform quality assurance activities such as standardized computer edits, hospital audits, and research on address at diagnosis. They provide training to hospital tumor registrars. In addition, the MCR identifies previously unreported cancer cases through death certificate clearance to further improve case completeness. This process identifies cancers mentioned on death certificates that were not previously reported to the MCR. Each year the North American Association of Central Cancer Registries (NAACCR) reviews cancer registry

data for quality, completeness, and timeliness. For 1998–2001, NAACCR estimated the MCR annual case count to be more than 95 percent complete each year. The MCR achieved the gold standard for this certification element as well as for six other certification elements for each of those same years.

**Race/Ethnicity**

The MCR uses an algorithm developed by NAACCR called the NAACCR Hispanic Identification Algorithm (NHIA) to help classify Hispanic ethnicity. The algorithm is only applied to cases with an unknown Spanish/Hispanic origin or cases that have been classified as Hispanic based on a Spanish surname only. The race/ethnicity categories used by the MCR are mutually exclusive. Cases are only included in one race/ethnicity category.

**National Data**

The MCR uses incidence data from the North American Association of Central Cancer Registries (NAACCR) to compare to Massachusetts incidence data. The NAACCR incidence rates include data from 28 states and five metropolitan areas and cover 55 percent of the United States population including Massachusetts. More information about NAACCR is available at www.naaccr.org.

**For More Information**

Massachusetts Department of Public Health, Massachusetts Cancer Registry, (617) 624-5658

Massachusetts Cancer Registry Web page: http://www.mass.gov/dph/bhsre/mcr/canreg.htm

105 CMR 301.000: Cancer Registry. Available from
http://www.mass.gov/dph/bhsre/mcr/regs/regulations_0404.doc.

# Appendix C: Age Adjustment

Age-adjusted incidence rates were developed using the direct method. They were standardized to the age distributions of the United States 2000 standard population. Following the age-adjustment procedures used by the National Cancer Institute, five-year age groups were used to calculate age-adjusted rates. The age distribution of the 2000 U.S. Standard Population is shown below.

**U.S. Standard Population Proportions**

| Age group | 2000 proportion | Age group | 2000 proportion |
|---|---|---|---|
| 0-4 | 0.0691 | 45-49 | 0.0721 |
| 5-9 | 0.0725 | 50-54 | 0.0627 |
| 10-14 | 0.0730 | 55-59 | 0.0485 |
| 15-19 | 0.0722 | 60-64 | 0.0388 |
| 20-24 | 0.0665 | 65-69 | 0.0343 |
| 25-29 | 0.0645 | 70-74 | 0.0318 |
| 30-34 | 0.0710 | 75-79 | 0.0270 |
| 35-39 | 0.0808 | 80-84 | 0.0178 |
| 40-44 | 0.0819 | 85+ | 0.0155 |

**Direct method of age adjustment**

Multiply the age-specific rates in the target population by the age distribution of the standard population. Where $m$ is the number age groups, $d_i$ is the number of deaths in age group $i$, $P_i$ is the population in age group $i$, and $s_i$ is the proportion of the standard population in age group $i$. This is a weighted sum of Poisson random variables with the weights being ($s_i$ / $P_i$).

$$\hat{R} = \sum_{i=1}^{m} s_i (d_i / P_i) = \sum_{i=1}^{m} w_i d_i$$

**Confidence Intervals**

Confidence intervals for the age-adjusted rates were calculated with a method based on the gamma distribution (Fay and Feurer, 1997). This method produces valid confidence intervals even when the number of cases is very small. When the number of cases is large, the confidence intervals produced with the gamma method are equivalent to those produced with the more traditional methods, as described by Chiang (1961) and Brillinger (1986). The formulas for computing the confidence intervals are given below. Although the derivation of this method is based on the gamma distribution, the relationship between the gamma and the Chi-squared distributions allows the formulas to be expressed in terms of quantiles of the Chi-squared distribution, which can be more convenient for computation.

$$\text{Lower Limit} = \frac{v}{2y}\left(\chi^2\right)^{-1}_{\frac{2y^2}{v}}(\alpha/2)$$

$$\text{Upper Limit} = \frac{v + w_M^2}{2(y + w_M)}\left(\chi^2\right)^{-1}_{\frac{2(y+w_M)^2}{v+w_M^2}}(1-\alpha/2)$$

where *y* is the age-adjusted death rate, v is the variance as calculated as shown below, wm is the maximum of the weights, $s_{iPi}$, *1-a* is the confidence level desired (e.g., for 95% confidence intervals, *a*-0.05,) and $_{X}^{2}$ is the inverse of the $_{X}^{2}$ distribution with *x* degrees of freedom.

$$v = \sum_{i=1}^{m} d_i (s_i / P_i)^2$$

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# Appendix D: Death Certificate System (Mortality Data)

**Purpose**

The purpose of mortality data is to establish legal benefits and provide public health information.

**Coverage**

Data include all events that occur to Massachusetts residents, regardless of death occurring in or out of state.

**Years**

Vital Records have been registered in Massachusetts since 1635. Statewide collection began in 1841. The Registry of Vital Records and Statistics maintains records for deaths occurring in Massachusetts from 1911 to the present.

**Data Elements**

Examples of data elements are age, gender, race/ethnicity, date of death, underlying and contributing causes of death, place of residence, place of occurrence, zip code of residence, occupation, education.

**Reporting System**

Physicians and medical examiners assign cause of death through a system that acknowledges the possibility of multiple causes. The funeral director records demographic information on the certificates, such as age, race, Hispanic ethnicity, gender, educational attainment, marital status, and occupation based on information provided by an informant, usually a family member, or in the absence of an informant, based on observation.

Massachusetts Deaths 2003. Available from:
http://www.mass.gov/dph/bhsre/death/2003/report.doc

**Classification and Coding for Causes of Death**

Classification and coding of data on Massachusetts death records follow the National Center for Health Statistics (NCHS) guidelines as defined in *Vital Statistics Instruction Manual* parts 1–20. (Published by U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Health Statistics, Hyattsville MD.) Causes of death are coded according to the International Classification of Disease, World Health Organization, Eighth Revision (ICD-8) for 1968–1978; Ninth Revision (ICD-9) for 1979–1998; Tenth Revision (ICD-10) for 1999 and later.

**Data Quality Procedures**

Instruction manuals are provided to physicians, coroners, and medical examiners as well as to local health jurisdictions and others involved in completing and managing death certificates. Edits and a physician query system are used to check for internal consistency and logic/completeness of cause of death.

**Changes to the Presentation of Race and Ethnicity Data**

In response to readers' feedback, the presentation of race and ethnicity data beginning with the 1999 publication has been changed. Previously, race and ethnicity data were presented according to federal definitions of race and ethnicity; that is, persons of Hispanic ethnicity could

be of any race group. Beginning with the 1999 report, race and ethnicity are now presented as mutually exclusive categories; that is, persons of Hispanic ethnicity are not included in a race group. All race and ethnicity data presented in trend tables have been updated to reflect this change. Thus, race and ethnicity data tables include the categories White non-Hispanic, Black non-Hispanic, Asian non-Hispanic, and Hispanic. In addition, table A1 in the appendix contains data according to the federal definitions so that data can be compared with the nation and other states. Race data presented in table A1 are for Whites (including persons of Hispanic ethnicity) and Blacks (including persons of Hispanic ethnicity). Furthermore, starting with the 2001 publication, there has been a nomenclatural change in the way data for Asians are presented: the *Asian/Pacific Islander non-Hispanics* category will be renamed *Asian non-Hispanics,* which includes Pacific Islanders.

**Cape Verdeans**

The U.S. Federal Census and the National Center for Health Statistics (NCHS) place persons who are Cape Verdean in the race category Black. Historically this federal definition has been followed in order to be consistent with the National Center for Health Statistics. Beginning with 1999 data, the concept of Race has been separated from Ethnic Group for reporting birth statistics. This enables placement of Cape Verdeans where they self-identify: Cape Verdeans are classified as Cape Verdean in ethnicity tables. With respect to race, 70 percent of Cape Verdeans classified their race as Other while only 24 percent classified themselves as Black and 6 percent as White in 1999. Accurate Cape Verdean population counts or estimates needed to calculate rates either statewide or at the substate level are not available. Thus, Cape Verdean can be removed from the numerator (the count of deaths) but not from the denominator (population data) when calculating rates. A more detailed table and figure summarizing age and cause-specific patterns of deaths among Cape Verdeans were added beginning with the 2000 report.

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**For More Information**

Massachusetts Department of Public Health, Massachusetts Registry of Vital Records and Statistics, (617) 740-2600

Massachusetts Department of Public Health, Massachusetts Registry of Vital Records and Statistics, Web page: http://www.mass.gov/dph/bhsre/rvr/rvr.htm

# Appendix E: Behavioral Risk Factor Surveillance System (BRFSS)

**Purpose**

The BRFSS provides indicators of health risk behavior, preventive practices, attitudes, health care use and access, and prevalence of selected diseases in Massachusetts.

**Coverage**

The system surveys English-speaking adults 18 years and older in households with telephones. In 2000 the sample size was 8,149.

**Years**

The BRFSS has conducted surveys from 1992 to the present. Annual data is generally available six months after the close of the calendar year.

**Data Elements**

Examples of data elements are health risk behaviors (smoking, physical inactivity, nutrition); use of preventive services (cancer screening); use of health care; attitudes about health-related behavior; socio-demographics (age, income, education); and health conditions (asthma, diabetes).

**Reporting System**

The Massachusetts Behavioral Risk Factor Surveillance System is a random-digit-dial telephone health survey of Massachusetts adults conducted in English, Spanish, and Portuguese. The survey involves only non-institutionalized adults residing in households with telephones. The questionnaire includes core questions used by all states and questions on topics of specific interest to Massachusetts. The BRFSS is supported in part by a cooperative agreement with the Centers for Disease Control and Prevention.

**Data Quality Procedures**

Survey administration procedures (e.g., callbacks to difficult-to-reach households) are used to improve the representativeness of the sample, efforts are made to achieve response rates recommended by CDC, and computer-assisted interviewing is used to minimize errors by interviewers. CDC does cognitive testing on all questions and has assessed many, but not all, questions for reliability and validity. Interviewers are trained professionally and calls are monitored regularly.

**Limitations**

Some limitations should be considered when interpreting results from the BRFSS. Households that do not have a telephone do not have the opportunity to participate in the survey. Although only 2 percent of Massachusetts households lack a telephone, almost 10 percent of households living below poverty lack a phone based on 1990 census data. A substantial percentage of households contacted to participate in the BRFSS do not complete the survey. Although households are telephoned on repeated occasions, interviewers are not always able to reach the randomly selected adult in the household. In addition, some adults contacted do not agree to participate in the survey. To the degree that respondents who participated in the survey differed significantly from those not included in the survey, bias is present in the results. The weighting of the data partially takes into account this non-response.

All data collected by the BRFSS are based on self-report from the respondents. By its nature, self-reported data may be subject to error for several reasons. An individual may have difficulty remembering events from a long time ago or the frequency of certain behaviors. Some respondents may overreport socially desirable behaviors and underreport behaviors they perceive to be less acceptable. Finally, because the BRFSS surveys a randomly selected sample of Massachusetts adults, these results may differ from another random sample to some extent simply due to chance.

**For More Information**

Massachusetts Department of Public Health, Center for Health Information, Research and Evaluation, (617) 624-5623

Massachusetts State BRFSS Web page: http://www.mass.gov/dph/bhsre/cdsp/brfss/brfss.htm

# Appendix F: Youth Risk Behavior Survey (YRBS) and Youth Health Survey (YHS)

**Purpose**

The Youth Risk Behavior Survey (YRBS) is administered by the Massachusetts Department of Education. The YRBS measures the prevalence of tobacco use, alcohol and other drug use, sexual behaviors that might lead to unintended pregnancy or sexually transmitted disease, dietary behaviors, physical activity, and behaviors associated with intentional or unintentional injuries. YRBS data is available only in aggregate and not by individual schools or communities.

The Massachusetts Youth Health Survey (MYHS) is a biannual survey of Massachusetts students in grades 6 through 12. The 2002 survey examined a broad range of health behaviors but emphasized tobacco, alcohol, and other drug use. However, questions about physical and emotional health status, academic aspirations, personal safety, peer/parental relationships, and extra-curricular activities were included. The Centers for Disease Control and Prevention, the Massachusetts Department of Education, and the Massachusetts Department of Public Health's Bureau of Substance Abuse Services, Bureau of Family and Community Health, and Tobacco Control Program collaborated on survey design, methodology, implementation, and data management/analysis.

Like the YRBS data, YHS data is available only in aggregate and not by individual schools or communities.

**Coverage**

YRBS participants include students in randomly selected high schools. YHS students are in grades 6–12 in public schools statewide.

**Years**

YRBS has been conducted every other year since 1990. YHS is conducted on alternate years to complement YRBS.

**Key Data Elements**

This research provides important information about the behaviors students engage in that may compromise their health and safety. These behaviors include tobacco, alcohol, and illegal drug use; weapon carrying and physical violence; suicidal behaviors; drinking and driving; lack of seat belt and helmet use; sexual activity; unhealthy dietary behaviors; and lack of physical activity.

**Reporting System**

The surveys have been administered in their respective years since 1990 to randomly selected middle schools and high schools. A trained survey administrator from the Department of Education staff traveled to each participating school and administered the survey to selected classrooms using a standardized administration protocol. Survey administrators notified all students that the survey was both anonymous and voluntary.

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Massachusetts Department of Education Web page:
http://www.doe.mass.edu/hssss/program/youthrisk.html

# Appendix G: Abbreviations

The following abbreviations appear in this report:

| | |
|---|---|
| AAFP | American Academy of Family Practitioners |
| AAP | American Academy of Pediatrics |
| ABCD | Action for Boston Community Development |
| ACOS | American College of Surgeons |
| ACS | American Cancer Society |
| AHRQ | Agency for Healthcare Research and Quality |
| ATSDR | Agency for Toxic Substances and Disease Registry |
| BEHA | Bureau for Environmental Health Assessment |
| BMI | Body Mass Index |
| BRFSS | Behavioral Risk Factor Surveillance System |
| BSAS | Bureau of Substance Abuse Services |
| BSE | Breast self-examination |
| CAM | Complementary and alternative medicine |
| CBE | Clinical breast examination |
| CDC | Centers for Disease Control and Prevention |
| CGN | Cancer Genetics Network |
| CICRF | Catastrophic Illness in Children Relief Fund |
| CRC | Colorectal Cancer |
| CME | Continuing Medical Education |
| CMS | Centers for Medicare and Medicaid Services |
| COC | Commission on Cancer |
| CRPF | Cancer Research and Prevention Foundation |
| DPH | Department of Public Health |
| DRE | Digital Rectal Exam |
| ELNEC | End of Life Nursing Education Consortium |
| EPA | Environmental Protection Agency |
| FOBT | Fecal occult blood test |
| Community Guide | Guide to Community Preventive Services |
| HBV | Hepatitis B virus |
| HIV | Human Immunodeficiency Virus |
| HPV | Human papillomavirus |
| IARC | International Agency for Research on Cancer |
| ICU | Intensive Care Unit |
| IDM | Informed Decision making |
| IOM | Institute of Medicine |
| MAHPERD | Massachusetts Alliance for Health, Physical Education, Recreation and Dance |
| MA-NOCC | Massachusetts-National Ovarian Cancer Coalition |
| MBCCTP | Massachusetts Breast and Cervical Cancer Treatment Program |
| MBTA | Massachusetts Bay Transit Authority |
| MCCC | Massachusetts Compassionate Care Coalition |
| MCCCC | Massachusetts Comprehensive Cancer Control Coalition |
| MCR | Massachusetts Cancer Registry |

| | |
|---|---|
| MDPH | Massachusetts Department of Public Health |
| MGP | Massachusetts Genetics Program |
| MHP | Men's Health Partnership |
| MMF | Massachusetts Melanoma Foundation |
| MOPCI | Massachusetts Overweight Prevention and Control Initiative |
| MPCC | Massachusetts Prostate Cancer Coalition |
| MTCP | Massachusetts Tobacco Control Program |
| NASPE | National Association for Sport and Physical Education |
| NBCCEDP | National Breast and Cervical Cancer Early Detection Program |
| NCI | National Cancer Institute |
| NCPB | National Cancer Policy Board |
| NECCS | New England Coalition for Cancer Survivorship |
| PSA | Prostate Specific Antigens |
| PCB | Polychlorinated Biphenyls |
| PCS | Palliative Care Service |
| PDQ | Physician Data Query |
| PHEN | Prostate Health Education Network |
| PHEP | Project Healthy Exercise Plus |
| PHW | Partnership for Healthy Weight |
| REACH 2010 | Racial and Ethnic Approach to Community Health |
| STD | Sexually Transmitted Disease |
| TIOG | Targeted Intervention Opportunity Grant |
| TWC | The Wellness Community |
| UV | Ultraviolet |
| USPSTF | United States Preventive Services Task Force |
| WHN | Women's Health Network |
| WIC | Women, Infants and Children |

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