

Maryland Plan  
Comprehensive  
Cancer Control  
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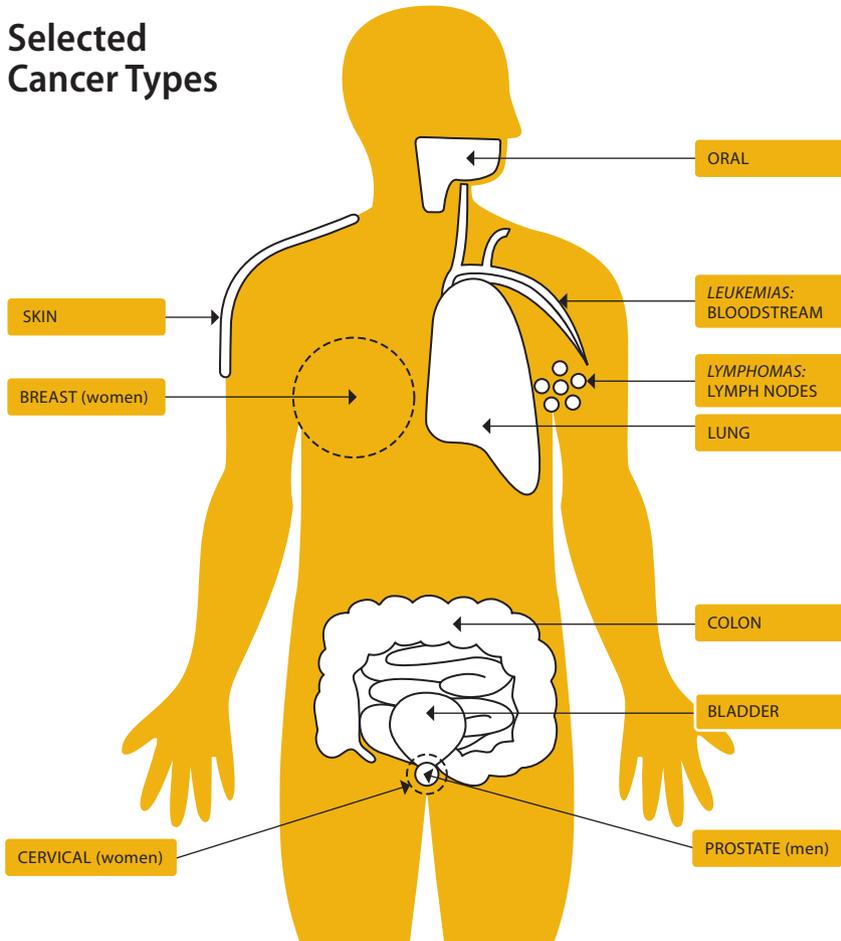


# CANCER PLAN BASICS

## Cancer Basics

- Cancer is the second leading cause of death in Maryland.
- Many cancers are preventable or can be successfully treated, especially if they are detected early.
- Cancer happens when abnormal cells divide and invade other tissues. This uncontrolled growth causes tumors.
- Tumors that cannot spread throughout the body are benign (not cancerous). Tumors that can spread throughout the body are malignant (cancerous).
- There are more than 100 different types of cancer.

## Selected Cancer Types



## What is Comprehensive Cancer Control?

**COMPREHENSIVE CANCER CONTROL IS A METHOD OF** communities working together to control cancer by:

- Reducing risk.
- Detecting cancers early.
- Improving treatment.
- Enhancing survivorship.

The Centers for Disease Control and Prevention (CDC) provides funding to every US state, and some tribes and territories for a Comprehensive Cancer Control Program. One of the roles of the program is to create and promote a Comprehensive Cancer Control Plan.

## What is the purpose of the Maryland Comprehensive Cancer Control Plan?

**THE PLAN IS A RESOURCE FOR ALL MARYLANDERS** (individuals, healthcare providers, and organizations) on cancer control topics. It is also a guide for health professionals who are involved in planning, directing, implementing, evaluating, or performing research on cancer control in Maryland.

Individuals, communities, and health professionals throughout the state can use the goals, objectives, and strategies in the plan to help guide their cancer control activities. The plan's goal is to encourage collaboration and cohesiveness among these many stakeholders as they work towards reducing the burden of cancer in Maryland.

**For more information on comprehensive cancer control, visit [www.marylandcancerplan.org](http://www.marylandcancerplan.org).**

## What can you do?

### Individuals

- Educate yourself. Read the plan!
- To lower your chances of getting cancer and other diseases:
  - Don't use tobacco. If you do, ask your doctor or nurse about quitting.
  - Get at least 30 minutes of physical activity on five or more days each week.
  - Eat plenty of vegetables, fruits, and whole grains, and only small amounts of red meat and high-fat dairy products.
  - Maintain a healthy weight.
  - Drink less alcohol, if you drink at all.
  - Protect yourself from the sun.
- Talk to your doctor about cancer screenings that are right for you.
- Support cancer-related organizations and efforts in the community.
- Advocate for policies that support cancer control.

### Healthcare Providers

- Be aware of the comprehensive cancer control planning efforts in Maryland.
- Educate patients about preventive behaviors, early detection, clinical trials, and survivorship groups.
- Participate in community cancer control efforts and work toward the elimination of disparities in underserved populations.
- Understand reporting requirements for cancer cases and report properly to the Maryland Cancer Registry.
- Advocate for policies that support cancer control.

### Local Health Departments and Community Organizations

- Use the plan as a guide when selecting and planning cancer control and research efforts.
- Promote wellness initiatives and events that encourage preventive behaviors and offer early detection opportunities.
- Advocate for policies, programs, and funding that support cancer control.

## Terms to Know

**CARCINOGEN** Any substance that causes cancer.

**HEALTHCARE PROVIDER** A health professional who delivers healthcare services. Providers may include doctors (internists, family physicians, pediatricians, surgeons, and specialists), nurse practitioners, physician assistants, dentists, and others.

**INCIDENCE** The rate of newly diagnosed cases during a specific time period. Cancer incidence rates in this plan are the number of cases diagnosed per 100,000 people in the given population.

**IN SITU** In its original place. When cancer is “in situ,” abnormal cells are found only in the place where they first formed. They have not spread. If left untreated, this form of cancer can become invasive.

**MALIGNANT** Cancerous. Malignant tumors can invade and destroy nearby tissue and spread to other parts of the body.

**MORBIDITY** A disease or the incidence of disease within a population. Morbidity also refers to adverse effects caused by a disease or a treatment.

**MORTALITY** The rate of deaths during a specific time period. Cancer mortality rates in this plan are the number of deaths per 100,000 people in the given population.

**PRIMARY PREVENTION** Action taken to decrease the chance of getting a disease or condition. Primary prevention of cancer includes avoiding risk factors

(such as smoking, obesity, lack of exercise, and radiation exposure), increasing protective factors (such as getting regular physical activity, staying at a healthy weight, and having a healthy diet), and having early pre-cancers removed before they become invasive.

**RISK FACTOR** Something that may increase the chance of developing cancer. Examples of risk factors for cancer include age, a family history of certain cancers, use of tobacco products, certain eating habits, obesity, lack of exercise, exposure to the sun or other radiation, exposure to other cancer-causing agents at work or at home, and certain genetic changes.

**SECONDARY PREVENTION** Action taken to find and treat a disease at the earliest possible stage. Secondary prevention of cancer includes screening examinations such as mammograms to screen for breast cancer, fecal occult blood testing to screen for colorectal cancer, and Pap tests to screen for cervical cancer.

**STAGE** The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.

**TERTIARY PREVENTION** Action taken to treat and support people with an existing disease. Tertiary prevention of cancer includes providing appropriate services to minimize clinical complications, delay the advancement of the disease, reduce the risks of complication, prolong life, and promote quality of life.

**T**his cancer plan is dedicated to all the courageous Marylanders and their families who fight or have fought a battle against cancer. The Maryland Comprehensive Cancer Control Plan serves as a tribute to your valiant efforts.

## **Statement of Funding**

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## **Note**

The Maryland Comprehensive Cancer Control Plan was directed by the Department of Health and Mental Hygiene with broad input from a partnership of public and private stakeholders. The purpose of the Plan is to set forth measurable objectives and strategies to reduce the burden of cancer in Maryland. The Plan fulfills grant requirements for the Centers for Disease Control and Prevention.

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## Acknowledgments

**O**VER THE COURSE OF A TWO-YEAR PLANNING PROCESS, individuals and organizations from around the state of Maryland donated their time, expertise, and experience to the development of this Maryland Comprehensive Cancer Control Plan (MCCCP).

Sincere thanks must go to the individuals who made up the committees that were charged with developing this plan's chapters. The combined efforts of the researchers, lay citizens, public health staff, healthcare providers, and cancer survivors who served on the committees resulted in chapters that capture current issues in cancer control and offer strategies that will make an impact on the cancer burden in this state. A list of committee members is provided at the beginning of each chapter.

The members of the Maryland State Council on Cancer Control participated in, and, in some cases, provided leadership for, various committees. Council members also participated in chapter review and contributed their time, organizational resources, and expertise during the entire planning process. Various offices within the Maryland Department of Health and Mental Hygiene contributed staff resources to the creation of the plan, including:

### **Family Health Administration**

- Center for Cancer Surveillance and Control
- Center for Health Promotion, Education, and Tobacco-Use Prevention
- Center for Maternal and Child Health
- Office of Chronic Disease Prevention
- Office of Health Policy and Planning
- Office of the Maryland WIC (Women, Infants and Children) Program
- Office of Oral Health

### **Infectious Disease and Environmental Health Administration**

- Environmental Health and Food Protection Program

### **Office of Minority Health and Health Disparities**

The collaborative efforts exerted in this process were integral to the writing of the MCCCP. This same collaboration will continue to be vital as we work to implement the strategies of the plan and to impact the cancer burden in Maryland.

## Preface

The plan is a resource for all Marylanders (individuals, healthcare providers, and organizations) on cancer control topics. It is also a guide for health professionals who are involved in planning, directing, implementing, evaluating, or performing research on cancer control in Maryland.

**T**HIS PLAN represents the coordinated effort of nearly 250 individuals across the state who came together through 14 committees to develop a document that reflects the needs of Marylanders. It was developed by a broad partnership of public and private stakeholders whose common mission is to reduce the burden of cancer in Maryland. This plan was developed by Marylanders for Marylanders.

Comprehensive cancer control is a method of communities working together to control cancer by reducing risk, detecting cancers early, improving treatment, and enhancing survivorship. The goal is to maximize limited resources to achieve desired cancer prevention and control outcomes. The benefits of comprehensive cancer control are shown in Table 1.

The structure of this plan is similar to previous versions and follows the definition of comprehensive cancer control, including topics on primary prevention through survivorship and palliative care. Each chapter contains goals, objectives, and strategies to serve as a guide for cancer control in Maryland. Although there are more than 100 different cancer sites, it was not feasible to cover every cancer site in this plan. Rather, this plan covers those cancer sites, interventions, or issues that we know from research will have an impact on cancer incidence, morbidity, mortality, and quality of life.

### A LIVING DOCUMENT

**THIS MCCCPC** will be a living document for cancer control planning in Maryland. The plan was designed with the intent of updating chapters individually as needed. To accomplish this, the cancer plan Web site ([www.marylandcancerplan.org](http://www.marylandcancerplan.org)) will be the central location for cancer plan information.

A PDF version of the plan is available on the Web site, along with additional resources, background information, and links. Each chapter

of the plan has a page on the Web site, which will be updated regularly as new research and recommendations are released and as implementation efforts take place across the state.

### DATA IN THE PLAN

**SIGNIFICANT EFFORTS WERE MADE** toward consistency of data years reported throughout this plan. Incidence and mortality statistics are reported through 2006, the most recent data year available at the time of writing. Behavioral Risk Factor Surveillance System (BRFSS) and Maryland Cancer Survey data are reported for the most recent year available at the time of writing, which varies from topic to topic, based on which survey questions were asked in various years.

Some of the Goals and many of the Objectives in the Plan give specific data targets to be met by the year 2015. In most cases, trend data through

TABLE 1

### The Benefits of Comprehensive Cancer Control

#### A UNITED FRONT IS MORE POWERFUL.

Comprehensive Cancer Control offers the power of collaboration to what otherwise might be a lonely fight. The result is a powerful network of groups that speaks with one voice about reducing cancer risk, detecting cancers earlier, improving access to quality cancer treatment, and improving quality of life for cancer survivors.

#### WORKING TOGETHER IS MORE EFFICIENT.

By putting Comprehensive Cancer Control plans into action, coalitions prevent overlap and direct resources to where they matter most in every state and in many tribes and US territories.

#### COLLECTIVE ACTION CREATES NEW ALLIES.

People from all corners of the cancer community are gaining new allies by participating in Comprehensive Cancer Control. This allows them to pool resources, share expertise, and gain new insights into better ways to get the job done.

#### COALITIONS CAN TACKLE CROSS-CUTTING ISSUES.

A united front against cancer can tackle major issues—like better access to quality care, survivorship, health disparities, and quality of life—that are too broad and cross-cutting for any one organization to confront alone.

Source: Centers for Disease Control and Prevention. National Comprehensive Cancer Control Program. Comprehensive Cancer Control Fact Sheet, 2008.

the most recently available data years were used to establish these targets. Through this method, known data values were used to predict a future value for the year 2015 by using the statistical method of linear regression. If the trend was moving in the desired direction to control cancer, the 2015 target was set according to this trend. If the trend was not moving in the direction desired to control cancer, the target was set at a rate that would reflect the reversal of this undesired trend. In a few cases, this method was not used. Rather, targets were set to mirror those previously set by another plan or program. When this is the case, the source of the target is described in a footnote.

It is recognized that many factors influence data from year to year, and this method of projecting targets based on actual data does not take into account demographic, screening, funding, or other factors that may influence the trend in the future. For this reason, the 2015 targets may be overly aggressive in some chapters. However, for standardization across all chapters, we have used a single method with consistent data. See the Appendix for more information on data and targets in the plan.

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#### DEVELOPMENT PROCESS

**BECAUSE THE BASIS OF THIS PLAN** was the 2004-2008 MCCCCP, the planning process followed a similar structure. A committee was formed for each chapter, and in general consisted of no more than 25 members including epidemiologists, health-care providers, researchers, cancer survivors, the general public, and other representatives from local and state health departments, governmental agencies, community-based organizations, academic health centers, hospitals/other health-care facilities, and cancer support groups.

Co-chairs were selected for each of the 14 committees. The DHMH staff worked closely with the chairs to develop agendas, timelines, and materials for committee meetings and to coordinate operational matters. Over the course of several meetings, the committees reviewed materials and employed a variety of methods to accomplish their goal: to revise or write a new chapter and develop a set of recommendations to improve cancer control on their given topic. Committee members, as well as guest speakers

and chapter contributors, are listed at the beginning of each chapter.

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#### PLAN IMPLEMENTATION

**THE GOALS, OBJECTIVES, AND STRATEGIES** at the end of each chapter serve as a guide to all organizations in the state and show areas where additional attention is needed. Collectively, the goals, objectives, and strategies are far-reaching and complex. No one organization can carry out all of these activities. Rather, these goals, objectives, and strategies are listed as our call to action to encourage any organization involved in any aspect of cancer control to address one or more of these goals and objectives and to apply the appropriate strategies as resources and opportunities arise. The implementation of the MCCCCP will be further facilitated by committees that will meet to select priorities and create specific action plans.

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#### MEASURING PROGRESS

**A PROGRESS REPORT ON THE 2004-2008 MCCCCP** was created with input from the nearly 250 committee members involved in writing the new plan. Committee members reviewed the goals, objectives, and strategies of the 2004-2008 MCCCCP and reported on progress known for each. In the future, progress on the goals, objectives, and strategies of the new plan will be recorded on an ongoing basis as the plan is implemented.

# 1 • Burden of Cancer in Maryland



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# 1

## BURDEN OF CANCER IN MARYLAND

Improvements in the prevention, early detection, and treatment of many types of cancer have led to a decline in cancer incidence and death rates in Maryland and the nation.<sup>1,2</sup> Despite these declines, the cancer burden in Maryland remains large when measured by human suffering, loss of life, loss of quality of life, and expenditure for medical care.

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**TABLE 1.1**

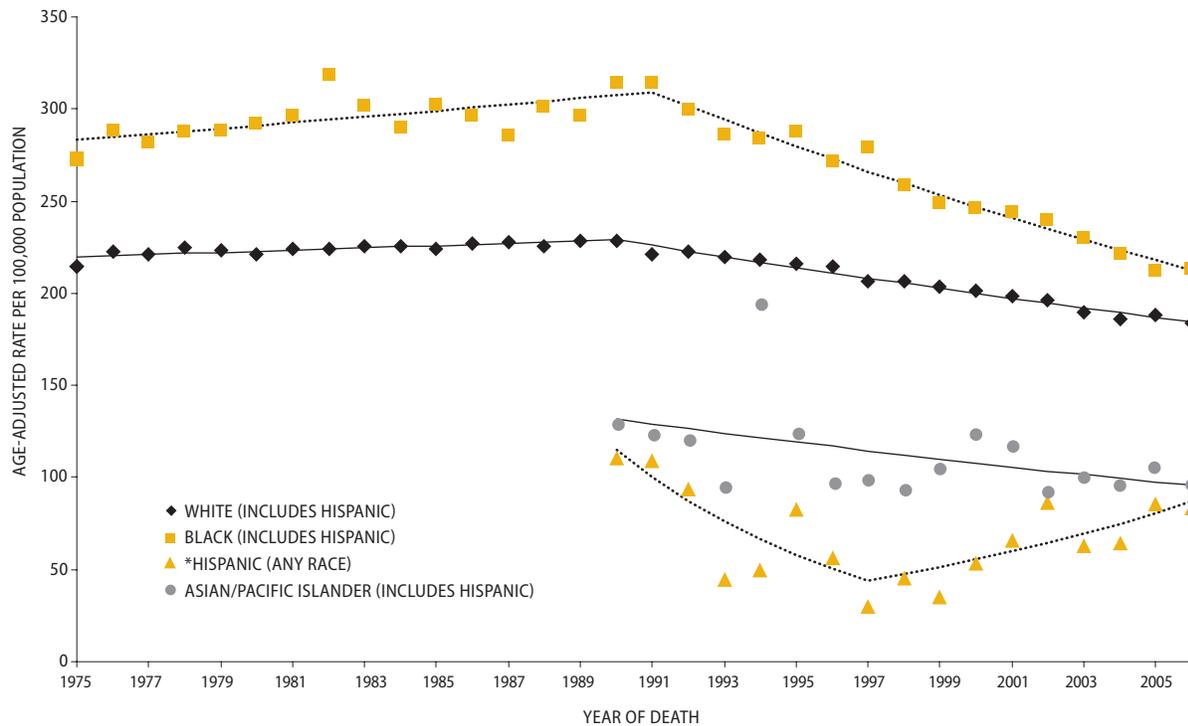
**The Ten Leading Causes of Death in Maryland, 2006**

RANK*	CAUSE OF DEATH	NUMBER OF DEATHS	PERCENTAGE OF TOTAL DEATHS
	<b>All Causes</b>	43,491	
1	<b>Heart Disease</b>	11,191	25.7%
2	<b>CANCER</b>	10,336	23.8%
3	<b>Cerebrovascular Disease</b>	2,358	5.4%
4	<b>Chronic Respiratory Disease</b>	1,827	4.2%
5	<b>Accidents</b>	1,424	3.3%
6	<b>Diabetes</b>	1,230	2.8%
7	<b>Influenza and Pneumonia</b>	1,091	2.5%
7	<b>Septicemia</b>	964	2.2%
9	<b>Alzheimer's Disease</b>	908	2.1%
10	<b>Nephritis, Nephrotic Syndrome, and Nephrosis</b>	756	1.7%

\*Ranking is based on number of deaths.  
Source: Maryland Vital Statistics Annual Report, 2006.

FIGURE 1.1

Historical Trends in Cancer Mortality in Maryland for All Cancer Sites, Both Genders, and All Ages, 1975-2006



Rates are age-adjusted to the 2000 US standard population. Regression lines reflect the estimate calculated using the "Joinpoint Regression Program."  
 \*Data on Hispanic and non-Hispanic mortality may be unreliable for 1991-1993 and the user is cautioned against drawing conclusions from such data. This was based on the value of the Hispanic Index for these years.  
 Source: State Cancer Profiles (accessed September, 2010).

**THE GOALS FOR COMPREHENSIVE CANCER CONTROL** are to decrease overall cancer mortality and reduce cancer disparities among ethnic minorities.

Cancer is the second leading cause of death in Maryland after heart disease, and approximately one in four deaths in Maryland is due to cancer (Table 1.1).

## Demographic Trends and Cancer Burden

**CANCER MORTALITY RATES IN MARYLAND** have continued to decline after peaking in 1990 (Figure 1.1). Cancer mortality rates have fallen among whites, blacks or African Americans, and Asian/Pacific Islanders in Maryland. Although mortality rates from cancer remain lower, the cancer mortality rates among individuals of Hispanic or Latino ethnicity have been increasing in Maryland since 1998 at a time when the Hispanic or Latino population in the state has increased from nearly

5% of the Maryland population in 2002 to nearly 7% of the population in 2008.<sup>3</sup>

Disparities in cancer rates by race have improved; however, blacks or African Americans continue to suffer a disproportionate burden of cancer compared to whites. In 2006, the overall cancer mortality rate for blacks or African Americans in Maryland was 211.6 deaths per 100,000 population compared to a rate of 183.8 deaths per 100,000 population for whites in the state (Figure 1.1). The overall cancer mortality rate for Maryland blacks or African Americans was 15% higher than the cancer mortality rate for Maryland whites in 2006, showing improvement over the 26% rate disparity in 1999. See Chapter 3 of this cancer plan for discussion regarding cancer disparities.

The population in Maryland is continuing to age. The number of individuals ages 60 and older is expected to increase from just more than

**TABLE 1.2**

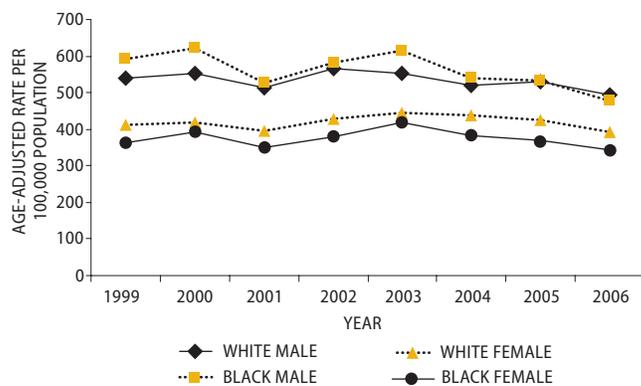
**Overall Cancer Incidence and Mortality by Gender and Race in Maryland and the United States, 2006**

INCIDENCE	TOTAL	MALES	FEMALES	WHITES	BLACKS	OTHER
<b>MD New Cases (#)*</b>	24,203	12,246	11,895	17,629	5,391	903
<b>MD Incidence Rate*</b>	426.3	495.6	376.9	434.3	395.7	353.1
<b>US SEER Rate</b>	450.5	521.9	401.0	458.1	467.3	299.7
MORTALITY	TOTAL	MALES	FEMALES	WHITES	BLACKS	OTHER
<b>MD Deaths (#)</b>	10,350	5,168	5,182	7,512	2,627	211
<b>MD Mortality Rate</b>	186.9	225.2	161.8	183.8	211.6	93.6
<b>US Mortality Rate</b>	180.7	220.0	153.6	179.9	217.4	108.4

Rates are per 100,000 population and are age-adjusted to the 2000 US standard population.  
 Sources: Maryland Cancer Registry, 2006.  
 SEER, National Cancer Institute, 2006.  
 NCHS Compressed Mortality File in CDC WONDER, 1999-2006.

**FIGURE 1.2**

**All Sites Cancer Incidence Rates by Race and Gender in Maryland, 1999-2006**



Rates are per 100,000 population and are age-adjusted to the 2000 US standard population.  
 Source: Maryland Cancer Registry, 1999-2006.

800,000 in 2000 to an estimated 1,220,000 in 2015.<sup>4</sup> Because cancer is a disease that affects predominantly people over 50 (Figure 1.3), the number of people who are diagnosed with cancer is expected to increase in Maryland despite the age-adjusted rate of cancer falling. The total annual number of cancer cases and the number of persons living with cancer in the United States are expected to double by the year 2050.<sup>5</sup> The increased number of persons living with cancer will place a growing demand on the healthcare system for more supportive, palliative, and general medical services. At the same time that the number of cancer cases is expected to rise, advances in and access to state-of-the-art cancer treatment and care are expected to lead to longer survival,

further reductions in cancer death rates, and an increase in the number of cancer survivors.<sup>6</sup> A focus on the quality of life of cancer survivors will become essential.<sup>7</sup> See Chapter 4 of this cancer plan for further discussion of long-term survivorship, Chapter 14 for a discussion of pain management, and Chapter 15 for information on palliative and hospice care.

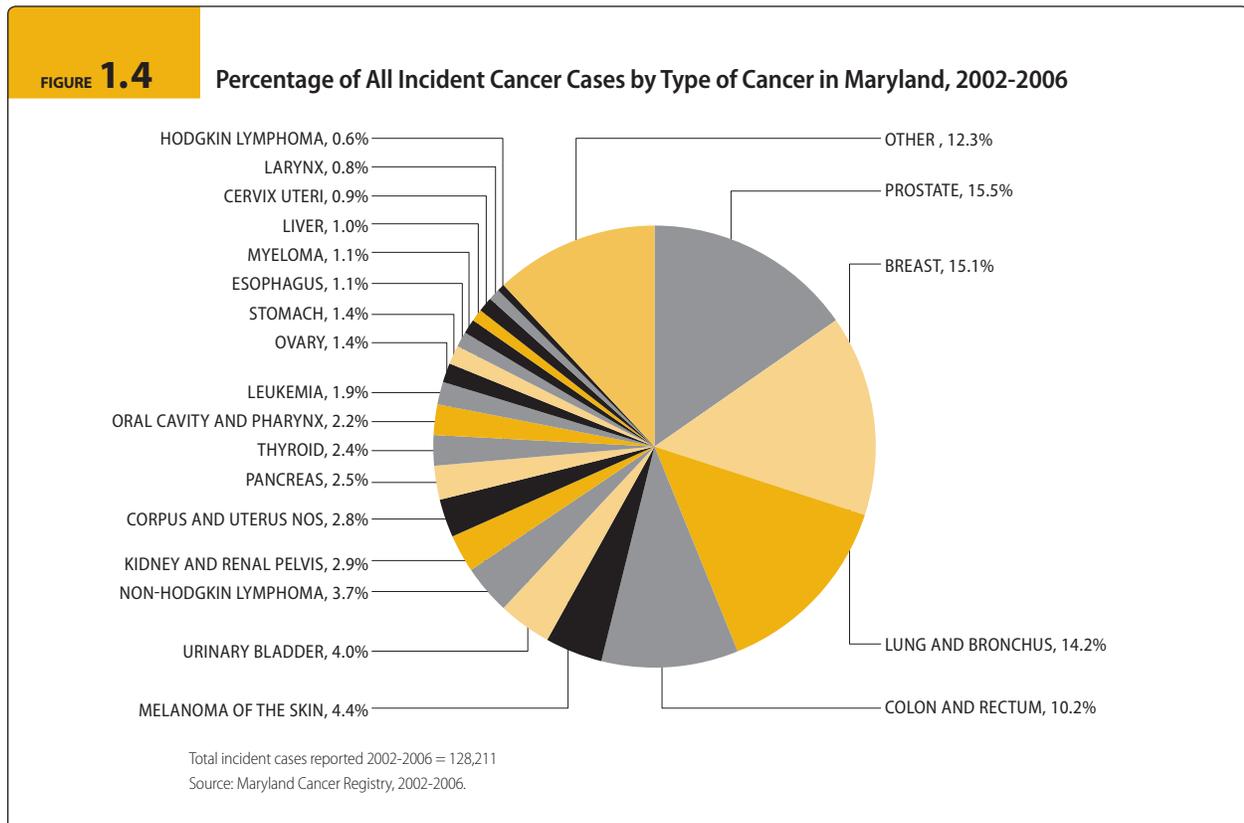
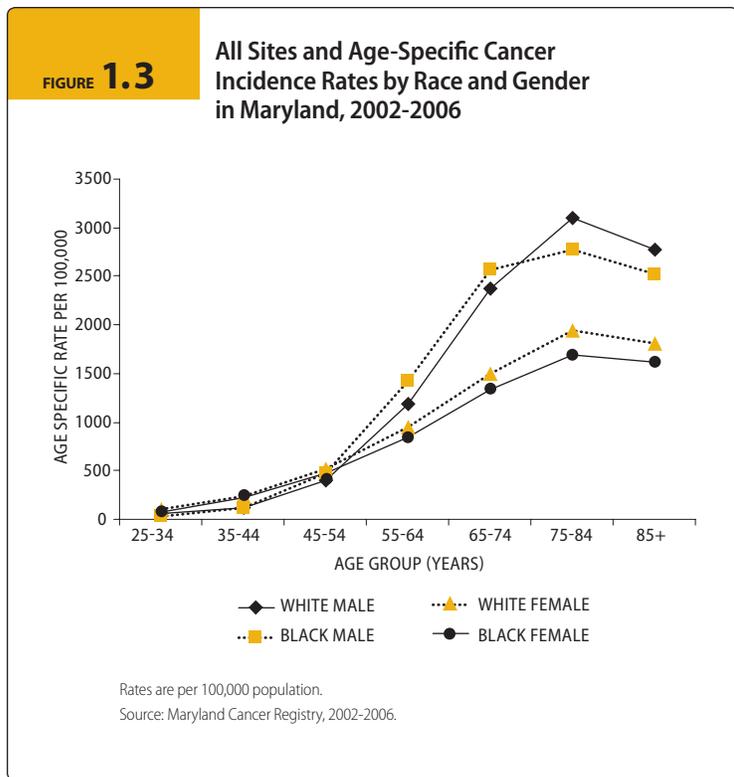
Finally, the population in Maryland has become increasingly overweight and obese. In 2009, an estimated 62.9% of Maryland's population was overweight or obese.<sup>8</sup> Being overweight or obese is thought to contribute to 14%-20% of all cancer-related mortality in the US.<sup>9</sup> Overweight and obesity are risk factors for developing some cancers. See Chapter 6 for further discussion of nutrition, physical activity, and healthy weight.

**Cancer Incidence (New Cases)**

**EACH YEAR** more than 24,000 Marylanders are diagnosed with invasive cancer (excluding basal and squamous cell skin cancer). The 2006 age-adjusted cancer incidence rate for Maryland is 426.3 cancer cases per 100,000, which is lower than the 2006 US SEER cancer incidence rate of 450.5 (Table 1.2). The 2006 overall cancer incidence rates for men, women, blacks or African Americans, and whites in Maryland are lower than the corresponding US incidence rates.

Overall cancer incidence rates in Maryland decreased from 2002-2006.<sup>10</sup> Total cancer incidence rates in black or African American and white men declined from 2005-2006, with the rate in black or African American men dropping slightly below the rate for white men in 2006. All sites cancer incidence rates in black or African American and white women have similarly declined from 2003-2006 (Figure 1.2).

Overall cancer incidence increases with age across all races and genders. In the US, 1 in 12 males and 1 in 11 females ages 40 to 59 will develop cancer, compared to 1 in 6 men and 1 in 10 women ages 60 to 69, and 1 in 3 men and 1 in 4 women ages 70 and older.<sup>11</sup> In Maryland, cancer incidence rates are higher in males than in females at ages 55 and older (Figure 1.3).



Black or African American males have the highest incidence rate among those ages 55 to 74, while white males have the highest rate among those ages 75 or older.

**CANCER IS NOT A SINGLE DISEASE;** there are more than 100 different types of cancer that are classified according to the organ or tissue that is the site of the tumor and the type of cells that have become cancerous. The most commonly diagnosed cancers among Marylanders are prostate (15.5%), breast (15.1%), lung and bronchus (14.2%), and colon and rectum (10.2%) cancers. Combined, these cancers comprise 55.0% of all cancers diagnosed (Figure 1.4). Among Maryland men, cancers of the prostate, lung and bronchus, and colon and rectum comprise 55.4% of all newly diagnosed cancers. Among Maryland women, cancers of the breast, lung and bronchus, and colon and rectum comprise 54.4% of all newly diagnosed cancer cases (Figure 1.5).

The most common sites of cancer vary by age. Among all persons in the US ages 20 to 49, the most commonly diagnosed cancers from 1999 to 2005 were breast cancer, melanoma, colorectal cancer, thyroid cancer, and cancers of the lung and bronchus. Among persons ages 50 and older, cancers of the prostate, lung and bronchus, breast, and colon and rectum were the most frequently occurring cancers.<sup>12</sup> Cancer in children is discussed later in this chapter.

TABLE 1.3

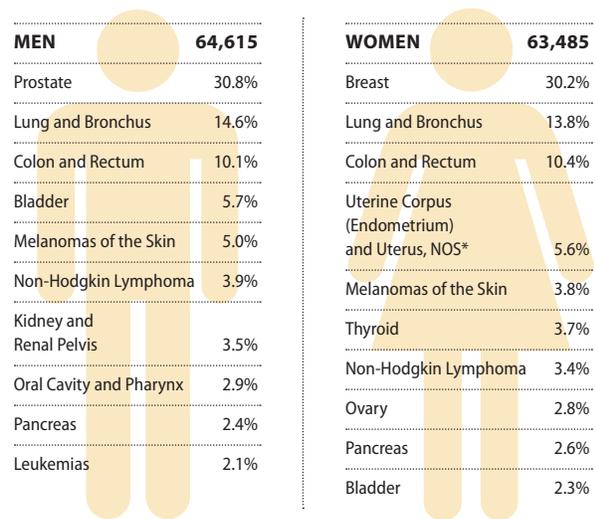
Leading Causes of Death by Age in Maryland, 2006

AGE	CAUSE OF DEATH	NUMBER OF DEATHS	PERCENTAGE OF DEATHS
1-4 years	Accidents	20	25.0%
	Congenital Abnormalities	12	15.0%
5-14 years	Accidents	33	31.1%
	CANCER	12	11.3%
15-24 years	Accidents	207	29.5%
	Assault	199	28.3%
	Suicide	70	10.0%
25-44 years	CANCER	352	13.3%
	Diseases of the Heart	343	12.9%
	Accidents	329	12.4%
45-64 years	CANCER	2,955	32.9%
	Diseases of the Heart	2,063	23.0%
	Cerebrovascular Disease	323	3.6%
65 years and older	Diseases of the Heart	8,751	28.8%
	CANCER	6,978	23.0%
	Cerebrovascular Disease	1,964	6.5%

Source: Maryland Vital Statistics Annual Report, 2006.

FIGURE 1.5

Ten Leading Cancer Incident Sites by Gender in Maryland, 2002-2006



\*NOS is defined as Not Otherwise Specified  
Source: Maryland Cancer Registry, 2002-2006

## Cancer Mortality (Deaths)

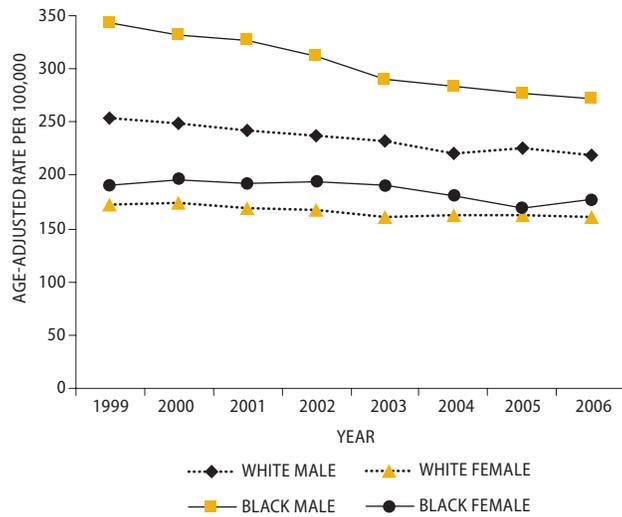
**M**ORE THAN 10,000 MARYLANDERS die from cancer each year. Maryland's age-adjusted overall cancer mortality rate of 186.9 deaths per 100,000 in 2006 was higher than the 2006 US cancer mortality rate of 180.7 (Table 1.2).

Maryland's rank in overall cancer mortality has been steadily improving compared to other states and the District of Columbia. For the time period 1986-1990, Maryland had the third highest cancer mortality rate in the nation. This rate decreased over the following ten years and Maryland had the 11th highest cancer mortality rate for 1996-2000. For the time period 2002-2006 Maryland dropped to having the 20th highest cancer mortality rate in the nation.<sup>13</sup>

Overall cancer mortality rates in Maryland are higher in males than females, with black or African American males having higher overall cancer mortality rates than white males, and black or African American females having higher overall cancer mortality rates than white females (Figure 1.6).

FIGURE 1.6

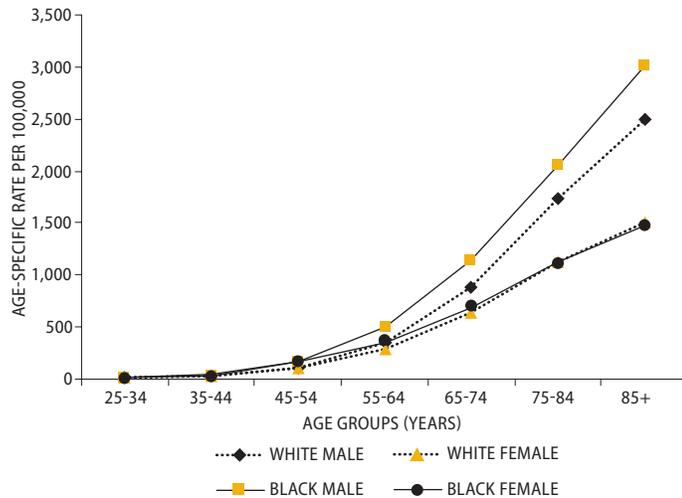
All Sites Cancer Mortality Rates by Race and Gender in Maryland, 1999-2006



Rates are per 100,000 population and are age-adjusted to the 2000 US standard population. Source: NCHS Compressed Mortality File in CDC WONDER, 1999-2006.

FIGURE 1.7

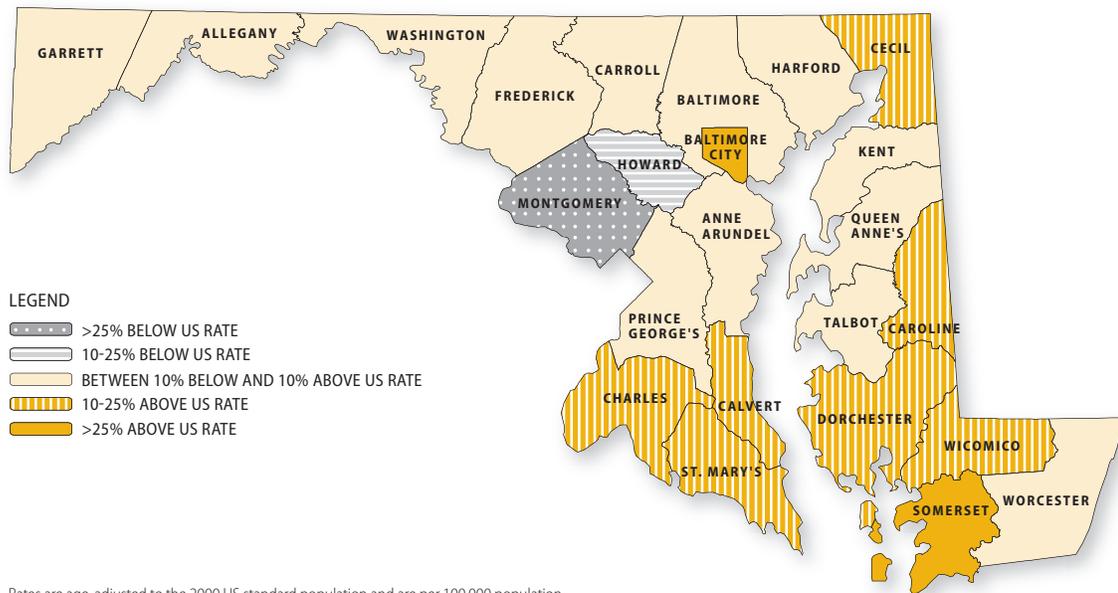
All Sites Cancer Age-Specific Mortality Rates by Race and Gender in Maryland, 2002-2006



Rates are per 100,000 population. Source: NCHS Compressed Mortality File in CDC WONDER, 1999-2006.

FIGURE 1.8

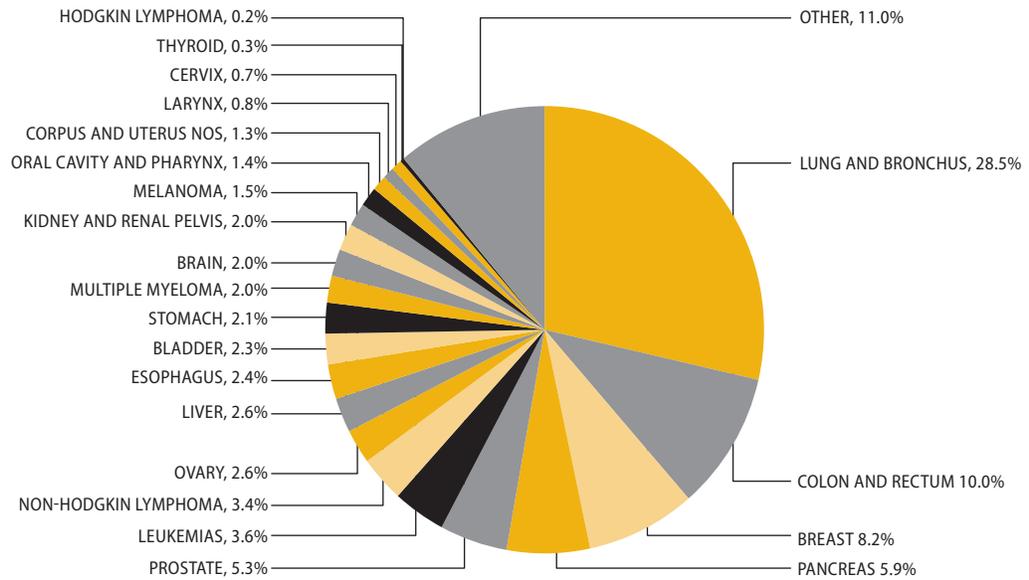
### Maryland All Cancer Sites Mortality Rates by Geographical Area: Comparison to US Rate, 2002-2006



Rates are age-adjusted to the 2000 US standard population and are per 100,000 population.  
 US all cancer sites mortality rate, 2002-2006: 186.7/100,000  
 Source: NCHS Compressed Mortality File in CDC WONDER, 2002-2006.

FIGURE 1.9

### Percent of Cancer Deaths by Type of Cancer in Maryland, 2002-2006



Source: NCHS Compressed Mortality File in CDC WONDER, 1999-2006.

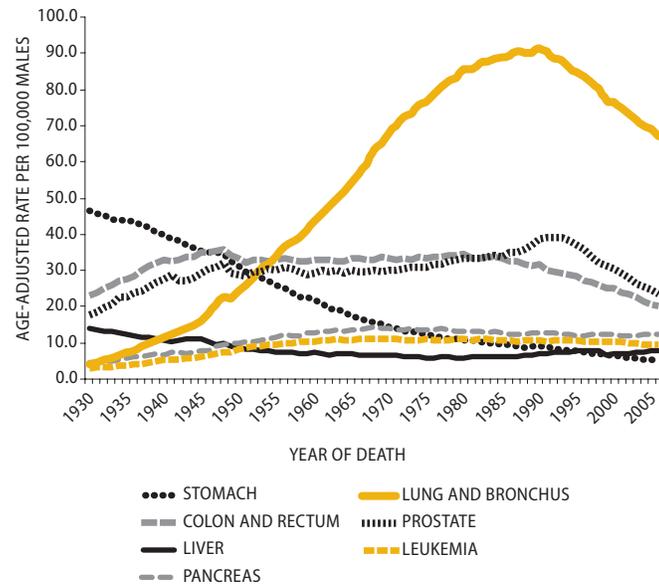
IN MARYLAND, AND IN THE US, cancer mortality rates increase with age for all races and genders (Figure 1.7). In 2006, cancer was the second leading cause of death in children ages 5 to 14 and the leading cause of death in adults ages 25 to 64 (Table 1.3). In 2006, cancers of the breast, lung and bronchus, brain, and colon were the most common causes of cancer death among adults ages 20 to 44 in Maryland (based on number of deaths); cancers of the lung and bronchus, colon, breast, pancreas, and prostate were the most common causes of cancer death among persons ages 45 and older in Maryland.<sup>14</sup>

Figure 1.8 shows the overall cancer mortality rates in Maryland’s 24 jurisdictions compared to the US rate for 2002-2006. The overall cancer mortality rates during the period 2002-2006 were at least 10% above the US rate in nine Maryland jurisdictions (Baltimore City, Calvert, Caroline, Cecil, Charles, Dorchester, St. Mary’s, Somerset, and Wicomico). Mortality rates were at least 10% lower than the US rate in two jurisdictions (Howard and Montgomery counties).

For the five-year period 2002-2006, lung cancer was the leading cause of cancer deaths, accounting for more than one quarter (28.5%) of all cancer deaths in Maryland (Figure 1.9). Colorectal cancer follows, accounting for 10.0% of all cancer deaths in the state. Breast cancer accounted for 8.2%, pancreatic cancer for 5.9%, and prostate cancer for 5.3% of all cancer deaths in Maryland. Collectively, these cancers accounted for 57.9% of all deaths due to cancer in Maryland.

FIGURE 1.10

Age-Adjusted Cancer Death Rates of US Males by Site, 1930-2006



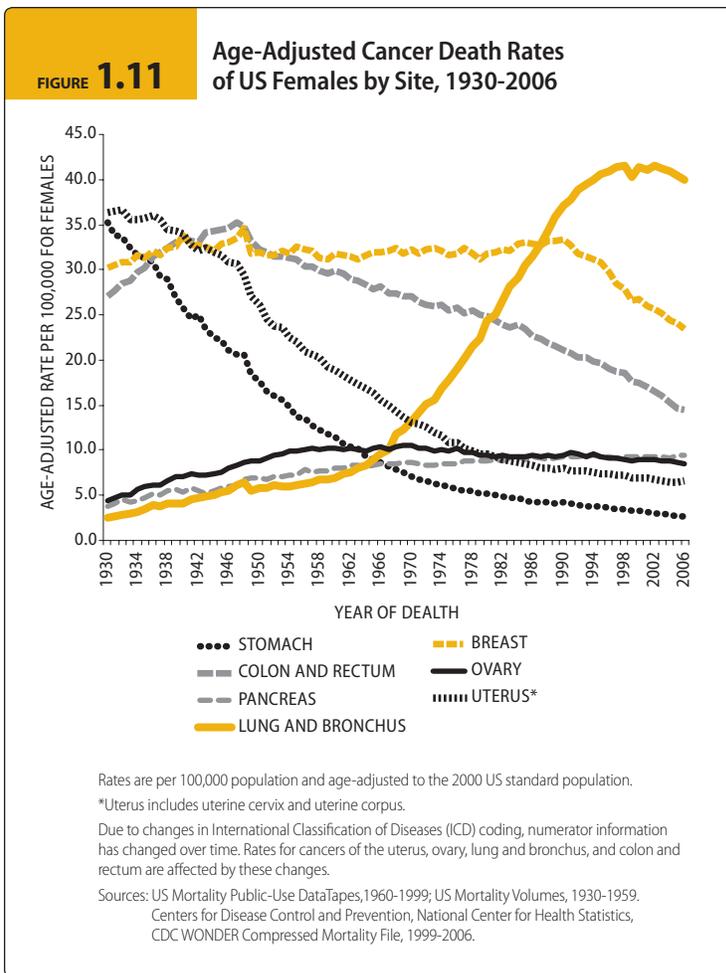
Rates are per 100,000 population and age-adjusted to the 2000 US standard population. Due to changes in International Classification of Diseases (ICD) coding, numerator information has changed over time. Rates for cancers of the lung and bronchus, colon and rectum, and liver are affected by these changes. Sources: US Mortality Public-Use Data Tapes, 1960-1999; US Mortality Volumes, 1930-1959. Centers for Disease Control and Prevention, National Center for Health Statistics, CDC WONDER Compressed Mortality File, 1999-2006.

TABLE 1.4

Trends in Five-Year Relative Survival Rates\* by Year of Diagnosis in the US, 1975-2005

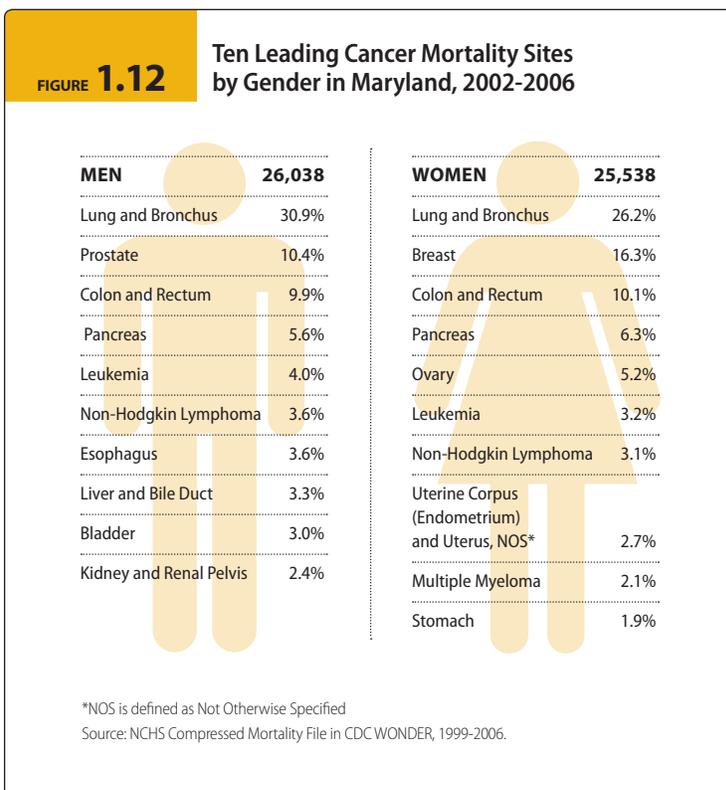
	1975-1977	1984-1986	1996-2005
All Cancers	50%	54%	68%
Lung and Bronchus	13%	13%	16%
Colon	52%	59%	66%
Rectum	49%	57%	69%
Breast	75%	79%	90%
Prostate	69%	76%	100%

\*Survival rates are adjusted for normal life expectancy and are based on cases followed through 2006. Source: American Cancer Society, Cancer Facts & Figures, 2010.



Figures 1.10 and 1.11 show the long-term US trends in cancer mortality by type of cancer and gender from 1930-2006 (note: the scale of the Y axis is different in the two figures). Lung cancer remains, by far, the leading cause of cancer deaths in both men and women in the US. In the US, lung cancer became the leading cause of cancer death among males in the mid-1950s and the leading cause of cancer death among females by the late 1980s. Lung cancer mortality in Maryland decreased among males from 80.7 deaths per 100,000 in 1999 to 66.6 deaths per 100,000 in 2006; however, the female lung cancer mortality rate of 43.5 deaths per 100,000 in 1999 had only decreased to 42.6 deaths per 100,000 in 2006.<sup>15</sup> See Chapter 5 for discussion of and approach to lung cancer and tobacco use prevention and cessation. Figure 1.12 shows the ten leading causes of cancer death among men and women in Maryland.

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## Stage of Disease and Survival

**THE FIVE-YEAR SURVIVAL RATE FOR CANCER** (that is, the proportion of persons who are living five years after their diagnosis of cancer) has been improving in the US for many cancers (survival data is not available for Maryland). Five-year relative survival rates for all cancers increased from 50% in 1975-1977 to 68% in 1996-2005 (Table 1.4). Of note, for nearly every cancer type, blacks or African Americans have lower five-year relative survival rates than whites (data not shown).<sup>16</sup>

## Childhood Cancer

IT IS ESTIMATED THAT 10,700 CHILDREN ages 0 to 14 will be diagnosed with cancer in the US in 2010.<sup>17</sup> The most frequently diagnosed cancers in children differ significantly from those in adults. Leukemia accounts for 31% of cancers in children, with acute lymphocytic leukemia being the most common type. Cancers of the brain and nervous system account for an additional 21% of childhood cancers. While less common, neuroblastoma, cancer of the kidney (i.e., Wilms tumor), lymphoma, soft tissue sarcoma (i.e., rhabdomyosarcoma), eye cancer (i.e., retinoblastoma), and bone cancer (e.g., osteosarcoma and Ewing sarcoma) also occur with relative frequency among children.<sup>18</sup>

From 2002–2006, there were 1,110 cases of cancer diagnosed in Maryland children younger than 20 (Table 1.5).

Childhood cancers represent less than 1% of all new cancer diagnoses in the US; however, cancer remains the second leading cause of death among those ages 0 to 14, and it is estimated that 1,340 cancer deaths will occur within this age group in 2010.<sup>19</sup>

Overall childhood cancer survival rates have improved markedly over the past 30 years due in large part to the development of better cancer treatments. In the US, five-year relative survival rates have risen from less than 50% prior to 1970 to 80% for the period 1999–2005.<sup>20</sup> Despite these advances, survival rates vary significantly depending on cancer type or subtype, and survivors of childhood cancer are susceptible to developing late-onset treatment side effects such as organ malfunction, secondary cancers, or cognitive impairment. Follow-up guidelines for screening and management of long-term effects have been developed to help preserve quality of life in survivors of childhood cancer.<sup>21</sup>

TABLE 1.5

Number of Cancer Cases in Children by Site and by Age in Maryland, 2002–2006

	0 YEARS	1-4 YEARS	5-9 YEARS	10-14 YEARS	15-19 YEARS
All Sites	93	214	150	225	428
Oral Cavity and Pharynx	0	0	0	6	13
Digestive System	8	6	0	<6	15
Bones and Joints	<6	<6	7	33	25
Soft Tissue including Heart	7	6	12	16	20
Melanoma of the Skin	<6	<6	<6	7	40
Ovary	0	0	0	<6	9
Testis	<6	0	0	<6	35
Kidney and Renal Pelvis	7	42	9	7	9
Eye and Orbit	12	6	<6	0	<6
Brain	9	36	36	39	33
Thyroid	0	0	<6	10	31
Other Endocrine including Thymus	10	11	<6	<6	<6
Hodgkin Lymphoma	0	<6	<6	19	73
Non-Hodgkin Lymphoma	<6	6	10	19	33
Acute Lymphocytic Leukemia	6	66	38	27	18
Chronic Lymphocytic Leukemia	0	0	0	<6	0
Acute Myeloid Leukemia	<6	13	10	9	11
Chronic Myeloid Leukemia	0	0	0	<6	7

<6 = Case counts of 1-5 are suppressed per DHMH.MCR Date Use Policy.  
Source: Maryland Cancer Registry, 2002–2006.

## Selected Cancer Types

**W**ITHIN THIS CANCER PLAN are chapters specific to lung, skin, colorectal, breast, prostate, oral, and cervical cancers. These cancers were selected based upon their relatively high incidence and/or mortality rates in Maryland or because they have effective screening or modifiable risk factors. Information on the following additional cancers is given in Table 1.6: leukemia, lymphoma, and cancers of the liver, ovary, pancreas, thyroid, urinary bladder, and uterine corpus (endometrium).

## Risk Factors

**CANCER CAN BE ATTRIBUTED** to a variety of factors. These factors may act together or in sequence to initiate or promote the growth of cancerous cells. There have been several studies done to estimate the proportion of cancer deaths attributable to certain factors, including an estimate from Doll and Peto in 1981, and an estimate from Harvard in 1996. These studies estimate that about one-third of cancer deaths are caused by tobacco, while another one-third of deaths are related to excess body weight, physical inactivity, and poor nutrition (Table 1.7). Additional discussion of environmental risk factors for cancer can be found in Chapter 8: Environmental/Occupational Issues and Cancer. More sophisticated analyses separate the risks for each cancer and list definite, probable, and possible exposures leading to each specific cancer.<sup>22,23,24</sup>

There are many risk factors for cancer that are non-modifiable, such as age, gender, genetic makeup, family history, personal medical history, receipt of indispensable medical treatments (radiation, chemotherapy, immunosuppressants, tamoxifen), and certain reproductive factors (hormonal); however there are also many modifi-

able risk factors that have been identified. It is thought that more than 50% of cancer could be prevented if our current knowledge of risk factors were successfully implemented to reduce risk factor prevalence.<sup>25</sup>

Modifiable risk factors for some cancers include lifestyle factors (tobacco and alcohol use, excess body weight, diet high in red meat, and lack of physical activity), environmental exposures (e.g., benzene, arsenic, aflatoxin, and ionizing radiation), reproductive factors (unopposed estrogen therapy), and certain infections (discussed in the next section). Protective factors have also been identified for several of these selected cancer types. For example, long-term oral contraceptive use, pregnancy, tubal ligation, and hysterectomy have all been shown to reduce the risk of ovarian cancer; use of oral contraceptives, pregnancy, and physical activity decrease risk of endometrial cancer; breastfeeding decreases the risk of breast cancer, and increased intake of fluids and vegetables may decrease risk of bladder cancer.<sup>26</sup>

The cancer-specific chapters in this plan (lung, skin, colorectal, breast, prostate, oral, and cervical cancers) include information on risk factors for those cancers. For further information on risk factors for those and other cancers, visit the National Cancer Institute Web site: <http://www.cancer.gov/>.

## Infectious Agents

**GROWING KNOWLEDGE** of the nature of carcinogenesis and the role of cell injury and repair has led to a better understanding of why some infectious agents play an important role in cancer causation. Chronic infections cause cell damage, which is then repaired. With each cycle of cell repair there is an opportunity for DNA “mistakes” to occur,

**TABLE 1.6** Selected Cancer Types

	SIGNS AND SYMPTOMS	EARLY DETECTION	TREATMENT	US 5-YEAR RELATIVE SURVIVAL RATE (1999-2005)
<b>Leukemia</b>	Fatigue, paleness, weight loss, repeated infections, fever, easy bruising, nosebleeds, or other hemorrhages.	Difficult to detect early. Diagnosis made by blood tests and bone marrow biopsy.	Chemotherapy.	AML* 23% ALL 66% CML 56% CLL 78%
<b>Liver</b>	Abdominal pain and/or swelling, weight loss, weakness, loss of appetite, jaundice, fever.	Screening not proven to improve survival; however doctors may screen high-risk individuals with ultrasound and blood tests.	Surgical resection or liver transplantation. If non-operable, tumor destruction, embolization (cutting off tumor blood supply), or chemotherapy.	14%
<b>Lymphoma</b>	Swollen lymph nodes, itching, night sweats, fatigue, unexplained weight loss, intermittent fever.	No screening method recommended for the general population. Initial diagnosis made by blood tests, imaging, and/or biopsy.	<b>Hodgkin:</b> Various combinations of chemotherapy, radiation, and bone marrow or stem cell transplantation. <b>Non-Hodgkin:</b> Usually chemotherapy; radiation less often. Antibody therapy for certain types.	Hodgkin: 85% Non-Hodgkin: 67%
<b>Ovary</b>	Usually no obvious symptoms. Occasionally pelvic pain or abdominal enlargement or fullness.	No routine screening recommended. Pelvic exam, ultrasound, and blood CA125 levels for women with increased risk or persistent symptoms.	Surgery and usually chemotherapy.	46%

which could potentially lead to uncontrolled cell growth and cancer. The immune status of an individual may also be altered by exposure to biological agents, which could prevent the body from recognizing and destroying tumor cells. Research and education on the role of infectious agents in cancer causation could lead to better cancer controls through the development of interventions such as vaccines, antibiotics, and changes in personal behavior to avoid infection.

Several infectious agents have already been linked to cancer. The Epstein-Barr virus has been implicated in some forms of lymphoma; the human papilloma virus (HPV) has been linked to cancers of the cervix, head, and neck and the

human immunodeficiency virus (HIV) has been linked to Kaposi’s sarcoma, cervical cancer, and non-Hodgkin lymphoma. Liver cancer has been linked to parasitic infections with liver flukes and schistosomiasis, as well as viral infections with hepatitis B and C. Hepatitis C is also probably linked to some forms of non-Hodgkin lymphoma. Finally, stomach cancer is strongly associated with infection by the bacterium *Helicobacter pylori*, which is also associated with gastrointestinal ulcer formation. Strategies to address each of these agents should be recognized as part of cancer control efforts.

**TABLE 1.6**

**Selected Cancer Types (continued)**

	SIGNS AND SYMPTOMS	EARLY DETECTION	TREATMENT	US 5-YEAR RELATIVE SURVIVAL RATE (1999-2005)
<b>Pancreas</b>	May include abdominal pain that radiates to the back, weight loss, occasionally high blood glucose or jaundice.	No method for early detection. Only 7% of cases are diagnosed at an early stage.	Surgery, radiation therapy, and chemotherapy may extend survival and/or relieve symptoms, but seldom provide a cure.	6%
<b>Thyroid</b>	Lump, tight feeling, or pain in neck/throat; difficulty breathing or swallowing; hoarseness or swollen lymph nodes.	No method for early detection. Physical examination to detect nodules and evaluation of thyroid nodules with blood tests for hormone levels, imaging, and/or biopsy.	Surgery and sometimes radioactive iodine treatment following surgery to destroy any remaining thyroid tissue.	97%
<b>Urinary Bladder</b>	Blood in the urine. Increased frequency or urgency of urination, or irritation during urination.	No screening method recommended. Diagnosis made by looking at cells from urine or bladder tissue, and examining the bladder wall.	For most types, surgery, sometimes in combination with chemotherapy and/or radiation prior to bladder removal.	80%
<b>Uterine Corpus (Endometrium)</b>	Abnormal uterine bleeding (especially post-menopausal). Pain with urination or intercourse, or in the pelvic area.	No standard or routine screening test for endometrial cancer. Diagnosis made by transvaginal ultrasound and uterine biopsy.	Surgery, radiation, hormones, and/or chemotherapy depending on the stage of disease.	83%

\*AML = acute myeloid leukemia, ALL = acute lymphocytic leukemia, CML = chronic myeloid leukemia, CLL = chronic lymphocytic leukemia

Sources: American Cancer Society, Cancer Facts & Figures 2010.

5-Year Relative Survival Rate: SEER Cancer Statistics Review, 1975-2006.

## Costs for Cancer Care

**THE ECONOMIC IMPACT OF CANCER IS LARGE.** The National Institutes of Health estimates that the overall cost for cancer in the US in the year 2006 to be \$206.5 billion, of which \$78.2 billion was for direct medical costs (i.e., the total of all health expenditures), \$17.9 billion was for indirect morbidity costs (i.e., the cost of lost productivity due to illness), and \$110.2 billion was for indirect mortality costs (i.e., the cost of lost productivity due to premature death). Breast cancer carried the highest cost at \$13.9 billion, followed by colorectal cancer at \$12.2 billion, and cancer of the lung and bronchus at \$10.5 billion

(Table 1.8). Maryland’s population represented approximately 1.88% of the total US population in 2006.<sup>27</sup> Taking this percentage of the national overall estimated cost for cancer, a rough estimate for the cost for cancer in Maryland in 2006 is \$3.9 billion, and the total direct medical cost is \$1.5 billion (costs of cancer care in Maryland can be estimated based on the assumption that in 2006 Maryland represented 1.88% of the US population).

## Cancer Control in Maryland

A Cancer Control Model has been developed in Maryland to provide a framework for decision-making regarding cancer control policies and services in the state, and is available at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

**A**T ANY GIVEN TIME, each individual may be susceptible to developing a cancer, or he or she may have asymptomatic, clinical, or advanced disease. Cancer for an individual exists on a continuum from susceptibility, to early cancer, late stage cancer, and survivorship or potentially death from cancer. Along the continuum there are various opportunities for cancer control and treatment interventions called primary, secondary, and tertiary prevention.

Cancer control begins with various types of research (basic, translational, applied, and community-based participatory research) and involves promoting and funding research; promoting education, risk-factor prevention, and screening efforts; facilitating treatment and post-treatment interventions for survivors; and conducting cancer surveillance for risk factors, incidence, and mortality. Making surveillance information available to policymakers will foster education and policies, appropriate and accessible health-care services, and healthcare payment to reduce the burden of cancer among Maryland’s citizens and to improve the health of the population.

TABLE 1.7

Estimated Proportions of Cancer Deaths Attributable to Various Risk Factors

RISK FACTOR	DOLL AND PETO ESTIMATE	HARVARD ESTIMATE
Tobacco	30%	30%
Adult Diet/Obesity	35%	30%
Sedentary Lifestyle	-	5%
Occupational Factors	4%	5%
Family History of Cancer	-	5%
Viruses/Other Biologic Agents	10%	5%
Perinatal Factors/Growth	-	5%
Reproductive Factors	7%	3%
Alcohol	3%	3%
Socioeconomic Status	-	3%
Environmental Pollution	2%	2%
Ionizing/Ultraviolet Radiation	3%	2%
Prescription Drugs/Medical Procedures	1%	1%
Salt/Other Food Additives/Contaminants	-	1%

Sources: Doll R, Peto R. The Causes of Cancer. Quantitative Estimates of Avoidable Risks of Cancer in the United States Today. New York, NY: Oxford University Press, Inc.; 1981 and the Harvard Center for Cancer Prevention. Harvard Report on Cancer Prevention. Volume 1: Causes of Human Cancer, 1996.

TABLE 1.8

Estimated Annual Costs of Cancer Care in the US, 2006

TOTAL COSTS	ESTIMATED ANNUAL COSTS
<b>Total Cancer Care</b>	<b>\$206.3 billion</b>
<b>Total Direct Medical Costs</b>	<b>\$78.2 billion</b>
DIRECT MEDICAL COSTS BY CANCER TYPE	ESTIMATED ANNUAL COSTS
<b>Breast</b>	<b>\$13.9 billion</b>
<b>Colorectal</b>	<b>\$12.2 billion</b>
<b>Lung and Bronchus</b>	<b>\$10.3 billion</b>
<b>Lymphoma</b>	<b>\$10.2 billion</b>
<b>Prostate</b>	<b>\$9.9 billion</b>
<b>Leukemia</b>	<b>\$4.5 billion</b>
<b>Ovary</b>	<b>\$4.4 billion</b>
<b>Brain</b>	<b>\$3.7 billion</b>
<b>Bladder</b>	<b>\$3.5 billion</b>
<b>Head and Neck Cancers</b>	<b>\$3.1 billion</b>

Sources: American Cancer Society, Cancer Facts & Figures 2006 (for total costs). National Cancer Institute, Cancer Trends Progress Report 2009/2010 Update (for cancer-specific costs).

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# 2 · Cancer Surveillance



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# 2

## CANCER SURVEILLANCE



Cancer surveillance is key to improving cancer control in Maryland. Public health surveillance—the ongoing, systematic collection, analysis, and interpretation of health data—is essential to the planning, implementation, and evaluation of public health practice.

**DID YOU KNOW?**

Cancer surveillance information contributes to public health action in Maryland and nationwide. This chapter presents real examples of how Maryland surveillance information is being used.

**SURVEILLANCE INVOLVES THE COLLECTION OF DATA AND MONITORING OF TRENDS**, and is closely tied to the timely dissemination of data to those who need it.<sup>1</sup> In addition, surveillance can provide data and information to raise awareness of public health problems and to inform public policies.

Cancer surveillance includes the collection of data on the occurrence of cancer (incidence), cancer deaths (mortality), risk factors for the development of cancer (for example, smoking, overweight, and fruit and vegetable intake), cancer screening behaviors (for example, the use of mammography, colonoscopy, and Pap tests), and diagnostic and treatment services. Factors affecting post-treatment quality of life and palliative care are increasingly important to cancer surveillance, as the scope of surveillance expands to include all phases of the disease.<sup>2</sup> A well-functioning cancer surveillance system transforms complete, timely, and high quality data into information that is easily accessible to those who use it to prevent and control the disease.

In Maryland, surveillance for cancer occurrences is conducted primarily through reporting of cancer diagnoses (incidence) and cancer deaths (mortality). Within six months after diagnosis of invasive and in situ cancer (excluding basal and squamous skin cancer of non-genital sites), information about the individual and the cancer must be reported, by legal mandate, to the Department of Health and Mental Hygiene’s (DHMH) Maryland Cancer Registry (MCR) by the state’s hospitals, radiation therapy centers, ambulatory care centers, laboratories, and physicians. Cases among Maryland residents diagnosed out of state are reported to the MCR through interstate data exchange agreements (with 12 states and the District of Columbia). Mortality from cancer is reported to, and analyzed by, the Vital Statistics Administra-

## Cancer Surveillance and Maryland's Colorectal Cancer Successes

### THE CHALLENGE

When the Maryland DHMH conducted surveillance of colorectal cancer (CRC) incidence and mortality in 2000, it found that Maryland rates were significantly above the national average. Racial disparities in CRC were also evident in Maryland, with statistically significantly higher incidence and mortality rates among blacks or African Americans compared to whites. In 2000, blacks or African Americans in Maryland had an age-adjusted CRC mortality rate 1.4 times that of whites (31.1 per 100,000 versus 22.1, respectively).<sup>4</sup> Although CRC is largely preventable through screening, screening was underutilized.

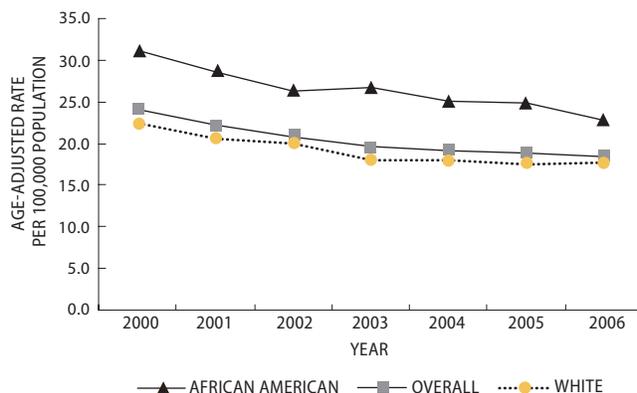
### THE INTERVENTION

CRC was one of seven cancers “targeted” by the Maryland Cancer Prevention, Education, Screening, and Treatment Program, which was established under the Cigarette Restitution Fund (CRF) Program. In 2000, public health programs in Maryland began promoting screening for CRC. In 2001, Medicare started paying for screening colonoscopies. Using CRF funding, local health departments established outreach and screening programs targeted to individuals who had low-income, were uninsured, or were of minority race or ethnicity. In 2006, the CDC allocated additional funds to Maryland to establish a CRC Screening Demonstration Program in Baltimore City. In 2009, the CDC funded Maryland as part of the new national CRC Control Program for CRC education, outreach, screening, and promotion of insurance benefits.

### THE OUTCOME

From 2000 through 2008, more than 17,000 underserved Marylanders were screened for CRC through local public health programs. The percentage of Marylanders age 50 and older who ever received a sigmoidoscopy or colonoscopy increased from 50% in 1999 to 75% in 2008,<sup>6</sup> and Maryland's age-adjusted CRC mortality rate dropped faster than the national rate. Maryland's national ranking in CRC mortality rates declined from 3rd highest (based on a five-year average mortality rate, 1996-2000) to 14th highest (2002-2006).<sup>7</sup> As shown in the chart, Maryland also made significant progress in closing the racial disparity gap in CRC mortality.

**Trends in Colorectal Cancer Age-Adjusted Mortality Rates in Maryland, by Race, 2000-2006**



Source: NCHS Compressed Mortality File in CDC WONDER.

tion (VSA), using the underlying cause of death on the death certificate. Deaths among Maryland residents who died out of state are reported to the VSA under interstate data exchange agreements.

Surveillance entails diagnosing the tumor, determining whether a case should be reported, and reporting case information that is timely, complete, and accurate to the MCR. MCR staff “consolidate” the information on each tumor, which may be reported from multiple sources, and develops the final tumor record retained in the MCR database. MCR data are then reported to the North American Association of Central Cancer Registries (NAACCR) and to the Centers for Disease Control and Prevention (CDC) National Program of Central Cancer Registries (NPCR). MCR reports are also posted to appropriate Web sites (see Table 2.1). These national agencies “grade” the Maryland reports on their quality. Within 24 to 35 months after diagnosis, data on cancer cases are finalized and ready for analysis. The MCR attempts to identify all reportable cases in Maryland residents, but cases can be missed if the tumor is not identified or not reported on time.

Cancer case and death data are routinely age-adjusted and standardized to the US population for comparison, and are analyzed by gender, race, and county of residence. If sufficient information is available, cases with onset after 1999 are geocoded

### DID YOU KNOW?

The Maryland Cancer Registry (MCR) collects and maintains confidential data on all reportable cancers diagnosed in people in Maryland. The MCR reports on the trends in cancer over time, which helps to identify program needs.

by latitude and longitude, county of residence, and ZIP code. In addition, census tracts are verified, corrected, or added.

As part of its mission to serve Marylanders, DHMH also conducts active surveillance on cancer screening and risk behaviors through several population-based statewide surveys. For example:

- The Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing survey of adults 18 and older designed to collect data on risk behaviors and other factors that affect chronic disease, including cancer.
- The Maryland Cancer Survey (MCS), a biennial statewide survey conducted from 2002–2008 among adults age 40 years and older, focused on cancer screening, knowledge, and risk behaviors in this older population most at risk for developing cancer.
- The Maryland Adult and Youth Tobacco Surveys (MATS and MYTS), conducted in 2000, 2002, and 2006, focused on current and past tobacco use, secondhand smoke exposure, and smoking cessation among Maryland adults and youth.

Cancer surveillance data and information have many uses: planning, policymaking (including resource allocation and evaluation of cancer prevention and control efforts), and applied research. Applied research may examine areas of cancer control, such as risk factors, cancer prevention, and disparities in incidence and mortality.

By monitoring trends in cancer incidence, stage, and mortality over time, cancer surveillance data can be used to evaluate cancer prevention and control programs. For example, cancer mortality rates in Maryland have been decreasing at a faster rate than national rates. For the time period 1986–1990, Maryland had the third-highest cancer mortality rate in the nation; for the time period 2002–2006 Maryland’s rank dropped to the 20th highest cancer mortality rate nationwide.<sup>3</sup>

This chapter includes real examples of how

## Research Uses of Cancer Surveillance Data

### Maryland Researchers Examine Cancer Risk Factors

The CLUE community-based cohorts, CLUE I and CLUE II, were established in Washington County, Maryland in 1974 and 1989, respectively, to study cancer and heart disease. These studies take their name from the campaign slogan “Give Us a Clue to Cancer and Heart Disease.” In both studies, participants completed a brief questionnaire and donated a blood specimen. CLUE II participants were also asked to complete a questionnaire about their diet in 1989, and to complete questionnaires every two to three years beginning in 1996. More than 23,000 adults took part in CLUE I and more than 32,000 participated in CLUE II. Participants are monitored for the development of cancer using the Washington County Cancer Registry and the Maryland Cancer Registry. Information collected in 1974 and 1989, including the blood samples, has been used to determine possible protective factors or risk factors for cancer.

**THE FOLLOWING EXAMPLES OF TOPICS INVESTIGATED** as part of the CLUE I and CLUE II studies were made possible by the ability to link to cancer registries:

- Risk of developing subsequent cancer among people diagnosed with nonmelanoma skin cancer.<sup>8</sup>
- The association between C-reactive protein, a blood serum marker of chronic inflammation, and other hormones, and the risk of ovarian cancer.<sup>9,10</sup>
- The potential role of serum biological markers, such as CA-125, for the early detection of ovarian cancer, and nonsteroidal anti-inflammatory medication in reducing risk of invasive breast cancer.<sup>11,12</sup>
- Possible association between high levels of serum cholesterol and the aggressiveness of prostate cancer.<sup>13</sup>
- Meat and dairy consumption and the risk of developing prostate cancer.<sup>14</sup>

cancer surveillance has contributed to public health knowledge, policymaking, program evaluation, and research that translates into public health action.

The text box on page 2, Cancer Surveillance and Maryland’s Colorectal Cancer Success, shows that surveillance of colorectal cancer incidence by the Maryland DHMH led to a program to increase colorectal cancer screening statewide.

Cancer surveillance in Maryland also supports research aimed at better understanding cancer risk factors. The text box above, Research Uses of Cancer Surveillance Data, provides examples of research studies that use Maryland cancer surveillance data to examine the roles of cancer risk factors and protective factors in the development of cancer. Studies such as these make important contributions to cancer prevention and control efforts in Maryland and nationwide.

## Types of Cancer Statistics

### INCIDENCE

The rate of newly diagnosed cases during a specific time period.

### MORTALITY

The rate of deaths during a specific time period.

### PREVALENCE

The total number of cases in the population during a specific time period.

### STAGE

The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.

## Data and Information for Cancer Surveillance in Maryland

Cancer surveillance in Maryland is supported by many types of data and information, including:

- Cancer incidence, mortality, and staging data.
- Prevalence of cancer screening and cancer-related risk behaviors.
- Cancer-related medical services and expenditures.
- Vital statistics data.

Table 2.1 (pages 6-7) summarizes key data and information resources relevant to cancer surveillance in Maryland. (A more detailed version of this table and a summary of data fields in key databases are available on the Cancer Surveillance page of the Maryland Cancer Plan Web site: [www.marylandcancerplan.org](http://www.marylandcancerplan.org)). For each resource listed, the table identifies the administering agency or organization, briefly describes the types of information provided, and lists a Web link to that source. Departments, agencies, and commissions in the state of Maryland (e.g., DHMH, Health Services Cost Review Commission, Maryland Health Care Commission), various federal agencies (e.g., National Cancer Institute, Centers for Disease Control and Prevention, National Center for Health Statistics), as well as nongovernmental organizations (e.g., American Cancer Society), provide open access to a wide range of databases, data portals, and surveys via the Web. Key data sources used for cancer surveillance activities in Maryland include the MCR, Maryland BRFSS, MCS, and Vital Statistics Administration. Some of these data sources collect information on the entire Maryland population (e.g., MCR, VSA), while others collect information only on certain segments (e.g., Maryland Medical Care Data Base, Maryland Hospital Data) or use representative survey samples (e.g., BRFSS, MCS). The US sources described in Table 2.3 include state-specific cancer data (including Maryland data), national cancer incidence and mortality data, and data on prevalence of health risk behaviors.

## Gaps and Solutions in Cancer Surveillance in Maryland

The following are gaps and possible solutions to enhance overall cancer surveillance in Maryland. Other chapters in this plan identify additional surveillance needs and recommendations specific to their area of concern.

### Gaps in Data Collection

- Need for timely and accurate MCR data that include all reportable cancers diagnosed among Marylanders. Although the MCR complies with national requirements for data elements, information in those elements can be incomplete. For example: 1) stage of disease may be unknown, especially for cases reported only from laboratories; 2) survival, and thus prevalence data, cannot be obtained for Maryland cancer cases because the MCR is an “incidence” registry and is not funded for long-term follow-up of individuals diagnosed with cancer; 3) information is incomplete for risk factors such as current or prior occupation, tobacco use, length of residency at address at time of diagnosis or prior addresses before diagnosis, and cancer screening; and 4) MCR does not collect quality of care and quality of life information.

Solutions may include participating in development of data systems such as the Maryland Health Information Exchange to enhance collection of registry data; enhancing registry functioning and funding to improve access to current and complete data; assuring that clinical information is obtained on cases reported only by laboratories; and performing special studies to obtain additional information.

- Need for more complete information on ethnicity. The MCR currently uses the NAACCR algorithm to derive Hispanic or Latino ethnicity based on last and maiden names when ethnicity is non-Hispanic/non-Latino or missing. Solutions include encouraging consistent collection and reporting of ethnicity from hospitals and other reporting facilities.
- Need to have Certified Tumor Registrars (CTRs) report cancer data from hospitals in Maryland and need for CTRs to know the latest standards. Although Maryland has made great progress in this area—with more hospitals having CTRs and more being accredited by the Commission on Cancer of the American College of Surgeons—some gaps still exist. Solutions include increasing the number of CTRs in Maryland that perform cancer registration, increasing the training of tumor registrars, and increasing the number of hospitals in Maryland accredited by the American College of Surgeons.
- Need for additional surveillance for cancer risk factors and enhanced quality assurance for data collected. As of 2010, funding for the MCS has been reduced. If these surveillance activities are to be restored, additional funding is needed. In addition, risk factor surveillance data are self-reported, without independent verification of data such as frequency of cancer screening, body mass index, smoking patterns, and exercise frequency.
- Need for better mortality data collection systems, more training on reporting death certificate information, and more evaluation of the quality of mortality data. Need for funding to support these activities.
- Need for additional data on environmental and occupational exposures, either through additional surveys, additional information collected from people with cancer, or additional environmental monitoring.

- Need for complete and accurate first course of treatment data on cancers reported to the MCR. Treatment data are missing for cases that are reported only by laboratories.
- Need for follow-back to the physicians to collect treatment and staging information for cases reported only by laboratories.

### Gaps in Access to Cancer Data

- Need for greater public awareness and access to cancer surveillance data on incidence, mortality, and behavioral risk factors. Solutions include creation of public-use data files (such as the MCS public-use dataset) and interactive access (e.g., Web-based, user-defined utility reports). The Maryland BRFSS has developed a public-use data application for analysis of BRFSS data and MCS data. Blending datasets is possible through tools such as the Maryland Environmental Public Health Tracking (EPHT) program (see Table 2.1, pages 6-7).
- Need for consistent agreements with other states for data exchange and data rerelease policies. Such agreements would enable out-of-state deaths and cancer diagnoses of Maryland residents to be rereleased 1) from Vital Records to the MCR and to EPHT, 2) from the MCR to EPHT, and 3) from the MCR, Vital Records, or the EPHT to researchers who meet Maryland standards for data release.

### Gaps in Data Analysis

- Need for expansion of proactive or reactive analysis of cancer surveillance data and need for statistical methods for analysis of cancer in small areas or rare cancers. Solutions may include:
  - Using small area analyses that determine the number of health (or other) events occurring in small geographic areas (such as ZIP codes, block groups, or census tracts) and comparing health events occurring in one area to those occurring in a similar geographic area or a larger, standard population.
  - Using analytic tools for geographic area analysis and geographic information systems.
  - Developing data resources and analyzing leading cancer indicators along with potential existing or new sources from which related data can be obtained. Indicators could include incidence, mortality, treatment, risk behaviors,

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TABLE 2.1 Cancer Surveillance Systems

DATABASE OR DATA SOURCE	LEAD AGENCY	DESCRIPTION
<b>MARYLAND DATA SOURCES</b>		
<b>MD Cancer Registry (MCR)</b> <a href="http://www.fha.state.md.us/cancer/mcr_home.cfm">www.fha.state.md.us/cancer/mcr_home.cfm</a>	DHMH	Collects, maintains, and reports on cancer incidence among Maryland residents, and serves as a resource for cancer prevention, control, and research efforts.
<b>MD Behavioral Risk Factor Surveillance System (BRFSS)</b> <a href="http://www.marylandbrfss.org">www.marylandbrfss.org</a>	DHMH	Population-based surveys of Maryland adults age 18 years and older that collect information on health risk behaviors, preventive health practices, healthcare access, chronic disease (including cancer), and injuries.
<b>MD Cancer Survey (MCS)</b> <a href="http://www.fha.state.md.us/cancer/surv_data-reports.cfm">www.fha.state.md.us/cancer/surv_data-reports.cfm</a>	DHMH	Population-based surveys of Maryland adults age 40 years and older that collect information on cancer screening practices, cancer-related risk behaviors, and healthcare access.
<b>MD Vital Statistics Administration (VSA)</b> <a href="http://www.vsa.state.md.us">www.vsa.state.md.us</a>	DHMH	Source of Maryland vital statistics data, analyses, and reports; cancer deaths reported by jurisdiction, age, gender, and race.
<b>MD Adult Tobacco Survey (MATS) and MD Youth Tobacco Survey (MYTS)</b> <a href="http://www.crf.state.md.us/html/stats.cfm">www.crf.state.md.us/html/stats.cfm</a>	DHMH	Surveys to collect information on tobacco-use behaviors and prevalence, smoking cessation, and other information supporting CRF Tobacco-use Prevention and Cessation Program.
<b>MD Hospital Data (Inpatient and Outpatient Data Sets)</b> <a href="http://www.hscrc.state.md.us">www.hscrc.state.md.us</a>	HSCRC	Medical record abstract and billing data on hospital inpatient discharges and outpatient services; useful data for estimating costs of cancer treatment.
<b>MD Medical Care Database</b> <a href="http://www.mhcc.maryland.gov/health_care_expenditures/mcdb.html">www.mhcc.maryland.gov/health_care_expenditures/mcdb.html</a>	MHCC	Data on ambulatory services and expenditures in Maryland, obtained from Maryland healthcare insurance carriers and EPOs.
<b>MD Environmental Public Health Tracking (EPHT)</b> <a href="http://eh.dhmh.md.gov/tracking">http://eh.dhmh.md.gov/tracking</a>	DHMH	Resource for data on Maryland environmental health topics (air quality, drinking water, lead, pesticides, children's environmental health) and health outcomes, including cancer.
<b>FEDERAL DATA SOURCES</b>		
<b>Surveillance, Epidemiology, and End Results (SEER) Program</b> <a href="http://www.seer.cancer.gov/publications">www.seer.cancer.gov/publications</a>	NCI	Data and statistics on cancer incidence, prevalence, and survival from specific geographic regions in the US, and national cancer mortality data.
<b>State Cancer Profiles</b> <a href="http://www.statecancerprofiles.cancer.gov">www.statecancerprofiles.cancer.gov</a>	NCI, CDC	National, state, and county-level cancer data, including incidence and death rates, graphical trends analyses, interactive maps, and comparative data displays; focus is on cancer sites with evidence-based control interventions.
<b>Cancer Control Plan, Link, Act, Network with Evidence-based Tools (Cancer Control P.L.A.N.E.T.)</b> <a href="http://cancercontrolplanet.cancer.gov">http://cancercontrolplanet.cancer.gov</a>	NCI (with other sponsors)	Portal providing access to Web-based data and resources useful in design, implementation, and evaluation of evidence-based cancer control programs.
<b>CDC Wide-ranging Online Data for Epidemiologic Research (CDC WONDER)</b> <a href="http://wonder.cdc.gov">http://wonder.cdc.gov</a>	CDC	Query-based system for access to cancer incidence and mortality data, and other health-related data available from CDC.
<b>National Program of Cancer Registries (NPCR)</b> <a href="http://www.cdc.gov/cancer/npcr">www.cdc.gov/cancer/npcr</a>	CDC	Official federal statistics on cancer incidence and mortality, for US and individual states; aggregated county-level cancer incidence rates and counts for major cancers.
<b>National Vital Statistics System (NVSS)</b> <a href="http://www.cdc.gov/nchs/nvss.htm">www.cdc.gov/nchs/nvss.htm</a>	NCHS	State and national vital statistics data, including cancer deaths and death rates.

**TABLE 2.1** CONT. **Cancer Surveillance Systems**

DATABASE OR DATA SOURCE		LEAD AGENCY	DESCRIPTION
<b>FEDERAL DATA SOURCES</b>			
<b>Youth Risk Behavior Survey (YRBS)</b> <a href="http://www.cdc.gov/HealthyYouth/states/md.htm">www.cdc.gov/HealthyYouth/states/md.htm</a>		CDC	Prevalence of health-risk behaviors, including tobacco and alcohol use, diet, physical activity, and sexual behaviors among Maryland students in grades 9-12; comparisons between state and national survey results also available.
<b>Health Information National Trends Survey (HINTS)</b> <a href="http://hints.cancer.gov">http://hints.cancer.gov</a>		NCI	Survey to examine use of cancer-related information by American adults.
<b>National Health Interview Survey (NHIS)</b> <a href="http://www.cdc.gov/nchs/nhis.htm">www.cdc.gov/nchs/nhis.htm</a>		NCHS	Annual national household survey on health behaviors, chronic conditions, healthcare coverage and use, and health status; supplemental modules have included topics such as cancer, immunization, and complementary and alternative medicine.
<b>National Health and Nutrition Examination Survey (NHANES)</b> <a href="http://www.cdc.gov/nchs/nhanes.htm">www.cdc.gov/nchs/nhanes.htm</a>		NCHS	Health and nutritional status of adults and children in the US. Examples of data include: disease or condition prevalence, risk factors, nutrition monitoring, growth and development, disease monitoring.
<b>OTHER DATA SOURCES</b>			
<b>Cancer Facts and Figures</b> <a href="http://www.cancer.org">www.cancer.org</a>		ACS	Annual reports of cancer incidence and death data by state, probability of developing cancer by age, cancer survival rates, cancer disparities, and special topics in cancer.
DHMH	Maryland Department of Health and Mental Hygiene	NCI	National Cancer Institute (U.S. National Institutes of Health)
CRF	Cigarette Restitution Fund	CDC	Centers for Disease Control and Prevention
HSCRC	Maryland Health Services Cost Review Commission	NCHS	National Center for Health Statistics (Centers for Disease Control and Prevention)
MHCC	Maryland Health Care Commission		
EPO	Exclusive Provider Organization	ACS	American Cancer Society

and avoidable cancer events. In addition, such indicators could include events that are sentinels of problems in cancer prevention, education, screening, and treatment services that can be used to monitor or track changes in cancer control in Maryland.

- Need to provide technical assistance to local health departments in cancer surveillance and analysis. Assistance in analyzing local data, compiling county-specific data (including trends over time), and directing further studies or collecting additional data could help in program planning, and targeting or monitoring cancer programs.
- Need to expand research into cancer risk factors, etiology, outcomes, and knowledge, attitudes, and behaviors of the public and of providers.
- Need to evaluate the quality of care provided to

cancer patients.

- Need for ongoing or increased funding to meet these surveillance needs.

### Gaps in Information Dissemination

- Need for enhanced dissemination of existing cancer surveillance data to the public and to those who are implementing programs and policies to improve cancer control. Solutions include increasing access to cancer reports and cancer statistics through the Internet.

# GOALS - OBJECTIVES - STRATEGIES

## GOAL 1

**Collect, analyze, develop, and disseminate Maryland cancer information.**

### OBJECTIVE 1

Through 2015, implement solutions to address at least three of the gaps in cancer surveillance data collection identified in the Surveillance Chapter of the Maryland Cancer Plan.

#### STRATEGIES

- 1 **MEET NATIONAL STANDARDS** for accuracy, timeliness, and completeness of Maryland Cancer Registry (MCR) data needed for cancer prevention and control including:
  - National Program of Cancer Registries (NPCR) data standards for US cancer statistics and multi-year data for NPCR Web site.
  - North American Association of Central Cancer Registries (NAACCR) data standards for one-year incidence data.
  - Cancer in North America (CINA) plus data standards (NAACCR Web-based and research data file) for multi-year incidence data.
- 2 **PROVIDE ONGOING, ADEQUATE STAFFING, FUNDING, AND SYSTEMS** to obtain, maintain, and support high quality, timely, and accessible cancer incidence and surveillance data.
- 3 **MAINTAIN THE MARYLAND CANCER REGISTRY ADVISORY COMMITTEE** to provide ongoing multidisciplinary advice to the MCR on cancer incidence data quality, release, use, timeliness, and reporting.

### OBJECTIVE 2

Through 2015, analyze cancer data and develop reports to assist with meeting the needs of the public and researchers.

#### STRATEGIES

- 1 **PERFORM ONGOING ANALYSES** of Maryland cancer data including small area analyses that address cancer cluster concerns and disparities among subgroups. Document results and findings in published reports.
- 2 **ESTABLISH METHODS** to measure the extent to which cancer data and information needs are being met.
- 3 **DEVELOP THE LEADING CANCER INDICATORS** (e.g., mortality, incidence, stage at diagnosis, treatment, risk behaviors, avoidable cancer events, and events

that are sentinels of problems in cancer prevention and control services) that are used to monitor cancer control in Maryland.

- 4 **COLLABORATE WITH OTHER ENTITIES** to standardize collection, analysis, and reporting of cancer-related data necessary for cancer surveillance. Explore opportunities for linking cancer databases with other cancer-related or non-cancer related databases to facilitate answering questions of interest.

### OBJECTIVE 3

Through 2015, increase public availability and awareness of Maryland cancer mortality, incidence, and risk factor information.

#### STRATEGIES

- 1 **EXPAND PUBLIC ACCESS** to Maryland cancer data by inclusion on the Internet sites such as:
  - State Cancer Profiles
  - Cancer Control P.L.A.N.E.T.
  - NPCR
  - CINA Plus Cancer Inquiry System
  - CDC WONDER
  - Maryland BRFS
  - Maryland Environmental Public Health Tracking
- 2 **EXPAND DISSEMINATION** of Maryland cancer data to the public by
  - Producing Maryland incidence and mortality reports and posting to the DHMH Web site.
  - Preparing Maryland Cigarette Restitution Fund Program biennial cancer reports and posting to the DHMH Web site.
  - Publishing information of interest such as leading indicators and data to answer research questions.
- 3 **INCREASE PUBLIC AWARENESS** of Maryland cancer publications through various forms of communications (e.g., memos, letters, Internet postings, news media).

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# 3 · Cancer Disparities



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# 3

## CANCER DISPARITIES

The persistence of health disparities continues to hamper the overall improvement of the nation’s health, despite tremendous technological advances in health and medical care that have helped to increase life expectancy and realize better health outcomes.<sup>1,2</sup>

**DID YOU KNOW?**

More than 30% of direct medical costs faced by some minorities are excess costs due to health inequities.

**OVERCOMING PERSISTENT HEALTH DISPARITIES** and promoting health for all Americans rank as our nation’s foremost health challenge.<sup>3</sup> The need to overcome this challenge is more urgent as the nation and indeed Maryland become more diverse. The US Census Bureau estimates that by 2050 minorities will constitute more than half of the total US population.<sup>4</sup>

While numerous initiatives by federal, state, and local governments have been put in place to address this challenge, there has been limited success, as minorities continue to experience higher disease incidence, morbidity, and mortality, thereby placing an undue burden on these populations.<sup>5</sup> The reasons for these health disparities and their persistence are related to the complex interaction among biological factors, the environment, specific health behaviors, socioeconomic differences, and unconscious bias.<sup>6,7</sup>

Despite scientific advances, cancer remains a threat to the health of the nation. In the United States, the number of living Americans who have been diagnosed with cancer as of January 2007 is 11,713,736.<sup>8</sup> One in four deaths is due to cancer both nationally and in Maryland. The total cost of cancer (including medical and economic costs) to the nation for 2009 is estimated at \$263.8 billion, and does not include intangible costs that have to do with emotions, anguish, and reduced or diminished quality of life for cancer patients and their families.<sup>9,10</sup> In Maryland, the total hospital charges for state residents in whom the primary diagnosis on discharge was any type of cancer was \$374,880,863 and is believed to be an underestimate of the total cost.<sup>11</sup>

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A 2009 study commissioned by the Joint Center for Political and Economic Studies looked at the direct costs associated with provision of care to sicker and disadvantaged populations and the indirect costs of health inequities (lost productivity, lost wages, and premature death, etc.).<sup>12</sup> It found that more than 30% of direct medical costs faced by some minorities—more than \$250 billion over four years—were excess costs due to health inequities. When adding the indirect cost of these inequities to the direct medical costs over the same period, the total cost comes to \$1.24 trillion. Because cancer contributes largely to health problems in these populations, the cancer-related costs are high.

## Overview of Health Disparities

Health disparities include cancer disparities and have been defined in several ways. For the purpose of this chapter a *health disparity* is a difference in the burden of illness, injury, disability, or mortality experienced between one population group and another. A *healthcare disparity* is defined as differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention.

**T**HE “POPULATION GROUPS” referred to in the definition are based on gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation. These population groups face obstacles that prevent them from accessing and receiving effective health services including health promotion, disease prevention, early detection, and high-quality medical treatment and as such are faced with poorer health outcomes. The following provides an overview of these specific health disparities in Maryland.

Gender differences are exemplified by the fact that in Maryland, men have higher death rates for some leading causes of deaths including cardiovascular diseases, cancer, stroke, and diabetes. Life expectancy of men is six years less than that of women in Maryland.<sup>13</sup> While overall death rates for women are lower than for men, women experience increased death rates in some areas where men have experienced improvements. One such area is pancreatic cancer mortality.

Racial or ethnic differences are illustrated in Maryland in many ways. For example, compared to whites:

- **BLACKS OR AFRICAN AMERICANS** are more likely to be uninsured and unable to afford healthcare, and experience higher death rates for cardiovascular disease, cancer, diabetes, stroke, and HIV/AIDS.
- **AMERICAN INDIANS OR ALASKA NATIVES IN MARYLAND** are also more likely to be uninsured and unable to afford care, have a higher rate of new cases of end-stage kidney disease, and experience higher rates of infant mortality.
- **ASIAN/PACIFIC ISLANDERS IN MARYLAND** are more likely to be uninsured and unable to afford care, have a higher rate of new cases of end-stage kidney disease, and experience higher death rates for stomach and liver cancers.
- **HISPANICS OR LATINOS IN MARYLAND** are more likely to be uninsured and unable to afford care, and have a higher rate of new cases of end-stage kidney disease.<sup>14</sup>

Geographic location differences can be seen for many diseases in Maryland. Both black or African American and white populations on the Eastern Shore of Maryland (a mainly rural region of the state) have higher-than-state-average mortality rates for their racial groups for heart disease, breast cancer, lung cancer, prostate cancer, and diabetes.

Disparities may exist for people living with disabilities, but in Maryland cancer statistics data for them are not currently available. A report entitled “National Study of Women with Physical Disabilities” concluded that women in the US with physical disabilities are at a higher risk for delayed diagnosis of breast and cervical cancer, primarily for reasons of environmental, attitudinal, and information barriers.<sup>15</sup>

America’s gay and lesbian population comprises a diverse community with disparate health concerns.<sup>16</sup> A supplement of The Healthy People 2010 report suggests that lesbians and bisexual women have higher rates of smoking, overweight, alcohol abuse, and stress than heterosexual women, and are at increased risk for certain cancers, including breast and gynecologic cancers.<sup>17</sup>

## Social Determinants of Health

The World Health Organization defines social determinants of health as “the conditions in which people are born, grow, live, work and age, including the health system.”<sup>18</sup>

**S**OCIAL DETERMINANTS have been called the fundamental causes of health and disease<sup>19</sup> and recent evidence suggests that these social, economic, and environmental factors (including education, occupation, access to health-care and delivery, racial injustice, poverty, income inequality, and chemical toxicants and pollutants associated with industrial development<sup>20,21,22,23</sup>) play a far more pivotal role in health disparities than biological factors.<sup>24</sup> The rationale for focusing on social determinants includes the need to move beyond controlling disease, to address factors that lay at the root causes of disease.<sup>25</sup> In order to attain true improvement in cancer health disparities and achieve health equity across populations, society must assure there are conditions in which people can be healthy. New opportunities exist with multilevel and interdisciplinary approaches recommended.<sup>26</sup> Future opportunities will need to address inequalities in the physical and social environment (e.g., housing, education, crime, transportation, food supply).

### Socioeconomic Status

Several factors that underlie the social determinants of health are encompassed in the term socioeconomic status (SES). SES can be described as the total combined measure of an individual’s social status based on factors such as income level, educational attainment, occupation, and neighborhood of residence. A strong association persists between SES and health, as people with low SES have higher rates of morbidity and mortality when compared to their counterparts with higher SES.<sup>27,28</sup>

SES is widely accepted as a major contributor to health status, and specifically cancer disparities. In a recent study assessing the impact of SES on cancer mortality rates in the US, high-SES whites, high-SES blacks or African Americans, and middle-SES Hispanics or Latinos had the largest declines in mortality rates.<sup>29</sup> Interestingly, middle-SES American Indian/Alaska Natives demonstrated the smallest decline. This trend was ascribed to a

fragmented healthcare system between the Indian Health Service and private insurance providers.

### Poverty and Income Inequality

Poverty drives health disparities more than any other factor.<sup>30</sup> People living in poverty experience higher stress, less access to quality health services, less resources to practice good health behaviors, and greater access to unhealthy foods. Long standing sustained stress reduces the body’s defenses to disease and has been found to increase the risk of some cancers. Overall, the incidence of cancer is higher among poor individuals compared to those with greater access to economic resources.<sup>31</sup> Between 1993 and 2007, the income of the wealthiest 1% of US families increased by 10.3% compared to a 3% US average income growth over this same time period.<sup>32</sup> Income inequality is further complicated by race. Between 1984 and 2005, the wealth gap between whites and blacks or African Americans increased from \$20,000 to \$95,000.<sup>33</sup>

Approximately 15.1% of Maryland’s 5.5 million residents are living in poverty (in 2008, the U.S. Census Bureau defined poverty as a family of four with an income less than \$21,834).<sup>34</sup> From 2007 to 2008, blacks or African Americans and Hispanics or Latinos composed 37% of the state’s population but accounted for 40.8% of the poverty rate.<sup>35</sup> Consequently, these demographic groups may be at an increased risk for cancer. Additionally, some research shows that poor and minority communities are selectively targeted by marketing strategies of tobacco companies, further increasing cancer risk for these demographic groups.<sup>36</sup>

### Occupational and Residential Environments

Occupational and environmental exposures can also play an important role in the etiology of cancer. Various occupational hazards, including exposure to ionizing radiation and asbestos, may lead to some cancers. These occupational exposures are thought to have a greater burden on ethnic minority groups as opposed to whites, due to increased job placement in less skilled and more hazardous positions.<sup>37</sup> Residential environmental exposures (such as indoor and outdoor air pollution) can also be carcinogenic for humans.

The residential environment can also influence other cancer risk factors. Poor nutrition,

obesity, and physical inactivity are risk factors for some types of cancer. However, eating well and exercising may be difficult in some low-income urban areas that do not have amenities such as sidewalks, bike paths, and recreational areas, and where the threat of violent crime keeps many people inside.<sup>38,39</sup> Additionally, lack of supermarkets in these neighborhoods limits residents’ access to fresh, healthy foods.

The population in Maryland’s rural communities is more likely to be poor, uninsured, unemployed, and experience physician shortages and inadequate health infrastructure compared to the state as a whole. Consequently, rural residents have poorer health outcomes than the statewide average.<sup>40</sup>

### Racial Injustice

When combined with racial and ethnic demographics, many of these social determinants of health show an increased adverse occurrence among minority populations compared to non-minority populations. Even when individuals have the same health insurance and comparable access to a healthcare provider, research indicates that racial and ethnic minorities tend to receive a lower quality of healthcare than whites.<sup>41,42</sup> Differential treatment and access to services based on an individual’s race impact the daily experiences of individuals, including their treatment-seeking, healthcare delivery, and patient-provider interactions. Regardless of whether racism takes the form of institutionalized racism (“differential access to the goods, services, and opportunities of society by race”), personally mediated racism (“prejudice and discrimination”), or internalized racism (“acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth”), the effects of racism on health outcomes warrant further exploration.<sup>43</sup>

### Classification of Race and Ethnicity

**T**HIS CHAPTER WILL USE FOUR SINGLE RACE CATEGORIES: American Indian or Alaska Native, Asian or Pacific Islander, black or African American, and white. For ethnicity, the two categories: “Hispanic or Latino” and “Not Hispanic or Latino” will be used. For more information on data sources, see the Appendix: Data Terms, Sources, and Considerations.

### Factors Associated with Racial and Ethnic Cancer Disparities

The influence of economic, social, and cultural factors on these risk factors is thought to contribute to the development of racial and ethnic cancer disparities.

- **POVERTY** is believed to be an important influence on health disparities, and is associated with lack of resources, information, and knowledge; substandard living conditions; risk-promoting lifestyles; and less access to healthcare.<sup>44</sup> In Maryland, almost half a million people live below poverty; 60% of them are minorities.
- **LOW SOCIOECONOMIC STATUS.** Minorities are believed to be more likely to present with advanced stage cancer at diagnosis due to factors such as low socioeconomic status, and not having health insurance, both of which disproportionately affect minorities.
- **CULTURAL BELIEFS** have a role in seeking healthcare such as cancer screening services. For example, studies of some Asian/Pacific Islanders reveal beliefs that cancer is a result of karma, that death from cancer is inevitable, and that western medicine is not to be trusted.<sup>45</sup>

Studies have also indicated that Hispanic or Latina and Asian/Pacific Islander women are reluctant to participate in an examination of the breast and genitals because of fear of embarrassment and as a result are less likely to have breast or cervical cancer screening services.<sup>46</sup>

Among black or African American women, cultural barriers have also been shown to influence participation in cancer screening activities. Such barriers include mistrust of medical providers due to fear of being misdiagnosed or improperly treated, poor experiences with mammograms, and beliefs that cancer is fatal.<sup>47</sup>

- **SOCIAL INJUSTICE, INCLUDING INSTITUTIONAL RACISM,** is also believed to play an important role in racial and ethnic cancer disparities. Blacks or African Americans are more likely to live in areas of low social economic status that tend to be targeted by marketing from tobacco companies, lack adequate and safe environments to conduct physical activities, and lack groceries stores that sell fresh and healthy foods.<sup>48</sup>
- **RACIAL BIAS** is also believed to influence patient-provider communication and the patient-provider relationship as evidenced by the IOM report that revealed that blacks or African Americans compared with whites with the same socioeconomic and insurance status are less likely to receive the same treatments for cancer.<sup>49</sup>

For any intervention or policy to be effective in eliminating racial and ethnic cancer disparities, it must incorporate strategies that help minorities to overcome these economic, social, and cultural barriers.

## Emerging Populations of Concern for Cancer Disparities

Cancer disparities in ethnic minorities have been documented and continue to be investigated, but other population groups are also experiencing poor health outcomes.

### LESBIAN, GAY, BISEXUAL, OR TRANSGENDER PERSONS (LGBT)

- According to the National Coalition for LGBT Health, LGBT people are more likely to have poor health due to their reluctance to seek care from health providers, and gay men and lesbian women are at an increased risk for certain cancers such as lung, cervical, breast, and anal cancer, due to a higher prevalence of smoking and inadequate risk assessments.
- To address these disparities, the Healthy People 2010 Companion Document for LGBT Health was developed. Some of the recommendations in the document include prohibiting federally funded organizations from discriminating against LGBT individuals, incorporating LGBT cultural competence into the training of all health professionals, designating the LGBT population as a “special population” of concern by federal health agencies, targeting the LGBT population in regards to smoking-cessation health promotion campaigns, and increasing national surveys in regards to health to better identify the LGBT populations’ health status.

### IMMIGRANTS

- Maryland’s foreign-born population increased by more than 150,000, a 33% increase between 2000 and 2008. Immigrants are at an increased risk for some cancers because of risk factors that they are exposed to from their countries of origin. An indication of this is that the higher rates of stomach cancer experienced by Asian/Pacific Islanders in Maryland is believed to reflect the higher prevalence of *H. pylori* infection in their countries of origin, particularly Japan and Korea.<sup>50</sup>
- Another study concluded that Mexican-born women were at a higher risk of contracting HPV infection, a significant risk factor for cervical cancer, than US-born Mexican-American women.<sup>51</sup> This becomes especially important for Maryland as Hispanic/Latina females have higher incidence rates for cervical cancer than any other racial/ethnic minority group in the state. Other studies have also revealed that other non-English-speaking immigrant women face language and cultural barriers to Pap smear screening, including modesty, fatalism, and prohibitions against receiving pelvic examination from male practitioners.<sup>52,53</sup>

The definitions of these racial and ethnic categories are as follows:

- **AMERICAN INDIAN OR ALASKA NATIVE:** A person having origins in any of the original peoples of North and South America and who maintains tribal affiliations or community recognition.
- **ASIAN OR PACIFIC ISLANDER:** A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent or the Pacific Islands. This area includes, for example, China, India, Japan, Korea, the Philippine Islands, and Samoa.
- **BLACK OR AFRICAN AMERICAN:** A person having origins in any of the black racial groups of Africa.
- **HISPANIC OR LATINO:** A person of Cuban, Mexican, Puerto Rican, Central or South American, or other Spanish culture or origin, regardless of race.
- **WHITE:** A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

## Cancer Disparities in Maryland

In Maryland, data indicate that cancer disparities exist by race and ethnicity, gender, and geographic location. These disparities are seen in cancer incidence, mortality, and stage at diagnosis.

**T**HEY ALSO EXIST IN ACCESS and use of cancer screening tests such as mammograms, Pap tests, colonoscopy, and fecal occult blood test (FOBT).

While the availability of data for cancer disparities by language, disabilities, and sexual orientation are almost nonexistent in Maryland (mostly due to inadequate data collection and reporting) studies done nationally and in other states have shown that they exist.

### Race and Ethnicity

In Maryland, the total racial and ethnic minority population as of July 2008 was more than 2 million or 41% of the total population. This includes a black or African American population of 1,692,495; an Asian/Pacific Islander population of 305,847; an American Indian population of 23,468; and a Hispanic population of 375,830. For some cancers, minority populations have higher cancer incidence, mortality and/or survival rates and may present at a later stage of diagnosis than the white population.

TABLE 3.1

**Maryland Cancer Incidence and Mortality, All Sites Combined, 2002-2006**

RACE/ETHNIC GROUP	OVERALL INCIDENCE	OVERALL MORTALITY
African American/Black	448.8	222.6
White	473.5	188.7
Hispanic/Latino	330.6	76.8
Asian/Pacific Islander	233.4	97.6
American Indian/Alaska Native	155.4	102.1

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

TABLE 3.2

**Colorectal Cancer Incidence and Mortality by Race in Maryland, 2002-2006**

RACE/ETHNIC GROUP	INCIDENCE	MORTALITY
African American/Black	53.4	25.2
White	46.7	18.1
Hispanic/Latino	35.5	8.1
Asian/Pacific Islander	28.4	9.0
American Indian/Alaska Native	N/A	N/A

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

TABLE 3.3

**Prostate Cancer Incidence and Mortality by Race in Maryland, 2002-2006**

RACE/ETHNIC GROUP	INCIDENCE	MORTALITY
African American/Black	217.4	56.3
White	147.3	23.1
Hispanic/Latino	136.3	12.3
Asian/Pacific Islander	64.2	10.5
American Indian/Alaska Native	58.2	N/A

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

Barriers thought to play a role in minority cancer disparities include:<sup>54,55</sup>

- Poverty, cultural and language differences, poor nutrition, physical inactivity, high smoking rates, and lack of or inadequate health insurance.
- Lack of access to early detection, treatment, palliative care, and clinical trials.

Cancer disparities by race and ethnicity are presented in Tables 3.1-3.12. Some rates are not available for Asian/Pacific Islanders, Hispanics/Latinos, and American Indians/Alaska Natives for some cancer sites due to statistical limitations. In the tables, the categories of race include Hispanic ethnicity; Hispanic/Latinos include those of Hispanic/Latino ethnicity regardless of race.

**CANCER DISPARITIES IN AFRICAN AMERICANS**

Blacks or African Americans in Maryland have the highest overall cancer mortality rate of any racial or ethnic group, including whites (Table 3.1), as well as the highest incidence rates for some specific cancer sites, like colorectal and prostate cancer (Tables 3.2 and 3.3). Cancer mortality is also higher among blacks or African Americans than whites for specific cancer sites such as colorectal, prostate, lung, and breast (Tables 3.2-3.5).

Black or African American males in Maryland have the highest incidence and mortality rates (Table 3.3) and the highest late-stage diagnosis for prostate cancer.<sup>56</sup> The incidence of prostate cancer in black or African American males is almost 50% higher than that in white males, and mortality rates are more than 2.4 times higher in black or African American males than white males.

Among all women in Maryland, black or African American females have the highest incidence and mortality rates for colorectal, cervical, and pancreatic cancer.<sup>57</sup> While white females have the highest overall breast and uterine cancer incidence rates, black or African American females experience higher mortality rates from breast and uterine cancer than any other racial or ethnic group (Tables 3.5, 3.6). Additionally, in 2006, only 49.1% of black or African American females were diagnosed at the most treatable stage of breast cancer, the local stage, compared to 60.4% of whites who were diagnosed at the local stage.<sup>58</sup>

Blacks or African Americans are diagnosed

**TABLE 3.4**

**Lung and Bronchus Cancer Incidence and Mortality by Race in Maryland, 2002-2006**

RACE/ETHNIC GROUP	INCIDENCE	MORTALITY
African American/Black	66.2	59.2
White	69.8	55.4
Hispanic/Latino	32.1	12.8
Asian/Pacific Islander	26.8	22.1
American Indian/Alaska Native	N/A	32.2

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

**TABLE 3.5**

**Female Breast Cancer Incidence and Mortality by Race in Maryland, 2002-2006**

RACE/ETHNIC GROUP	INCIDENCE	MORTALITY
African American/Black	114.6	32.5
White	127.6	25.2
Hispanic/Latino	81.9	8.9
Asian / Pacific Islander	61.5	11.1
American Indian/Alaska Native	41.9	N/A

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

**TABLE 3.6**

**Female Uterine Cancer Incidence and Mortality by Race in Maryland, 2002-2006**

RACE/ETHNIC GROUP	INCIDENCE	MORTALITY
African American/Black	20.0	7.1
White	23.9	3.7
Hispanic/Latino	19.8	N/A
Asian/Pacific Islander	10.6	N/A
American Indian/Alaska Native	N/A	N/A

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.  
N/A means rates were suppressed if counts were fewer than 16 or if the population of the specific category (race, ethnicity) is less than 50,000.

**TABLE 3.7**

**Distribution of Cancer Stage at Diagnosis, All Sites Combined, Maryland, 2006**

	LOCALIZED	REGIONAL	DISTANT
MD Whites	44.4 %	20.9 %	20.5 %
MD Blacks	40.4 %	21.7 %	21.7 %

Source: Maryland Cancer Registry, 2006.

with cancer at later stages than whites, based on all cancers diagnosed in Maryland in 2006 (Table 3.7). The same is also true for several site-specific cancers. For example, blacks or African Americans with invasive cervical, breast, and prostate cancers are less likely to be diagnosed in Stages I or II than are whites.<sup>59</sup> Data from the Maryland BRFSS reveals that blacks or African Americans have similar prevalence rates to whites for screening exams such as colonoscopy, mammograms, Pap tests, and prostate-specific antigen (PSA) tests. However, low follow-up rates for abnormal results of screening exams may influence higher mortality, poorer survival rates, and greater late-stage diagnosis rates seen among blacks or African Americans for colorectal, breast, cervical, and prostate cancers.<sup>60</sup>

**CANCER DISPARITIES IN AMERICAN INDIANS AND ALASKA NATIVES (AI/AN)**

It is estimated that Maryland has 46,076 American Indians or Alaska Natives who belong to approximately 28 Native American tribes, several of which are indigenous to the state.<sup>61</sup> Data that specifically identify or define cancer disparities in incidence, mortality, and screening prevalence in this population in Maryland are scarce or nonexistent. Data from United States Cancer Statistics do show that American Indians or Alaska Natives have the third-highest mortality rate for lung cancer of all races/ethnic groups in Maryland (Table 3.4), similar to what is seen nationally. Other disparities that are seen nationally are that American Indians or Alaska Natives have higher mortality rates than whites for liver and stomach cancers (Table 3.8). This may be similar in Maryland. The American Indian and Alaska Native population of Maryland increased nearly 12.4% from 2004 to 2008,<sup>62,63</sup> so improved surveillance and reporting are needed to provide a description of cancer at the state level.

**TABLE 3.8**

**Cancer Mortality Rates for Selected Cancer Sites by Race, United States, 2002-2006**

CANCER SITE	US WHITE	US AMERICAN INDIANS/ ALASKA NATIVES	US TOTAL
Liver and Intra-hepatic Bile Duct	4.7	6.2	5.1
Stomach	3.5	4.5	4.0

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

**TABLE 3.9**

**Cancer Incidence Rates for Selected Cancer Sites by Race, Maryland, 2002-2006**

CANCER SITE	MD WHITE	MD ASIAN/PI	MD TOTAL
Bile Duct	4.5	8.2	5.1
Stomach	5.2	12.6	6.6

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

**TABLE 3.10**

**Cancer Mortality Rates for Selected Cancer Sites by Race, Maryland, 2002-2006**

CANCER SITE	MD WHITE	MD ASIAN/PI	MD TOTAL
Liver and Intra-hepatic Bile Duct	4.2	7.9	4.8
Stomach	3.1	7.9	4.0

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

**TABLE 3.11**

**Cervical Cancer Incidence Rates by Race in Maryland and the United States, 2002-2006**

	WHITE	BLACK	HISPANIC	ALL RACES
Maryland	7.2	9.6	14.4	8.0
United States	7.9	11.1	12.8	8.3

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

**CANCER DISPARITIES IN ASIAN/PACIFIC ISLANDERS**

Cancer disparities in Asian/Pacific Islanders in Maryland include stomach cancer incidence and mortality rates being the highest in the state and liver cancer mortality rate being 65% higher than the state liver cancer mortality rate (Tables 3.9, 3.10). Another disparity for this population is evident in the stage of diagnosis for female breast cancer: only 55% of Maryland’s Asian/Pacific Islander female breast cancer cases were diagnosed in the most treatable local stage compared to 60% in whites (2002-2006).<sup>64</sup> Though Asian/Pacific Islanders in Maryland experience lower overall cancer incidence and mortality rates (where reported and/or available) compared with other racial/ethnic groups, Asian/Pacific Islanders are not a homogenous population and contain subgroups that have different cancer rates. In Maryland this population increased nearly 12% from 2004 to 2008,<sup>65,66</sup> so improved surveillance and reporting are needed to provide an accurate description of cancer at the state level.

**CANCER DISPARITIES IN HISPANICS OR LATINOS**

Hispanic or Latina females have higher incidence rates for cervical cancer than any other racial or ethnic group in Maryland (Table 3.11) and also experience disparity in the early diagnosis of breast cancer: only 50% are diagnosed in the most treatable localized stage compared to 60% in whites (2002-2006).<sup>67</sup> Considering the rapid population growth in this particular population in Maryland—an increase of more than 25% between 2004 and 2008<sup>68,69</sup>—there is a need for more complete and accurate cancer data for this population.

**Gender**

Cancer incidence and mortality data reveal the existence of disparities by gender for some cancers. Generally men have higher cancer incidence and mortality rates for all cancer sites combined in Maryland, and nationwide. As seen in Table 3.12, cancer incidence in Maryland is higher for men in cancers of lung and bronchus, colon and rectum, oral cavity and pharynx, and melanoma of the skin. Women have higher incidence for thyroid cancer. A similar disparity for men is seen in mortality from several major cancers in Table 3.13.

**TABLE 3.12**

**Cancer Incidence Rates for Selected Cancer Sites by Gender, Maryland, 2002-2006**

	MD MALES	MD FEMALES	MD TOTAL
Lung and Bronchus	82.4	57.7	68.0
Colon and Rectum	56.0	42.7	48.4
Melanoma of the Skin	25.9	16.1	20.1
Oral Cavity and Pharynx	14.7	5.6	9.7
Thyroid	5.5	15.6	10.8

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

**TABLE 3.13**

**Cancer Mortality Rates for Selected Cancer Sites by Gender, Maryland, 2002-2006**

CANCER SITE	MD MALES	MD FEMALES	MD TOTAL
Lung and Bronchus	71.5	43.8	55.3
Colon and Rectum	23.3	16.3	19.3
Pancreas	12.9	10.3	11.9
Melanoma of the Skin	4.3	1.7	2.8
Oral Cavity and Pharynx	4.2	1.4	2.7

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
Source: United States Cancer Statistics: 1996-2006 Incidence and Mortality Web-based Report.

### Geographic Location

Cancer disparities are also seen by geographic location in Maryland. Baltimore City, a densely populated region with more than 8,000 persons per square mile, illustrates such geographic disparities. The 2010 Baltimore City Health Disparities Report Card released by the City’s health department details those disparities. For all cancer sites, the cancer mortality rate in Baltimore City is 23% higher than the statewide cancer mortality rate (Baltimore City not included).<sup>70</sup> Disparity in cancer mortality is further complicated by sociodemographic factors such as race, gender, educational attainment, and access to healthcare. Geographic differences in cancer largely result from geographic differences in race and in the social determinants of health.

Maryland’s rural population also experiences cancer disparities. According to the 2007 Maryland Rural Health Plan, the cancer mortality rate in rural populations is higher than the state average.

Thirty percent of the of the state’s population reside in rural communities which vary in population density, remoteness from urban areas, and economic and social characteristics. Nine out of the 24 jurisdictions in Maryland are referred to as “federally designated rural” jurisdictions. In these jurisdictions, the population is faced with many challenges that promote poor health outcomes including higher-than-state-average rates for unemployment, poverty, uninsured persons, smoking, obesity, and limited availability of healthcare providers and services.<sup>71</sup>

### Language

In Maryland, the population of individuals ages five years and older who speak a language other than English at home is approaching 1 million. Out of this, 40% have limited English proficiency or speak English less than very well.<sup>72</sup> The role of language as a barrier in accessing healthcare services has been adequately documented by various studies nationwide. An Institute of Medicine (IOM) report that examined inequities in healthcare indicates that language barriers prevented minorities and underserved from receiving quality healthcare.<sup>73</sup>

One study found that women who report not reading or speaking English at all, or who report speaking English “less well” than any other language, are less likely to receive breast and cervical cancer screening than are women of the same race/ethnicity who read and speak only English “very well.”<sup>74</sup> Another study showed that Hispanic/Latina women with higher English proficiency had a higher prevalence of Pap tests after controlling for sociodemographic factors.<sup>75</sup>

Language barriers are not insurmountable. For example, one study demonstrated that providing interpreter services increases usage of preventive healthcare services and adherence to healthcare provider recommendation by increasing trust and patient satisfaction.<sup>76</sup>

**FAST FACT**

To address health disparities in Maryland, the Maryland Office of Minority Health and Health Disparities published the “Maryland Plan to Eliminate Minority Health Disparities, Plan of Action 2010-2010.”

**Sexual Orientation**

Cancer disparity issues for the lesbian, gay, bisexual, and transgender (LGBT) population are not fully understood due to inadequate data collection and reporting at the state and national level. At least eight state Behavioral Risk Factor Surveillance System surveys (BRFSS) include questions relevant to LGB or LGBT populations; Maryland does not.<sup>77</sup>

Based on available research studies, “Healthy People 2010: Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health” suggests that LGBT people may be disproportionately affected by some types of cancers, including breast cancer, lung cancer, and cancers linked to human papillomavirus (HPV), such as cervical and anal cancer.<sup>78</sup>

California collects data on sexual orientation through the California Health Interview Study (CHIS). That statewide data confirms a cancer disparity based on sexual orientation with 6% of heterosexual adults ever diagnosed with cancer versus 9% for LGB adults. The study also found a significant difference in smoking, a cancer-related behavioral risk factor. LGB adults smoked at a rate of 27%, while 16% of heterosexuals in the survey were smokers. The gap in current smoking rates was even wider for LGB youth (38% vs. 14%).<sup>79</sup> A disparity was also seen in breast cancer screening rates. The percentage of women who had a mammogram in the past two years was similar for black or African American and white heterosexuals (69% and 68%) but lower for white lesbians/bisexuals (60%) and lowest of all for black or African American women who are lesbian/bisexual at just 35%.<sup>80</sup>

Cancer disparities are also likely to be related to differential access to healthcare in the LGBT community. Data from the CHIS found that LGBT adults are significantly less likely to have health insurance, and they are more likely to delay or not seek medical care, to not get needed prescription medication, and to receive healthcare services in emergency rooms.<sup>81</sup>

## New Interventions and Promising Practices to Eliminate Cancer Disparities

**Maryland has committed and continues to commit substantial resources to interventions aimed at reducing cancer incidence and mortality in its residents.**

**I**N PARTICULAR, the state of Maryland in 2009 alone provided \$21.8 million through its Cigarette Restitution Fund Program, to assist local health departments and community health coalitions in planning and implementing comprehensive cancer prevention, education screening, and treatment programs with the aim of reducing cancer mortality and cancer health disparities.<sup>82</sup>

The Maryland Office of Minority Health and Health Disparities (MHHD) utilizes a model designed to reduce minority disparities in a variety of disease categories. This model includes developing coalitions of local stakeholders, developing culturally and linguistically competent materials, employing lay health communicators/workers, and tracking process and outcome measures. The MHHD published its “Maryland Plan to Eliminate Minority Health Disparities, Plan of Action 2010-2014,” in which this model and strategies for cultural competency are identified for the state.<sup>83</sup> The MHHD also

recognizes three key roles of data in the elimination of disparities: identifying and quantifying disparities, understanding causes to design intervention, and tracking progress toward elimination of disparities. To promote the use of data in disparities-reduction planning, the MHHD published its “Maryland Chartbook of Minority Health and Minority Health Disparities Data,” Second Edition in 2009.<sup>84</sup>

These and other programs have contributed to some positive progress in the reduction of cancer disparities in Maryland. From 2000–2008, the overall cancer mortality disparity for blacks or African Americans compared to whites was reduced by 14.9%.<sup>85</sup> This disparity reduction can be seen in many individual cancers for the period 2002–2006, where although rates are decreasing for both blacks or African Americans and whites, there have been greater declines among blacks or African Americans. These disparity reductions were seen during the 2002–2006 period in breast cancer mortality rates, colorectal cancer mortality rates, prostate cancer incidence and mortality rates, and cervical cancer incidence and mortality rates.<sup>86</sup>

Despite these efforts and some progress, disparities still remain a concern in the state. Interventions that have been designed to eliminate health disparities have been limited by several factors. Some interventions target only a limited number of health determinants, are unable to be repeated or adapted to other settings, and/or are not culturally tailored for the ethnic minority groups that they seek to help. Some interventions that focus on changing provider behavior do not address barriers such as lack of self-efficacy or a lack of outcome expectancy, which may prevent providers from changing their behaviors.<sup>87</sup>

Literature suggests that any efforts to reduce or eliminate cancer disparities without addressing social issues such as poverty, culture, and social injustice are likely to be unsuccessful.<sup>88,89,90</sup> Though these issues are fundamental and might require a total restructuring of society to resolve them, their effect on cancer disparities can be minimized by designing and implementing interventions that alleviate the effect of poverty, culture, and social injustice on society.

Careful reviews of several interventions in which minority groups have experienced improved health outcomes indicate that such interventions are modeled on several factors associated with success, including:<sup>91</sup>

- Using intensive recruitment and follow-up methods.
- Ensuring community commitment and input from community leaders and stakeholders.
- Using culturally competent intervention staff and educational materials.
- Employing the use of multidisciplinary teams and multiple strategies.
- Conducting a prior needs assessment that helps to define the specific areas of concentration.
- Providing resources that help the intervention to be sustainable.

## GOALS · OBJECTIVES · STRATEGIES

### GOAL

Reduce cancer disparities in Maryland.

#### OBJECTIVE 1

Reduce racial/ethnic minority vs. white cancer disparities in Maryland to reach the following:

- By 2015, reduce the black or African American vs. white all-cancer mortality disparity by achieving the all-cancer mortality rates listed below.

##### ALL-CANCER MORTALITY TARGETS (2011-2015)

BLACK OR AFRICAN AMERICAN	164 per 100,000 (2002-2006 baseline: 221 per 100,000)
WHITE	161 per 100,000 (2002-2006 baseline: 189 per 100,000)

Source: CDC WONDER, NCHS Compressed Mortality files.

- By 2015, reduce the Asian/Pacific Islander vs. white liver cancer and stomach cancer mortality disparities by achieving the liver cancer and stomach cancer mortality rates listed below.

##### LIVER CANCER MORTALITY TARGETS (2011-2015)

ASIAN/PACIFIC ISLANDER	Less than 4.2 per 100,000 (2002-2006 baseline: 7.9 per 100,000)
WHITE	Less than 4.2 per 100,000 (2002-2006 baseline: 4.2 per 100,000)

##### STOMACH CANCER MORTALITY TARGETS (2011-2015)

ASIAN/PACIFIC ISLANDER	6.4 per 100,000 (2002-2006 baseline: 7.8 per 100,000)
WHITE	2.4 per 100,000 (2002-2006 baseline: 3.1 per 100,000)

Source: CDC WONDER, NCHS Compressed Mortality files.

Note: Current Maryland data systems are unable to define cancer disparities and/or develop targets for Maryland's Hispanic/Latino and American Indian/Alaska Native populations.

### STRATEGIES

- 1 INCREASE COMMUNITY ENGAGEMENT** to provide further outreach and education to minority populations on cancer risk, community cancer screening services, and tools to overcome barriers to cancer screening and follow-up. (This may include promotion of obesity prevention, healthy diets, physical activity, and reduction of exposures to environmental carcinogens, such as second-hand smoke.)
- 2 ENHANCE MARYLAND'S SAFETY-NET INSURANCE PLANS** and safety-net healthcare systems to supply cancer screening and follow-up services to a greater proportion of minority populations who are eligible for and/or enrolled in these plans and systems.
- 3 INCREASE DIVERSITY IN THE HEALTHCARE WORKFORCE** and build healthcare provider cultural and linguistic competency and understanding of health disparities to improve cancer prevention practices and experiences among minority population patients.
- 4 INCREASE PROVISION OF CANCER SCREENING SERVICES** targeted to minority populations with an emphasis on timely follow-up for abnormal screening results to improve rates of cancer detection and timely treatment.
- 5 INCREASE RIGOROUS PUBLIC HEALTH RESEARCH** at the state and local levels to develop, test, and implement effective interventions for reducing cancer disparities. At the local level, utilize a community-based participatory research model to engage community stakeholders, including healthcare providers with minority population patients.

#### OBJECTIVE 2

By 2015, conduct an assessment and create and implement a plan to improve data systems to better identify and track cancer disparities defined by race, ethnicity, language, disabilities, sexual orientation, and other factors.

### STRATEGIES

- 1 PARTNER WITH MARYLAND BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEMS (BRFSS)** to ensure accuracy and completeness of individual data and inclusion of all segments of Maryland's population.
- 2 PARTNER WITH THE MARYLAND CANCER REGISTRY** to ensure accuracy and completeness of individual data and inclusion of all segments of Maryland's population.
- 3 PARTNER WITH THE VITAL STATISTICS ADMINISTRATION** to ensure accuracy and completeness of individual data and inclusion of all segments of Maryland's population.

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# 4 • Patient Issues and Cancer Survivorship



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# 4

## PATIENT ISSUES AND CANCER SURVIVORSHIP

**E**ach person with a cancer diagnosis deals with many difficult issues that affect his or her life and chances for survival as well as the lives of loved ones. The issues confronting cancer patients cut across all diagnoses, cultures, demographics, and situations. This chapter identifies problems faced by cancer survivors in Maryland and recommends solutions.

**THE TERM “CANCER SURVIVOR”** refers to someone living with, through, or beyond cancer from the moment of diagnosis. Because family members, friends, and caregivers are also impacted by the survivorship experience, they are included in this definition.

This chapter identifies four major problem areas faced by cancer survivors:

- Access to care, information, and resources.
- Psychosocial issues.
- Long-term survivorship.
- Financial issues.

Throughout the chapter, recommendations for addressing these problem areas are targeted to both cancer survivors and healthcare providers. Empowering survivors is of utmost importance. In today’s health systems, survivors must be advocates for their own health and work together with healthcare providers throughout the cancer journey.

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## Access to Care, Information, and Resources

### Access to Cancer Care

**ACCESSING LIFE-SAVING** and evidence-based cancer care is a major concern to newly diagnosed cancer survivors and their families. There are several key questions that a newly diagnosed cancer survivor may want answers to:<sup>1</sup>

- Who is the best medical professional to consult?
- What tests should I have?
- How can I manage my cancer treatment and its health effects?
- Which treatment options allow for the best preservation of fertility?
- What services are available to help me and my family deal with the disease?

Cancer patients often endure many health effects of cancer and its treatment including difficult symptoms, preventable conditions such as osteoporosis, and potentially lethal late effects such as heart failure. In addition to these health effects, cancer survivors are at risk for recurrence

of the same cancer and developing other forms of cancer.<sup>2</sup>

To ensure optimal treatment, minimize the health effects of treatment, and prevent future cancers, the Institute of Medicine (IOM) has developed a plan for four key aspects of survivorship care:

- Preventing and diagnosing new and recurring cancers.
- Ensuring surveillance of existing or new cancers.
- Developing a plan for addressing the negative effects of treatment.
- Creating a coordination plan ensuring the well being of cancer survivors.<sup>3</sup>

It is recommended that healthcare providers develop a survivorship care plan for each of their cancer patients. The plan should describe treatment and post-treatment care that includes:<sup>4</sup>

- Giving survivors a record of the cancer care services they have received, including screening and diagnostic tests, information about their cancer, type of treatment and its duration, and

### Nutrition and Physical Activity for Cancer Survivors

The World Cancer Fund/American Institute for Cancer Research's Second Expert Report (2007) recommends that "All cancer survivors [should] receive nutritional care from an appropriately trained professional. If able to do so, and unless otherwise advised, [cancer survivors should] aim to follow the recommendations for diet, healthy weight, and physical activity."<sup>5</sup>

The nutritional recommendation for survivors is the same as the recommendation for improved health and fitness: eat plenty of fruits and vegetables, exercise, do not use tobacco, and limit alcohol consumption. The American Cancer Society recommends the following for cancer survivors; this combination of foods ensures intake of plenty of the vitamins and nutrients needed for a strong body:<sup>6</sup>

- Eat five or more servings of vegetables and fruits every day.
- Choose healthy fats, including omega-3 fatty acids, rather than saturated fats or trans fats.
- Select proteins that are low in saturated fat, such as fish, lean meats, eggs, nuts, seeds, and legumes.
- Opt for healthy sources of carbohydrates, such as whole grains, legumes, and fruits and vegetables.

Survivors should seek advice from their physicians for personal nutritional information especially in cases where treatment or cancer site may have resulted in dietary challenges, including those associated with digestion, chewing, taste, and bowel elimination.

Across all domains of cancer treatment and therapies, physical activity is recognized to have a positive impact on recovery of function and improved quality of life. A routine of physical activity during cancer treatment may reduce the negative effects of cancer treatment. For instance, exercise can decrease fatigue levels, improve bone mass, reduce pain, encourage return to prior level of functional activity, and may improve overall recovery.<sup>7,8,9,10,11,12,13</sup> Physical activity also attenuates weight gain, a common side effect experienced after cancer treatment.<sup>14,15</sup>

Due to many of the side effects associated with common cancer therapies, it is important to exercise caution with undertaking a physical activity program during and after treatment. Specific guidelines may assist the survivor in determining what type of physical activity intervention is best. This decision is optimally made in consultation with a knowledgeable healthcare provider.<sup>16</sup>

contact information of all physicians involved in their treatment.

- Giving survivors post-treatment standards of care that includes the health and personal effects of treatment, the possibility of recurrence, suggestions for healthy lifestyle (see text box, Nutrition and Physical Activity for Cancer Survivors, on page 2), and resources for supportive services (e.g., legal, financial, counseling).

In addition to treatments for cancer, many cancer survivors need access to other treatment services, such as mental health care. Approximately 10% to 25% of cancer survivors develop major depressive disorders, a rate that is four times higher than the general public. Other health problems cancer survivors may suffer from include sexual dysfunction, infertility, physical changes, and limitations in mobility, communication, and memory loss.<sup>17</sup>

Some of the barriers to healthcare that cancer survivors experience include a lack of or limited health insurance, coordinated care, and post-treatment care. Cancer survivors, even those with health insurance, may have difficulties paying for their treatments. According to a 2005 Institute of Medicine Report, 11% of cancer survivors under the age of 64 years in the United States are uninsured.<sup>18</sup> While the percentage of cancer survivors in Maryland without health insurance is unknown, 12% of Marylanders reported being uninsured in 2008.<sup>19</sup> Uninsured survivors mostly depend on government-run programs (Medicaid, Medicare) or private health agencies for treatment. See the Financial Issues section of this chapter for more information.

### TERMS TO KNOW

*Cancer survivor* refers to someone living with, through, or beyond cancer from the moment of diagnosis. Because family members, friends, and caregivers are also impacted by the survivorship experience, they are included in this definition.

## Access to Information and Resources

EACH CANCER PATIENT OR SURVIVOR is unique and has an individual learning and coping style. Some may want extensive disease, treatment, and resource information; others may want little or no information. It is critical that healthcare providers consider how active a role the patient wants to play in healthcare decision-making, in addition to considering the degree to which the patient desires information.

In addition, there is a need to overcome barriers to patients being able to receive and understand the information given to them. It can

### Potential Survivorship Quality of Care Measures

#### PROCESSES OF CARE

Provision of a survivorship care plan, a written post-treatment summary outlining the proposed follow-up plan.  
Assessment of psychosocial distress, referral to mental health providers.  
Assessment of employment, insurance, and financial issues, referral to rehabilitation and social work providers.  
Provision of written information on available community support services.

#### SCREENING GUIDELINES

Adherence to evidence-based follow-up and surveillance guidelines, where available (e.g., annual mammography for breast cancer survivors; non-routine use of inappropriate follow-up scans and tests for breast cancer; follow-up colonoscopy for colorectal cancer survivors).

#### SURVIVORSHIP INTERVENTIONS

Adherence to adjuvant therapy (e.g., hormonal therapy for breast cancer).  
Assessment and management of pain.  
When appropriate, referral to enterostomal care.  
When appropriate, referral for lymphedema management.  
When appropriate, assessment of sexual function and referral to sexuality counseling.  
When appropriate, referral to genetic counseling.  
Recommendation of exercise for fatigue.  
Smoking cessation counseling, if necessary.

#### SURVIVOR ASSESSMENTS OF CARE

Ratings by survivors of their satisfaction with care, coordination of care, and quality of care.

Source: Institute of Medicine and National Research Council of the National Academies. "From Cancer Patient To Cancer Survivor: Lost in Transition." November 2005.

## DID YOU KNOW?

The Institute of Medicine Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting reported that it is imperative to directly address a patient's psychosocial issues and needs in order to provide the most comprehensive cancer care.

sometimes be difficult for patients to receive and understand information pertaining to their cancer diagnosis, and there may be a need for education and assistance with the cancer decision-making process. This may be especially true for those at low levels of literacy proficiency. According to estimates from the 2003 National Assessment of Adult Literacy Survey (NAAL), 11% of Maryland adults lack basic prose literacy skills.<sup>20</sup>

A new specialty—that of patient navigator—has emerged to increase patient access to information, resources, and care. Patient navigators are trained, culturally competent healthcare professionals who work with patients, families, physicians, and the healthcare system to ensure cancer patients' needs are appropriately and effectively addressed. The navigator's role is to ensure that individuals receive timely diagnosis and treatment, to advocate for the patient, and to teach the patient to advocate for him- or herself. The navigator may also coordinate doctors' visits, maintain telephone contact between patients and physicians, arrange rides to and from the hospital, help with insurance forms, and even suggest what to ask at future appointments.

In October 2005, the National Cancer Institute, with support from the American Cancer Society, awarded grants to nine academic research institutions to establish the Patient Navigator Research Program (PNRP). These institutions are charged with developing innovative patient navigator interventions to reduce or eliminate cancer health disparities and test their efficacy and cost-effectiveness. PNRP's overall aim is to decrease the time between a cancer-related abnormal finding, definitive diagnosis, and delivery of quality standard cancer care.

## Psychosocial Issues

A cancer diagnosis automatically evokes a wide range of emotions including, but not limited to, fear, anger, depression, shock, confusion, and denial, as well as optimism and hopefulness.

Some of the negative and positive psychosocial concerns that may arise are:<sup>21</sup>

### Negative

- Fear of recurrence, concerns about future and death.
- Depression, sadness.
- Inability to make plans.
- Adjustment to physical compromise, health worries.
- Sense of loss for what might have been (e.g., loss of fertility).
- Uncertainty and heightened sense of vulnerability.
- Alterations in social support.
- Fears regarding accomplishment of adult developmental tasks.
- Existential and spiritual issues.
- Psychosocial reorientation.
- Sexuality, fertility, and intimate relationships.
- Concerns about parenting.
- Employment and insurance problems.
- Relationship with the treatment team.

### Positive

- Feelings of gratitude and good fortune.
- Sense of self-esteem and mastery.

**C**ANCER SURVIVORS deal with many stresses that could be partially or completely alleviated with the help of psychosocial support services, including support groups (either in-person or internet-based), mental health counseling, peer support networks, patient education conferences, and support from trained professionals.

Depending on the patient's needs, these services may be used alone or in combination. Support services may aid a cancer patient and his or her family in understanding changes in relationships; changes in body image and physical capacity; emotions such as depression, anger, and fear; feelings associated with loss of control and independence; memory loss; and the cognitive

effects of treatment and medication. In addition, participation in any psychosocial support services has been shown to reduce anxiety and depression and generally improve quality of life for cancer survivors.<sup>22,23,24</sup>

One task for cancer survivors is to accept that life is different and to create normalcy both for themselves and their network of support.<sup>25</sup> This task is more manageable with the help of support staff who are trained in providing emotional and mental care to individuals who are learning to live with a chronic disease.

However, patients are often reluctant to communicate their psychological and emotional concerns to their physicians or other medical practitioners. In fact, the stigma associated with seeking and receiving counseling is one of the most common barriers for individuals with cancer to access mental health services.<sup>26</sup> Many individuals do not understand how mental health services may help them or the range of services that may be available. Early in the process of diagnosis, healthcare providers should inform patients that it is common to deal with depression and/or psychological distress at some point in the cancer journey and direct the patients to the help that is available.

Additional provider education may be necessary to give healthcare professionals the necessary understanding and appreciation of the cancer survivor's needs. Botti et al. reported that the high levels of stress associated with oncology nursing can be attributed to providing emotional support for patients and relieving the fears of their family members. Healthcare providers, particularly nurses, can benefit from psychosocial support training in order to enhance a cancer patient's outcome.<sup>27</sup> Various methods of continuing education have been shown to increase the confidence, knowledge, and skills of the participants in managing the psychosocial issues of cancer patients.<sup>28,29</sup>

The healthcare community realizes the importance of integrating a patient's medical and psychosocial care. In fact, the IOM Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting reported that it is imperative to directly address a patient's psychosocial issues and needs in order to provide the most

comprehensive cancer care. The IOM Committee concluded:

“Addressing psychosocial needs should be an integral part of quality cancer care. All components of the health care system that are involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices, and standards addressing clinical medical practice. These policies, practices, and standards should be aimed at ensuring the provision of psychosocial health services to all patients who need them.”<sup>30</sup>

## Long-Term Survivorship

**Survivorship is a relatively new term when discussing cancer. However, as advances in research are helping to slow the progress or impede recurrence of cancer, more and more individuals are living longer as survivors and living with high qualities of life.**

**W**ITH THIS TRANSITION to long-term survivorship new healthcare issues have emerged. Resources and support are necessary for long-term survivorship to help individuals adjust to life after cancer.

Oncologists and other healthcare providers should work to empower cancer survivors to be advocates of their own health through various methods including:

- Attending orientations offered at local treatment and infusion centers.
- Contacting patient navigators, social workers, or support staff to empower patients to take control of their own health.
- Using a journal or log to document doctor's visits, prescriptions, and blood work.
- Obtaining literature and other resources that give them suggestions on how to better communicate with their doctors.

Healthcare providers must also be educated about long-term survivorship issues such as cognitive deficiencies, secondary cancers, effects of some treatments on heart health, fertility problems, and others. Cancer treatment centers throughout the United States are looking at how best to address long-term survivorship. A good example is the University of Texas M.D. Anderson Cancer Center,

which has worked to develop a model for what happens after cancer is controlled.<sup>31</sup>

The IOM report, “From Cancer Patient to Cancer Survivor: Lost in Transition,”<sup>32</sup> states that upon discharge from an oncologist, a plan should be developed to instruct any primary care provider on how to care for the patient based on the type of cancer diagnosis, treatment, and potential long-term health issues that may result from treatment. The implementation of such a plan could help educate healthcare providers on the need to refer their patients to other specialists.

In addition to addressing long-term health issues, other aspects of long-term cancer survivorship inclusive of the “whole person” should be supported, including issues of self-esteem, sexuality, employment, healthy eating/exercise, and others. One method of completely addressing long-term survivorship issues is to create clinics in Maryland for both childhood and adult cancer survivors.

Other members of the community who interact with cancer survivors should also be considered. An increased awareness among educators and community leaders about the specific physical, emotional, and cognitive needs of cancer survivors as well as the emotional needs of family members and caregivers is needed.

## Financial Issues

**A major area of concern for people affected by cancer relates to financial issues.**

**C**ANCER DIAGNOSIS, treatment, and survivorship care are expensive, even for those individuals with comprehensive health insurance coverage. Cancer brings about many questions, including:

- How will I pay for my treatment?
- Do I have health insurance? If I cannot work because of my cancer, how will that impact my coverage?
- How will I afford co-pays for doctors’ visits and medications?
- How will I get transportation to my treatment centers?

### Federal Laws Providing Protection Against Work-Related Discrimination

- Americans with Disability Act (ADA)
- Family and Medical Leave Act (FMLA)
- Employee Retirement and Income Security Act
- Federal Rehabilitation Act

Source: Institute of Medicine and National Research Council of the National Academies. “From Cancer Patient To Cancer Survivor: Lost in Transition.” November 2005. (See source for details on federal laws.)

- How can I pay for child and/or elder care?
- Will I ever be able to go back to work?  
Will I need a different job?
- How will I support myself or my family?

The National Institutes of Health (NIH) estimates that overall costs for cancer in 2010 at \$265.8 billion: \$102.8 billion for direct medical costs (total of all health expenditures), \$20.9 billion for indirect morbidity costs (cost of lost productivity due to illness), and \$140.1 billion for indirect mortality costs (cost of lost productivity due to premature death).<sup>33</sup>

In addition to the direct cost of medical care and wages lost due to illness, the financial burden on cancer patients (those recently out of treatment and even long-term survivors) is exacerbated significantly by out-of-pocket expenses. Often even individuals and families with quality, comprehensive health insurance can be devastated by the expenses associated with high deductibles and co-payments, transportation, child and elder care, homecare expenses, special food or equipment, and compounded by lost wages.

Many cancer patients need health services that are not routinely considered part of their treatment. Most significant of these are mental health services.<sup>34</sup> Other services that cancer patients may need include fertility treatment, physical or occupational therapy, and integrative medicine therapies.

It is also important to consider the patient time costs associated with care, including time preparing for appointments, time spent in waiting rooms, and time recuperating at home from procedures, chemotherapy infusion, or radiation therapy.<sup>35</sup>

In addition to the financial burden of medical care and associated out-of-pocket expenses, cancer survivors may experience long-term financial and legal difficulties stemming from disability and other problems associated with returning to work. Accommodations in the workplace as well as survivors' perceived notions of employer support or discrimination play a key role in survivors re-entering the workforce.<sup>36</sup> Much of the discrimination likely results from employers' lack of understanding of the variability in prognosis of the many cancer types, misconceptions about the productivity of cancer patients and survivors, and inability to provide flexibility in the work schedule, job sharing, or telecommuting.

Employers in Maryland must be educated on their employees' rights (see text box, Federal Laws Providing Protection Against Work-Related Discrimination, on page 6) as well as resources that they can use, such as Cancer and Careers' Managing Through Cancer program ([www.cancerandcareers.org](http://www.cancerandcareers.org)). Quality of life for the off-treatment or long-term survivor can be significantly impacted when he or she does not explore new and desired employment opportunities for fear of losing health insurance or discrimination.

## Conclusion

**To address cancer survivorship effectively and comprehensively, the Centers for Disease Control and Prevention, along with the Lance Armstrong Foundation, developed a National Action Plan for Cancer Survivorship.<sup>37</sup>**

**T**HIS PLAN identifies 23 recommended needs, 18 of which are described as priority needs.

The following Goals, Objectives, and Strategies have been developed with attention to these priority needs, and specifically address the following five priorities:

- Develop strategies to educate the public that cancer is a chronic disease people can and do survive.
- Educate policy- and decision-makers about the role and value of providing long-term follow-up care, addressing quality-of-life issues and legal needs, and ensuring access to clinical trials and ancillary services for cancer survivors.
- Empower survivors with advocacy skills.
- Educate healthcare providers about cancer survivorship from diagnosis through long-term treatment and end-of-life care.
- Educate decision-makers about economic and insurance barriers related to healthcare for cancer survivors.

## GOALS - OBJECTIVES - STRATEGIES

### GOAL

**Enhance the quality of life of cancer survivors in Maryland through information and supportive services.**

#### OBJECTIVE 1

**By 2015, create an annual awareness campaign during the National Cancer Survivors Day to educate cancer survivors, the general public, policymakers, media, and healthcare providers about the needs of cancer survivors (including access to care, information and resources, psychosocial issues, long-term survivorship, and financial issues).**

#### STRATEGIES

- 1 Develop awareness campaign publications (e.g., proclamation fact sheets on elements of a Survivorship Care Plan and advocacy skills for cancer survivors, press releases, and public service announcements).
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to assist with the awareness campaign.
- 3 Host one statewide event during the National Cancer Survivors Day.
- 4 Post awareness publications on the Maryland Cancer Plan Web site: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

#### OBJECTIVE 2

**By 2015, develop a Web-based resource guide in English and Spanish for cancer survivors seeking support groups, financial/legal services, and psychosocial support services at no cost.**

#### STRATEGIES

- 1 Identify existing support groups and legal and counseling services available to cancer survivors at no cost. Include in the resource guide a brief summary of their services and contact information.
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to assist with the distribution of the resource guide to local cancer care providers.
- 3 Post the resource guide on the Maryland Cancer Plan Web site: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

#### OBJECTIVE 3

**By 2015, utilize the recommendations of the Institute of Medicine to develop and disseminate a fact sheet on elements of a Survivorship Care Plan for cancer survivors and healthcare providers.**

#### STRATEGIES

- 1 Identify the necessary information and develop a fact sheet with the elements of a Survivorship Care Plan.
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to assist with the dissemination of the elements of a Survivorship Care Plan to their respective cancer care providers.
- 3 Post the fact sheet on the Maryland Cancer Plan Web site: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

# GOALS - OBJECTIVES - STRATEGIES

## OBJECTIVE 4

By 2015, develop and disseminate materials to educate policy- and decision-makers, community leaders, and educators about the role and value of providing long-term care and support services to cancer survivors.

### STRATEGIES

- 1 Identify the necessary long-term care and supportive services information and develop the materials.
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to assist with the dissemination of the materials to their respective policy- and decision-makers, community leaders, and local educators.
- 3 Post the materials on the Maryland Cancer Plan Web site: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

## OBJECTIVE 5

By 2015, develop and disseminate materials such as a financial resource manual, fact sheet, and PowerPoint slide presentation, to teach and empower cancer survivors the advocacy skills to protect their financial and legal rights at work and within the healthcare system.

### STRATEGIES

- 1 Research and identify financial resources and state and federal laws that protect cancer survivors and include this information in the materials.
- 2 Utilize existing partners and collaborate with local health departments, community health coalitions, support groups, and other community-based organizations to distribute the materials.
- 3 Post the materials on the Maryland Cancer Plan Web site: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

## OBJECTIVE 6

By 2015, create a workgroup to explore methods to educate decision-makers on, and reduce, the economic and insurance barriers related to healthcare for cancer survivors in Maryland.

### STRATEGIES

- 1 Utilize existing partnerships to create a workgroup.
- 2 Research and explore methods such as implementing a "Maryland Supports Cancer Survivors" license plate program and drafting recommendations for insurers.

## OBJECTIVE 7

By 2015, create a workgroup to explore the need for and feasibility of providing formal training and/or certification for healthcare providers in the area of cancer survivorship, including psychosocial issues.

### STRATEGIES

- 1 Utilize existing partnerships to create a workgroup.

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# 5 • Tobacco-Use Prevention/ Cessation and Lung Cancer



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# 5

## TOBACCO-USE PREVENTION/CESSATION AND LUNG CANCER

**T**obacco use is the single most preventable cause of death and disease in the United States and Maryland. Smoking cigarettes increases the risk of dying from at least ten types of cancer and a variety of heart and respiratory diseases.

**SMOKERS HAVE SHORTER LIVES** and higher medical expenses as compared to non-smokers. In this chapter, the burden of tobacco use, risk of incidence for cancer, tobacco-use prevention and treatment programs, and policies are examined.

### Burden of Tobacco-Related Disease

#### Human Toll of Cigarette Smoking on Maryland Residents

**H**ALF OF ALL LONG-TERM CIGARETTE SMOKERS die prematurely from a smoking-related illness.<sup>1</sup> The Centers for Disease Control and Prevention (CDC) estimates an average of 6,861 Maryland adults die prematurely every year as a result of cigarette smoking.<sup>2</sup> Of these, 2,339 (34.1%) die prematurely as a result of cancers of the lung, bronchus, and trachea (Table 5.1). Another 149,600<sup>3</sup> suffer from one or more cancers, cardiovascular diseases, or respiratory diseases caused by past or current smoking.

Increasing both the number of Maryland residents who have never smoked a cigarette and the number of current cigarette smokers who quit and continue to stay quit will greatly reduce preventable deaths and suffering from smoking-related diseases. Together, tobacco-use prevention and cessation programs and policies are the primary mechanisms recommended to reduce cancers of the lung, bronchus, and trachea, while at the same

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**TABLE 5.1**

**Estimated Average Annual Cigarette Smoking-Attributable Mortality among Adults Ages 35 and Older, Maryland 2000-2004**

Number (#) and Percentage (%) of 6,861 Estimated Average Annual Premature Deaths

CANCER SITES	MALE #	FEMALE #	TOTAL #	MALE %	FEMALE %	TOTAL %
Lung, Bronchus, Trachea	1,404	935	2,339	20.5%	13.6%	34.1%
Esophagus	133	34	167	1.9%	0.5%	2.4%
Lip, Oral Cavity, Pharynx	74	20	94	1.1%	0.3%	1.4%
Stomach	31	13	44	0.5%	0.2%	0.6%
Pancreas	56	70	126	0.8%	1.0%	1.8%
Larynx	56	12	68	0.8%	0.2%	1.0%
Cervix Uteri	0	9	9	—	0.1%	0.1%
Kidney and Renal Pelvis	46	2	48	0.7%	—	0.7%
Urinary Bladder	66	23	89	1.0%	0.3%	1.3%
Acute Myeloid Leukemia	14	6	20	0.2%	0.1%	0.3%
<b>Cancer and Other Diseases</b>						
All Cancers	1,880	1,124	3,004	27.4%	16.4%	43.8%
All Cardiovascular Diseases	1,296	929	2,225	18.9%	13.5%	32.4%
All Respiratory Diseases	755	877	1,632	11.0%	12.8%	23.8%

Source: Smoking Attributable Mortality, Morbidity, and Economic Costs (SAMMEC), 2000-2004.

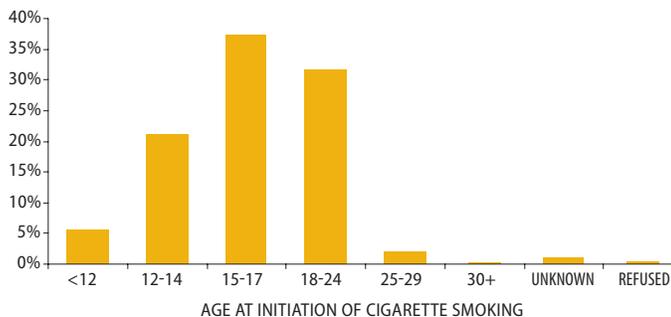
time reducing the other premature deaths from other cancers and diseases attributable to cigarette smoking. Other tobacco products (cigars, chew, snuff, etc.) also pose cancer and other health risks.

**Economic Burden on Maryland Residents**

ALMOST 8.5% OF ALL MEDICAL CARE EXPENDITURES in Maryland are avoidable, the direct result of treatment for cancers and other diseases caused by cigarette smoking.<sup>4</sup> The total annual direct cost of treating cancers and disease in Maryland caused by cigarette smoking was estimated at \$2.26 billion in 2000.<sup>5</sup>

**FIGURE 5.1**

**Age at Which Initiated Cigarette Smoking As Reported by Maryland Adults Ages 18 and Older, 2008**



Source: Maryland Adult Tobacco Survey, 2008.

**TABLE 5.2**

**Cancers of the Lung, Bronchus, and Trachea, Maryland 2004**

Proportion of Cases Attributable to Cigarette Smoking, by Gender and Age

MALE		FEMALE	
AGE 35-64	AGE 65+	AGE 35-64	AGE 65+
88%	86%	73%	71%

Source: Smoking Attributable Mortality, Morbidity, and Economic Costs (SAMMEC), 2004.

# Cancers of the Lung, Bronchus, and Trachea

## Risk of Cancers

**W**HEN ADDRESSING TOBACCO-USE PREVENTION and cessation and the impact of smoking on health, the CDC groups cancers of the lung, bronchus, and trachea together. In this chapter these cancers are similarly grouped where possible for consistency.

Lung cancer by itself is the leading cause of cancer deaths in both men and women in Maryland. Including the tobacco-related cancers of the bronchus and trachea increases the magnitude of the problem that tobacco use presents. Epidemiologic studies have firmly established that the incidence of these three cancers is largely due to past or present cigarette smoking by the individual with cancer (up to 88% of cases attributable, see Table 5.2).<sup>6</sup> Other known causes include exposure to secondhand smoke, exposure to naturally occurring radon gas, and occupational exposures to a number of substances including nickel, chromates, coal, arsenic, beryllium, and iron.

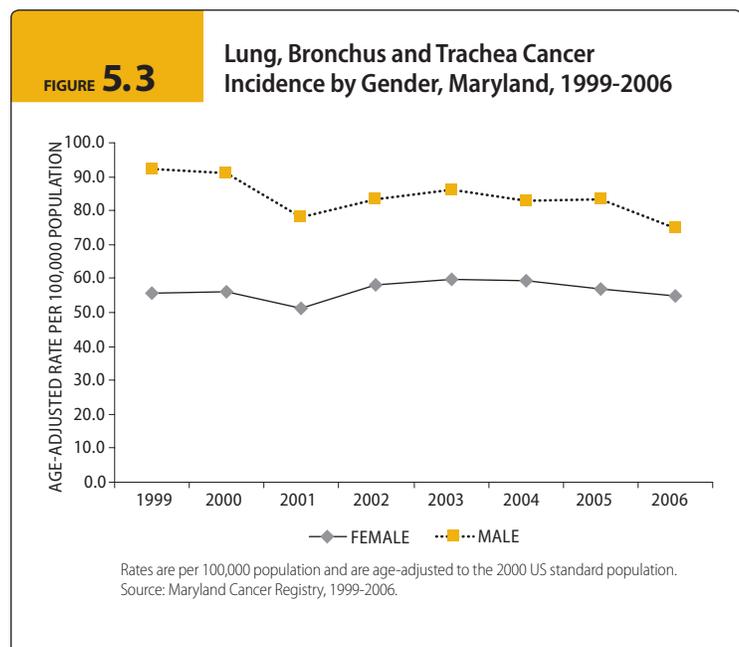
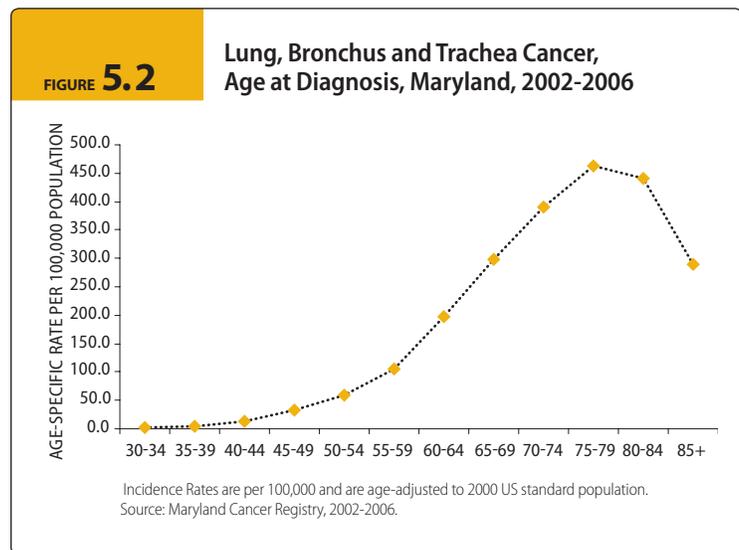
The relative risk for cancers of the lung, bronchus, and trachea are, accordingly, lowest for adults who have never smoked a cigarette and highest for those who currently smoke. Individuals who quit smoking and continue to stay quit (former smokers) have significantly reduced risk compared to current smokers, but still have a higher risk than never smokers.

Among smokers and former smokers, the risk for lung cancer is greater for those who initiated smoking at younger ages compared to those who initiated smoking when they were older.<sup>7</sup> In Maryland the majority (64.3%) of adult cigarette smokers report that they started smoking before they were 18 years old and 96% report that they started smoking before they were 25 years old (Figure 5.1).

In addition to increased risk due to a younger age of initiation, cancers of the lung, bronchus, and trachea are dose-dependent (i.e., dependent on how long the person has smoked, the number of cigarettes smoked per day, and the inhaling pattern).<sup>8</sup>

## Incidence of Cancer

**CIGARETTE SMOKING AT AN EARLY AGE** increases the risk for these cancers at any age, and the increased risk continues throughout the life of the smoker (although smokers who quit are at reduced risk as compared to current smokers). Figure 5.2 presents data on the average annual incidence rates of lung, bronchus, and trachea in Maryland, by age,



for the period 2002 through 2006. Although 96% of smokers initiate smoking before the age of 25, there is a long latency between smoking and the development of these cancers. Therefore, cancer rates are relatively low in persons less than 50 years of age. Case rates then increase, peaking at ages 75-79.

Maryland's incidence of cancers of the lung, bronchus, and trachea is higher than the US as a whole. The incidence rate for these cancers varies considerably among Maryland's 24 jurisdictions. These rates range from a low of 43.1 per 100,000 in Montgomery County to a high of 102.4 per 100,000 in Somerset County (Table 5.3) and likely reflect varying levels of historical cigarette smoking among county residents 25 to 60 years ago.

### Similarities and Differences in Incidence

**THE INCIDENCE RATE** for cancers of the lung, bronchus, and trachea in Maryland is higher than the US rate. Among blacks or African Americans in Maryland the rate is lower than the US rate, whereas the incidence rate for whites in Maryland is higher than the US rate. In Maryland, the lung, bronchus, and trachea incidence rate for blacks or African Americans is lower than the rate among whites (Table 5.4).

These cancer-specific incidence rates for both males and females in Maryland are higher than for their respective US rates, and Maryland males have higher incidence rates than Maryland females similar to US patterns of incidence (Figure 5.3). Historically, the prevalence of cigarette smoking among males has been higher than for females (although in the recent past smoking rates have been equivalent). This is consistent with finding higher incidence of these cancers in the male population.

#### MALES BY RACE

**BLACK OR AFRICAN AMERICAN MALES** in Maryland have lower incidence rates of smoking-related cancers of the lung, bronchus, and trachea than do black or African American males in the US, whereas white males in Maryland have higher incidence rates than white

TABLE 5.3

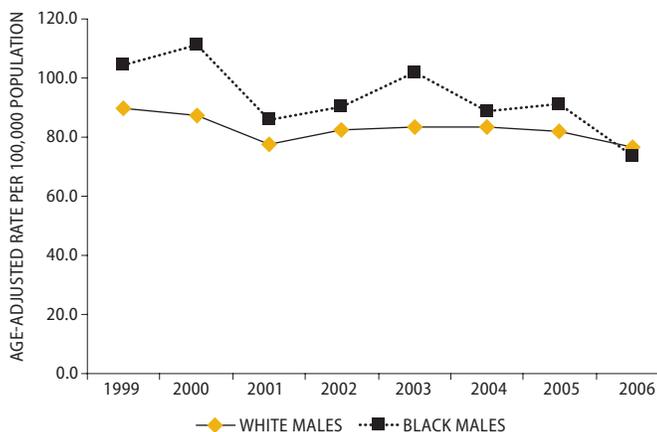
Lung, Bronchus, and Trachea Cancer Incidence Rates by Jurisdiction, 2002-2006

RANK	JURISDICTION	INCIDENCE RATE
1	Somerset	102.4
2	Caroline	92.8
3	Dorchester	90.3
4	Wicomico	88.3
5	Baltimore City	85.6
6	Allegany	84.4
7	Cecil	83.6
8	Kent	82.9
9	Queen Anne's	80.6
10	St. Mary's	78.3
11	Calvert	78.0
12	Worcester	77.6
13	Baltimore County	76.6
14	Harford	75.3
15	Frederick	75.1
16	Talbot	73.3
17	Carroll	71.8
18	Washington	71.2
19	Anne Arundel	70.8
20	Charles	66.3
21	Prince George's	55.3
22	Garrett	55.2
23	Howard	52.7
24	Montgomery	43.1

Rates are per 100,000 population and are age-adjusted to the 2000 US standard population. Source: Maryland Cancer Registry, 2006.

FIGURE 5.4

Lung, Bronchus and Trachea Cancer Incidence Rates by Race for Males, Maryland, 1999-2006



Rates are per 100,000 population and are age-adjusted to the 2000 US standard population. Source: Maryland Cancer Registry, 1999-2006.

**TABLE 5.4**

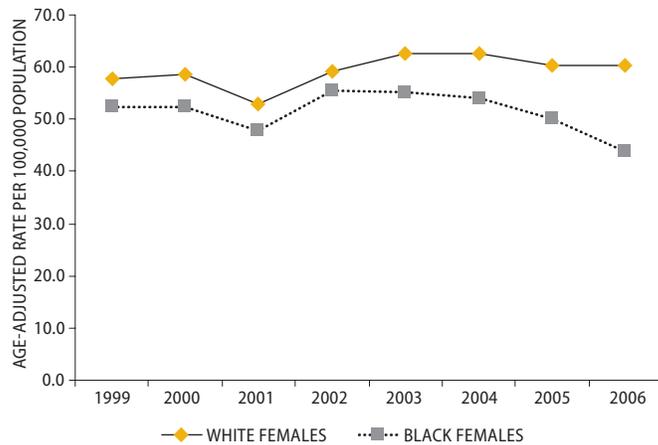
**Lung, Bronchus, and Trachea Cancer Incidence by Gender and Race, Maryland and US, 2006**

	TOTAL	MALES	FEMALES	WHITES	BLACKS
MD New Cases (count)	3,516	1,779	1,721	2,720	715
MD Incidence Rate	63.4	74.7	55.0	67.1	55.3
US SEER Rate	60.7	73.3	51.4	62.0	71.4

Rates are per 100,000 population and are age-adjusted to the 2000 US standard population.  
Source: Maryland Cancer Registry, 2006.

**FIGURE 5.5**

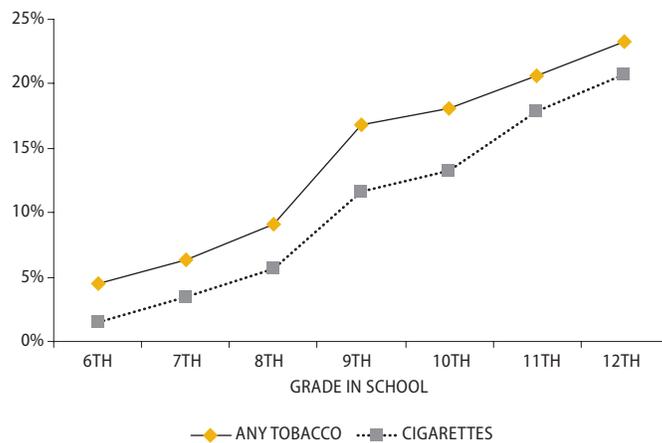
**Lung, Bronchus, and Trachea Cancer Incidence Rates by Race for Females, Maryland, 1999-2006**



Rates are per 100,000 population and are age-adjusted to the 2000 US standard population.  
Source: Maryland Cancer Registry, 1999-2006.

**FIGURE 5.6**

**Current Cigarette Smoking and Tobacco Use, Maryland Middle and High School Youth (All Ages), 2008**



Source: Maryland Youth Tobacco Survey, 2008.

males in the US. Within Maryland, black or African American males have historically had higher incidence rates as compared to white males, although this disparity has been decreasing in recent years (Figure 5.4).

**FEMALES BY RACE**

**BLACK OR AFRICAN AMERICAN FEMALES** in Maryland have slightly lower or about the same incidence rates for these cancers than black or African American females in the US, whereas white females in Maryland have higher incidence rates than white females in the US. Within Maryland, black or African American females have lower incidence rates compared to white females (Figure 5.5). Rates have been decreasing at a faster rate among black or African American women whereas the white female rate has been relatively stable since 2003.

**High-Risk Populations**

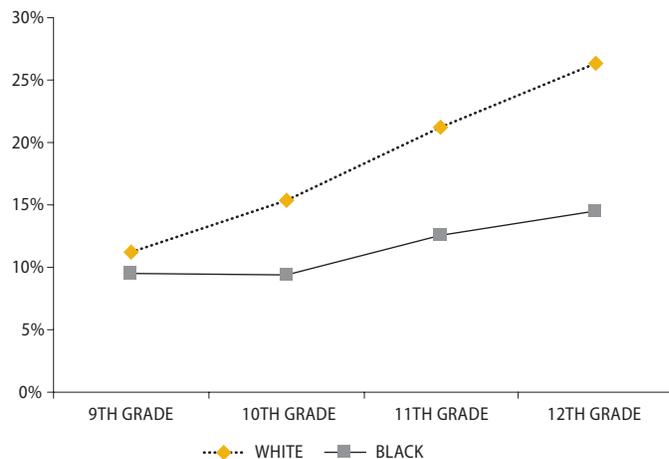
**A**S NOTED PREVIOUSLY, the risk for cancers of the lung, bronchus, and trachea are greatest among those who initiated smoking at younger ages (for former and current smokers). Among current smokers, identification of populations who have the highest rates of smoking can provide a foundation for targeting utilization of scarce resources to where the greatest risk for these cancers exists.

**Youth Cigarette Smoking and Tobacco Use**

**CIGARETTE SMOKING** increases as grade level increases, with 12th-grade youth having the highest rates of cigarette smoking (20.7%) (Figure 5.6). The largest relative increase in the proportion of students smoking occurs between the eighth and ninth grades (a 103.5% increase), which in Maryland coincides with the transition from middle to high school.

**FIGURE 5.7**

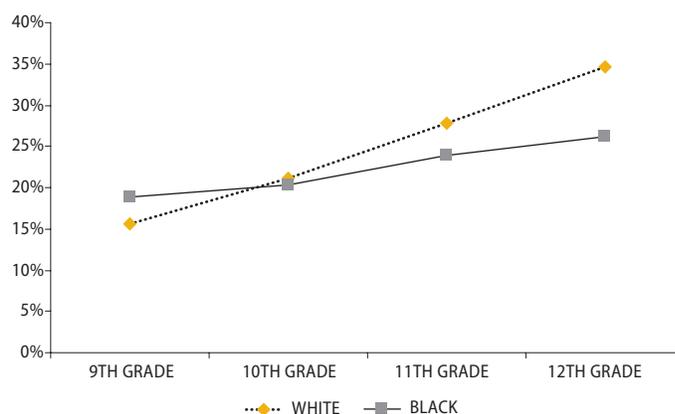
**Current Cigarette Smoking, by Race, Maryland High School Youth (All Ages), 2008**



Source: Maryland Youth Tobacco Survey, 2008.

**FIGURE 5.8**

**Current Use of Any Tobacco Product, by Race, Maryland High School Youth (All Ages), 2008**



Source: Maryland Youth Tobacco Survey, 2008.

Among youth attending public high schools, black or African American high school youth are less likely to smoke cigarettes or use any form of tobacco than are white high school youth. In 12th grade, 14.5% of black or African American youth and 26.3% of white youth report that they currently smoke cigarettes; 26.1% of black or African American youth and 34.7% of white youth report that they currently use some form of tobacco (Figure 5.7, Figure 5.8).

The pattern observed for use of any tobacco product by race holds true when comparing by both race and gender. White high school youth,

both male and female, report higher rates of tobacco products than do black or African American high school youth. That being said, the rate of tobacco use by males of both races is high. In 12th grade, 30.8% of black or African American males report that they currently use some form of tobacco as compared to 40.9% of whites.

In 2008, more than 50% of current 12th-grade smokers reported that they smoked both cigarettes and cigars during the past 30 days (12.5% of all 12th-grade youth). The use of cigarettes and cigars among Maryland 12th-grade youth declined steadily between 2000 and 2006. However, between 2006 and 2008 the decline in cigarette smoking stopped (Figure 5.9). At the same time, cigar smoking appears to have increased. This may be due to:

- The survey questionnaire containing a better explanation of what a cigar is.
- A shift towards cigars at least part of the time by youth seeking to escape the \$1.00 per pack increase in Maryland excise tax on cigarettes.
- The availability of cigars sold singly, and therefore more inexpensive.
- “Attractive” flavoring of cigars.
- A combination of these and other factors.

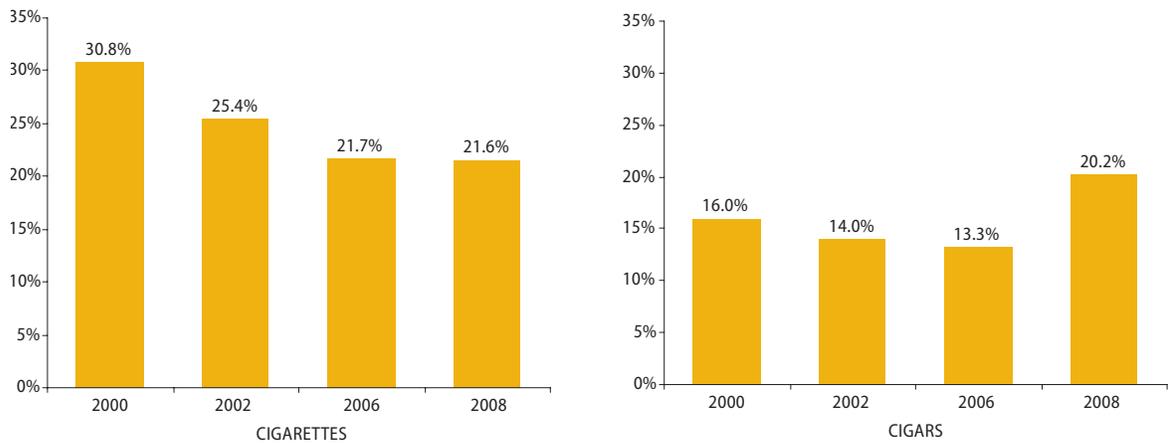
Because cigarette smoking most commonly starts before adulthood and only intensifies once an adult, jurisdictional differences in smoking rates among 12th-grade youth are equally

important as adult smoking rates when attempting to craft tobacco-control programs. Table 5.5 examines tobacco use by 12th-grade youth by jurisdiction (including those who were 18 years old at the time of the survey).

The data reviewed so far are limited to those youth who attend school. School-based surveys cannot reach those who have dropped out or are absent when surveys are administered. In an attempt to develop a proxy measure for tobacco use by youth who are not present when surveys are administered, youth were asked about the number of days that they had missed school

**FIGURE 5.9**

**Current Use of Cigarettes or Cigars, Maryland 12th-Grade High School Youth (All Ages), 2000-2008**



Source: Maryland Youth Tobacco Survey, 2000-2008.

**TABLE 5.5**

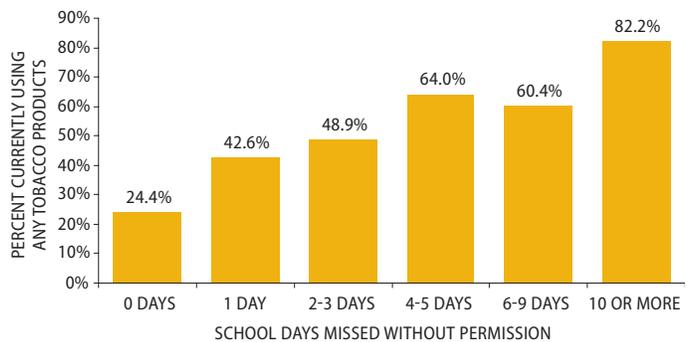
**Current Use of Any Tobacco Product, 12th-Grade Maryland Youth, 2008**

RANK	JURISDICTION	PREVALENCE
1	Garrett	40.8%
2	Washington	40.2%
3	Somerset	39.6%
4	Kent	39.5%
5	Frederick	39.5%
6	Queen Anne's	39.1%
7	Caroline	38.9%
8	Cecil	38.7%
9	Anne Arundel	38.2%
10	Talbot	37.7%
11	Dorchester	37.5%
12	Worcester	37.4%
13	Allegany	36.7%
14	Carroll	35.7%
15	Baltimore County	32.6%
16	Wicomico	32.3%
17	Harford	32.2%
18	St. Mary's	31.9%
19	Calvert	31.8%
20	Howard	31.0%
21	Charles	30.1%
22	Baltimore City	26.4%
23	Montgomery	25.8%
24	Prince George's	22.8%

Source: Maryland Youth Tobacco Survey, 2008.

**FIGURE 5.10**

**Current Use of Any Tobacco Product by School Days Missed without Permission, Maryland Middle and High School Youth, 2008**



Source: Maryland Youth Tobacco Survey, 2008.

without permission during the past 30 days. Figure 5.10 reveals that those youth who have a high rate of absenteeism have far higher rates of tobacco use. This statistic suggests that youth not regularly attending school or who have dropped out are at far higher risk for tobacco use (and cancers of lung, bronchus, and trachea later in life). Data for jurisdictions with higher drop-out rates or attendance issues are likely underestimated to the extent to which those issues are present.

## Adult Current Smokers

IN MARYLAND, adult cigarette smoking has decreased significantly over time (-26% from 1997 to 2009), with the greatest progress occurring since 2002 (Figure 5.11). However, there remains considerable variation in cigarette smoking among jurisdictions, from a low of 5.8% in Howard County to a high of 22.6% in Somerset County as shown in Table 5.6.

In Maryland, approximately 15% (642,000) of adults are at high risk for cancers of the lung, bronchus, and trachea due to their ongoing cigarette smoking. An additional 24% (1,100,000) are at moderate risk as former smokers, while 61% (2,600,000) are at low risk as never smokers. Because current research does not support lung-cancer screenings as an effective prevention measure, but rather tobacco-use prevention and cessation, this chapter focuses on effective cessation measures, as well as the prevention of tobacco-use initiation among youth and young adults in Maryland.

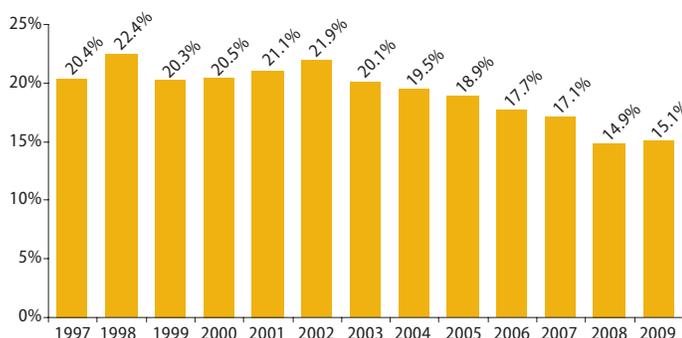
## Disparities in Adult Cigarette Smoking

THERE WERE NO STATISTICALLY SIGNIFICANT DIFFERENCES in the estimated prevalence of cigarette smoking in 2009 between Maryland adult black or African Americans (16.2%) and whites (15.3%).<sup>9</sup> However, when cigarette smoking was examined by income group and educational attainment, statistically significant differences were found. Low numbers of smokers within the survey sample for other races/ethnicities prevented development of estimates for those populations.

With respect to income, smoking rates were generally higher when household income was less than \$50,000 as compared to households earning \$50,000 or more. Cigarette smoking was found to be inversely related to educational attainment; that is, the higher the education level, the lower the prevalence of cigarette smoking. This relationship was found to be true for the general adult

FIGURE 5.11

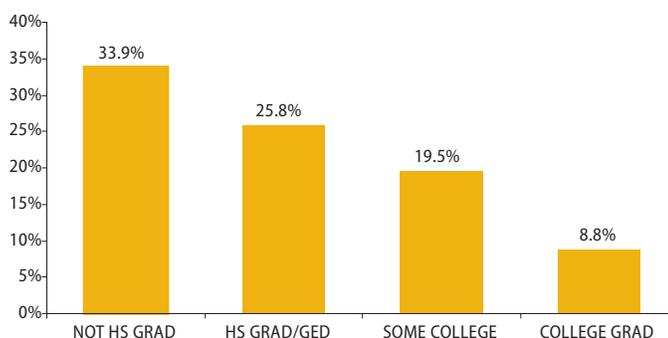
Estimated Current Cigarette Smoking, Maryland Adults Ages 18 and Older, 1997-2009



Source: Maryland Behavioral Risk Factor Surveillance System, 1997-2009.

FIGURE 5.12

Current Adult Cigarette Smoking By Highest Educational Attainment, 2004-2008



Source: Maryland Behavioral Risk Factor Surveillance System, 2004-2008.

population (Figure 5.12), as well as separately by race and gender. Differences in smoking prevalence between education levels are all statistically significant. (Analysis focuses on differences by educational attainment because fewer survey respondents provided income information, which precluded any examination by both income and race/gender).

Approximately 60% of adult black or African American smokers and 50% of adult white smokers had a high school diploma/GED (or less). Approximately 50% of adult female and male cigarette smokers' highest educational attainment stopped with a high school diploma/GED (or less).

## Reducing the Incidence of Cancers of the Lung, Bronchus, and Trachea

WITH UP TO 88% OF CANCERS of the lung, bronchus, and trachea being the result of past or current cigarette smoking,<sup>10</sup> the primary mechanisms for reducing incidence are (1) to prevent the initiation of cigarette smoking by youth and young adults, and (2) to encourage and assist current smokers to quit smoking and to stay quit.

**TABLE 5.6** Estimated Adult Current Cigarette Smoking, 2008

RANK	JURISDICTION	PREVALENCE
1	Somerset	22.6%
2	Allegany	20.4%
3	Caroline	20.3%
4	Cecil	19.3%
5	Talbot	17.9%
6	Worcester	17.7%
7	Baltimore City	16.7%
8	Wicomico	16.7%
9	Kent	16.1%
10	Calvert	16.0%
11	Charles	16.0%
12	St. Mary's	15.6%
13	Dorchester	15.3%
14	Queen Anne's	14.6%
15	Baltimore County	13.7%
16	Washington	13.0%
17	Prince George's	12.6%
18	Frederick	12.2%
19	Anne Arundel	11.5%
20	Harford	11.4%
21	Garrett	10.8%
22	Carroll	10.5%
23	Montgomery	7.2%
24	Howard	5.8%

Source: Maryland Adult Tobacco Survey, 2008.

## CDC “Best Practice Recommendations”

CDC has published evidence-based state-specific recommendations for implementation of comprehensive tobacco use prevention and cessation programs.<sup>11</sup> The program components recommended by the CDC include: State and Community Interventions; Health Communication Interventions; Cessation Interventions; Surveillance and Evaluation; and Administration and Management. These components are described in Table 5.7.

The CDC describes its best practice recommendations as “...an integrated programmatic structure for implementing interventions proven to be effective and provides the recommended level of state investment to reach these goals and reduce tobacco use in each state.” Further, the CDC stresses that “it is important to recognize that these individual components must work together to produce the synergistic effects of a comprehensive tobacco control program.”<sup>12</sup> Absent funding to support all of the individual components, efforts should focus on the most impactful interventions: statewide quitline, communications interventions, and surveillance.

## Goals, Objectives, and Strategies

THE FOLLOWING GOALS, OBJECTIVES, AND STRATEGIES are largely focused on broad population based strategies, such as policies and legislation. Focusing attention on policies, programs, and legislation that impact the larger environment has a greater potential for influencing individual level change. The Community Guide to Preventive Services and CDC Best Practices for Comprehensive Tobacco Control Programs were used to guide the development of the Goals, Objectives, and Strategies.

TABLE 5.7

## CDC Best Practice Program Components

**State and Community Interventions**

**STATE AND COMMUNITY INTERVENTIONS** include supporting and implementing programs and policies to influence societal organizations, systems, and networks that encourage and support individuals to make behavior choices consistent with tobacco-free norms. The social norm change model presumes that durable change occurs through shifts in the social environment, initially or ultimately, at the grassroots level across local communities. State and community interventions unite a range of integrated programmatic activities, including local and statewide policies and programs, chronic disease and tobacco-related disparity elimination initiatives, and interventions specifically aimed at influencing youth.

**Health Communication Interventions**

**AN EFFECTIVE STATE HEALTH COMMUNICATION INTERVENTION** should deliver strategic, culturally appropriate, and high-impact messages in sustained and adequately funded campaigns integrated into the overall state tobacco program effort. Traditional health communication interventions and counter-marketing strategies employ a wide range of efforts, including paid television, radio, billboard, print, and web-based advertising at the state and local levels; media advocacy through public relations efforts, such as press releases, local events, media literacy, and health promotion activities; and efforts to reduce or replace tobacco industry sponsorship and promotions. Innovations in health communication interventions include more focused targeting of specific audiences as well as fostering message development and distribution by the target audience through appropriate channels.

**Cessation Interventions**

**INTERVENTIONS TO INCREASE CESSATION** encompass a broad array of policy, system, and population-based measures. System-based initiatives should ensure that all patients seen in the health care system are screened for tobacco use, receive brief interventions to help them quit, and are offered more intensive counseling services and FDA-approved cessation medications. Cessation quitlines are effective and have the potential to reach large numbers of tobacco users. Quitlines also serve as a resource for busy health care providers, who provide the brief intervention and discuss medication options and then link tobacco users to quitline cessation services for more intensive counseling. Optimally, quitline counseling should be made available to all tobacco users willing to access the service.

Source: Centers for Disease Control and Prevention, 2007. Best Practices for Comprehensive Tobacco Control Programs.

**TABLE 5.7**

**CDC Best Practice Program Components**

**Surveillance and Evaluation**

**STATE SURVEILLANCE** is the process of monitoring tobacco-related attitudes, behaviors, and health outcomes at regular intervals. Statewide surveillance should monitor the achievement of overall program goals. Program evaluation is used to assess the implementation and outcomes of a program, increase efficiency and impact over time, and demonstrate accountability. A comprehensive state tobacco control plan—with well-defined goals; objectives; and short-term, intermediate, and long-term indicators—requires appropriate surveillance and evaluation data systems. Collecting baseline data related to each objective and performance indicator is critical to ensuring that program-related effects can be clearly measured. For this reason, surveillance and evaluation systems must have first priority in the planning process.

**Administration and Management**

**EFFECTIVE TOBACCO PREVENTION AND CONTROL PROGRAMS** require substantial funding to implement, thus making critical the need for sound fiscal management. Internal capacity within a state health department is essential for program sustainability, efficacy, and efficiency. Sufficient capacity enables programs to plan their strategic efforts, provide strong leadership, and foster collaboration between the state and local tobacco control communities. An adequate number of skilled staff is also necessary to provide or facilitate program oversight, technical assistance, and training.

Source: Centers for Disease Control and Prevention, 2007. Best Practices for Comprehensive Tobacco Control Programs.

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## GOALS - OBJECTIVES - STRATEGIES

### GOAL 1

**Substantially reduce tobacco use and exposure to secondhand smoke by high-risk Maryland adults and youth.**

#### OBJECTIVE 1

By 2015, adopt and implement statewide and local public policies that combat tobacco-industry marketing strategies used to promote and sustain the use of existing and emerging tobacco products.

#### STRATEGIES

- 1 **AMEND MARYLAND'S DEFINITION OF "CIGARETTES"** to include so-called "brown cigarettes" now classified as little cigars.
- 2 **REQUIRE THAT LICENSED TOBACCO RETAILERS** (a) display effective health warnings about the use of tobacco products; (b) display information on where to get help if you want to quit using tobacco; (c) ban so-called "power walls" (large display of tobacco products and ads) at all licensed tobacco outlets; and (d) ban the distribution of "free samples" of all tobacco products.
- 3 **ESTABLISH A STATEWIDE CIVIL FRAMEWORK** that does not pre-empt existing local civil frameworks that are at least as stringent for the purpose of enforcing Maryland's restrictions on the sale and distribution of tobacco products to minors, and require a photo identification check consistent with existing Food and Drug Administration (FDA) requirements that does not pre-empt local civil frameworks.
- 4 **STRENGTHEN TOBACCO-LICENSURE LAWS** so repeated violations on the sale of tobacco to minors result in mandatory suspension/revocation of licenses to sell tobacco products.
- 5 **ADOPT STATE AND LOCAL POLICIES** that restrict the sale, advertising, and promotion of tobacco products by (a) prohibiting the sale of menthol and any other flavored tobacco products; (b) require sale of non-premium cigars in packages of at least five cigars; and (c) adopt additional restrictions on the time, manner, and place of tobacco sales consistent with the First Amendment and in support of this objective.

#### OBJECTIVE 2

By 2015, reduce current tobacco use by 10%\* among:

- Maryland adults who do not have a four-year college degree to 14.5% (2008 Baseline: 16.1%)  
Source: Maryland Adult Tobacco Survey.
- Maryland high school youth to 21.8% (2008 Baseline: 24.2%)  
Source: Maryland Youth Tobacco Survey.

#### STRATEGIES

- 1 **EXPLORE AN INCREASE OF THE EXCISE TAX ON CIGARETTES** and all other tobacco products by an amount that corresponds to a 10% reduction in tobacco use by 2015, based on evidence cited in the Community Guide to Preventive Services. It is recommended that:
  - Each increase is in an amount of no less than the equivalent of \$1.00 per pack of 20 cigarettes.
  - All other tobacco products are taxed at an equivalent rate.
  - No discounts on excise tax rates are available for any reason.
- 2 **IMPLEMENT AND SUSTAIN EVIDENCE-BASED HEALTH COMMUNICATION INTERVENTIONS** through the Counter-Marketing and Media Component of the Tobacco Program in accordance with CDC recommendations, targeting high-risk youth and adult populations.
- 3 **ENSURE MEANINGFUL ONGOING ACCESS** to the Maryland Tobacco Quitline and other tobacco-use cessation counseling and widely promote such services. Support services through nicotine replacement therapy and/or pharmacotherapy. Provide coverage of services and therapies for all Maryland tobacco users through privately and publicly sponsored health insurance and direct provision of services for those without health insurance.
- 4 **ENGAGE WITH COLLEGE AND UNIVERSITY** administrators to ensure that all school campuses are tobacco-free at all times and that tobacco use by youth or adults is prohibited while engaged with all school-related activities.
- 5 **ADOPT POLICIES IN MARYLAND HOSPITALS** to provide inpatient counseling and treatment for patients that use tobacco.

*\*This target was developed based upon the recommendations by the Governor's Task Force to End Smoking in Maryland (1999) and updated by the Tobacco-Use Prevention/Cessation and Lung Cancer committee.*

# GOALS - OBJECTIVES - STRATEGIES

- 6 **PROMOTE AND ENHANCE THE STATEWIDE AND LOCAL ENFORCEMENT** of Maryland's restrictions on the sale of tobacco products to youth under 18 years of age.
- 7 **IMPLEMENT EVIDENCE-BASED PUBLIC HEALTH MESSAGING** that increases the demand for tobacco cessation and promotes awareness of the availability of cessation services.

## OBJECTIVE 3

By 2015, increase the percentage of youth not exposed to secondhand smoke indoors and in motor vehicles by 10%\* from 2008 rates to reach the following targets:

- **Indoors: 77.6% (2008 Baseline: 70.6%)**
  - **Motor vehicles: 79.6% (2008 Baseline: 72.4%)**
- Source: Maryland Adult Tobacco Survey.

## STRATEGIES

- 1 **ADOPT STATE AND LOCAL POLICIES** that prohibit the smoking of tobacco products inside multi-unit housing (including townhouses and rowhouses sharing common walls) in Maryland.
- 2 **ADOPT STATE POLICIES** that prohibit the smoking of tobacco products inside motor vehicles when young children who are required by state law to be in child-safety restraint seats are present in the vehicle.
- 3 **ADOPT STATE AND LOCAL POLICIES** that prohibit the smoking of tobacco products inside of any daycare facility (including private homes licensed as such) at all times, and regardless of whether children are present.
- 4 **INCREASE AWARENESS** of the health dangers from secondhand and third-hand smoke, and encourage voluntary adoption of smoke-free rules in all households.
- 5 **PROMOTE THE CESSATION OF TOBACCO USE**, ensure access to the Maryland Tobacco Quitline and other cessation services, and promote awareness of the dangers of secondhand smoke and available cessation services.

*\*This target was developed based upon the recommendations by the Governor's Task Force to End Smoking in Maryland (1999) and updated by the Tobacco-Use Prevention/Cessation and Lung Cancer committee.*

## GOAL 2

**Implement the CDC's Best Practice recommendations (2007) for Maryland's Comprehensive Tobacco Control Program.**

### OBJECTIVE 1

If funding for Maryland's Tobacco Comprehensive Control Program remains at FY 2011 levels, focus efforts on the most impactful, evidence-based programs.

## STRATEGIES

- 1 **INCREASE REIMBURSEMENT** from insurance providers and third party payers to ensure ongoing access to services provided by Maryland Tobacco Quitline (1-800-QUIT-NOW).
- 2 **IMPLEMENT A SUSTAINED**, effective statewide health communication Counter-Marketing and Media Component intervention.
- 3 **BROADEN THE SCOPE** of Maryland's youth and adult surveys beyond tobacco to include physical activity, nutrition, obesity, and use of other substances such as alcohol and drugs in order to maximize resources and integrate surveillance efforts of risk factors for cancer and other chronic diseases. Accurate and reliable county-level data should be available to local health departments for use in community health indicator reports.
- 4 **AWARD COMPETITIVE GRANTS** to organizations and local health departments that use best practices to target high-risk populations and educate physicians and other healthcare providers.
- 5 **ENSURE THAT GRANTS** targeting high-risk youth and young adults include only evidence-based or Centers for Disease Control and Prevention recommended interventions.

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- 10 See note 2
- 11 Centers for Disease Control and Prevention (US). Best practices for comprehensive tobacco control programs-2007. Atlanta (GA): US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 2007 Oct.
- 12 Ibid.

# 6 · Nutrition, Physical Activity, and Healthy Weight



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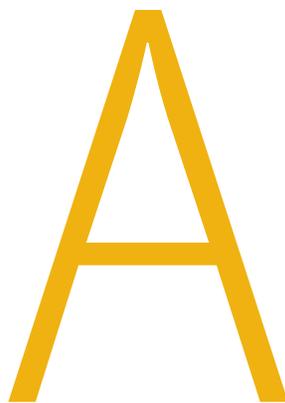
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# 6

## NUTRITION, PHYSICAL ACTIVITY, AND HEALTHY WEIGHT



fourth of all cancers are preventable through healthy lifestyles including healthy diet, physical activity, and healthy weight.<sup>1</sup> Epidemiologic studies show that a diet high in vegetables, fruits, and whole grains and low in animal fat, meat, alcohol, and calories reduces the risk of some of the most common cancers. Studies also show that obesity increases cancer risk.

**COMPREHENSIVE CANCER CONTROL STRATEGIES** include improved nutrition, increased physical activity, and achievement and maintenance of healthy weight. These steps, along with tobacco prevention and cessation, are the major cancer prevention measures as well as prevention measures for other chronic diseases.

Although these cancer prevention measures are important for the general population, special emphasis on certain target populations is necessary. African American or black, Hispanic or Latino, and low-income Marylanders have higher rates of obesity, poor diet, and physical inactivity. Instilling healthy lifestyle habits in childhood is important because of the rising rates of child and adult obesity. A growing body of evidence suggests a link between fetal exposures and the risk for obesity in adulthood, indicating that women of childbearing age are another important population. These same population groups are also important populations for preventing other chronic conditions impacted by nutrition, physical activity, and healthy

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TABLE 6.1

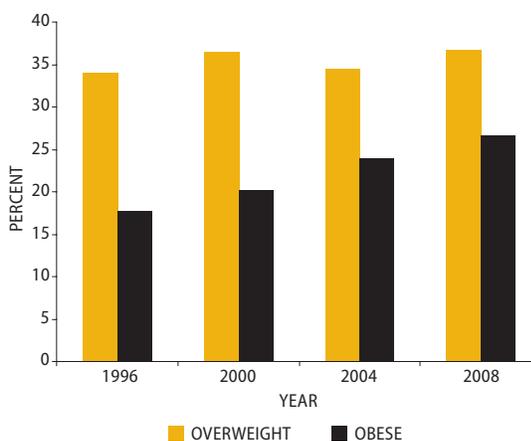
Prevalence of Healthy Weight, Physical Activity, and Adequate Consumption of Fruits and Vegetables among Maryland Adults, 1996, 2000, 2004, 2008

	1996	2000	2004	2008
Healthy weight (not overweight or obese)	48.2%	43.3%	41.5%	36.6%
Regular or sustained physical activity	13.3%	22.3%	n/a	n/a
Engaged in moderate physical activity for 30 minutes or more per day, five or more days per week	n/a	n/a	35.0%	35.6%
Consumption of five or more fruits and vegetables per day	24.7%	27.4%	30.1%	27.2%

Source: Maryland BRFSS, 1996, 2000, 2004, 2008.

FIGURE 6.2

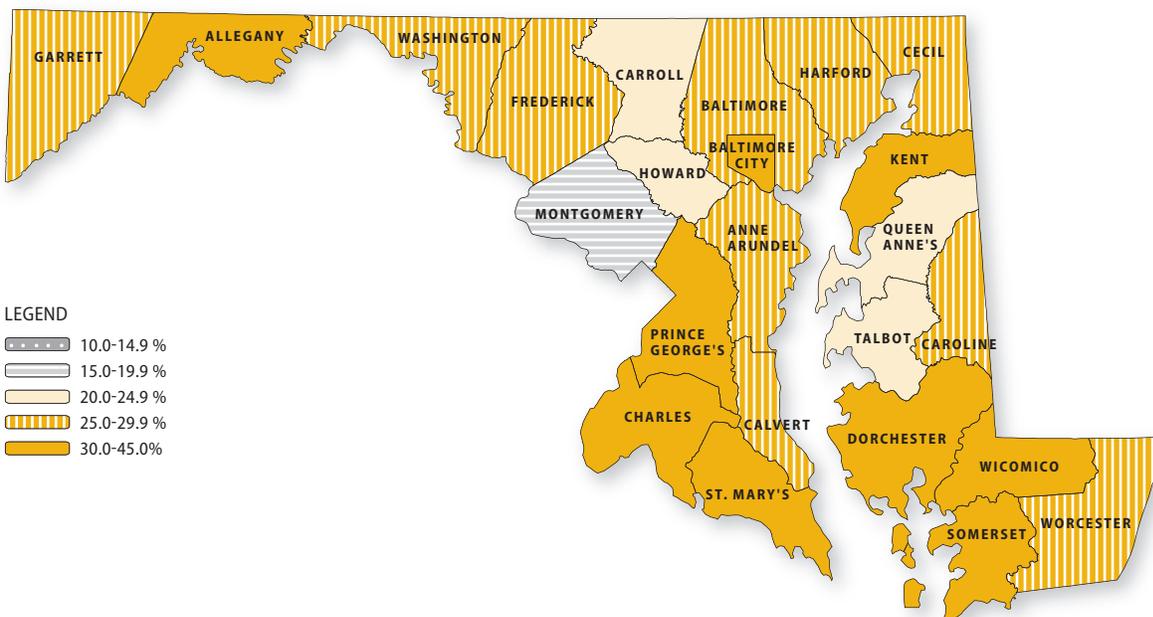
Prevalence of Overweight and Obesity in Maryland, 1996-2008



Source: Maryland BRFSS, 1996, 2000, 2004, 2008.

FIGURE 6.3

Adult Obesity Prevalence in Maryland by Jurisdiction, 2006-2008



Source: Maryland BRFSS, 2006-2008.

weight, such as high blood pressure and diabetes.

This chapter includes three sections:

- Summary of the key obesity, nutrition, and physical activity factors that promote or prevent cancer.
- Description of the social-ecological factors related to nutrition, physical activity, and body weight that impact cancer prevention, and highlights of potential opportunities for cancer prevention related to these factors.
- Goals, objectives, and strategies that detail Maryland-specific targets for action.

## Obesity, Nutrition, and Physical Activity Factors that Promote or Prevent Cancer

A summary of the World Cancer Research Fund/American Institute for Cancer Research expert panel on Food, Nutrition, Physical Activity, and the Prevention of Cancer identifies the critical factors that promote or prevent specific cancers and obesity as presented in Figure 6.1<sup>2</sup> (see pages 4-5).

### Obesity Factors and Cancer

**O**BESITY, OR EXCESS BODY FAT, increases the risk of cancer of the esophagus, pancreas, colorectum, breast, endometrium, and kidney and may increase the risk of cancer in general. Obesity may also increase risk for gallbladder cancer. Excess abdominal fat increases the risk of colorectal cancer and may increase the risk of cancer of the pancreas, breast, and endometrium.<sup>3</sup>

The leading cause of obesity results from an energy imbalance, meaning too many calories taken in or too few calories expended in activity. A calorie is a unit of measurement for energy. Eating and drinking too many calories and not burning these calories through physical activity results in weight gain in the form of body fat and may lead to overweight and obesity.

The most common way that overweight and obesity are identified is based on Body Mass Index (BMI), which is calculated using height and weight. The Centers for Disease Control and Prevention (CDC) adult and youth BMI calculators can be found at [www.cdc.gov](http://www.cdc.gov). Adults with a BMI between 25 and 29.9 are considered

overweight, and adults with a BMI of 30 or higher are considered obese.<sup>4</sup> For children over age two and adolescents, BMI scores are considered in terms of percentiles by age and sex. A child with a BMI above the 95th percentile for age and sex is considered obese. A child with a BMI between the 85th and 95th percentile is considered overweight.<sup>5</sup>

Waist circumference, a measure of abdominal fat, is another gauge of health risk in adults related to body size and composition. Waist circumference more than 40 inches in men and more than 35 inches in women indicates increased risk of obesity-related diseases, including cancer.<sup>6</sup>

The prevalence of obesity has increased dramatically in the US and in Maryland in recent decades. In 2008, nearly two-thirds of Maryland adults were either overweight or obese (Table 6.1, Figure 6.2). Figure 6.3 shows the adult obesity prevalence by jurisdiction in Maryland.

**THE PREVALENCE OF OBESITY** has tripled among children in the United States since 1980.<sup>7</sup> According to the 2008 Pediatric Nutrition Surveillance Survey, 15.7% of low-income two-to-five-year-old Maryland children are obese. According to the 2009 Youth Risk Behavioral Survey, 12.2% of high

#### Obesity Burdens Certain Population Groups More Than Others

- **Maryland African American or black women** 39% compared with 23% for white women  
Source: Maryland BRFSS, 2008.
- **Maryland adults with less than a high school education** 30% compared to 20% for college-educated adults  
Source: Maryland BRFSS, 2008.
- **Maryland adults with an annual household income less than \$15,000** 34% compared to 22.3% for adults with a household income greater than \$75,000  
Source: Maryland BRFSS, 2008.
- **Maryland African American or black adolescents** males: 17% vs. 11.8% for whites; females: 13.5% vs. 3.8% for whites Source: Youth Risk Behavior Surveillance System, 2009.
- **Low-income Hispanic or Latino children between the ages of two to five** 18.3% compared to 12.6% for whites and 12.0% for African Americans or blacks

FIGURE 6.1

World Cancer Research Fund/American Institute for Cancer Research Report:  
Summary of 'Convincing' and 'Probable' Risk

	MOUTH, PHARYNX, LARYNX	NASOPHARYNX	OEESOPHAGUS	LUNG	STOMACH	PANCREAS	GALLBLADDER	LIVER	COLORECTUM <sup>9</sup>
Foods containing dietary fibre									Probable Decreased Risk
Aflatoxins								Convincing Increased Risk	
Non-starchy vegetables <sup>1</sup>	Probable Decreased Risk		Probable Decreased Risk		Probable Decreased Risk				
Allium vegetables					Probable Decreased Risk				
Garlic									Probable Decreased Risk
Fruits <sup>2</sup>	Probable Decreased Risk		Probable Decreased Risk	Probable Decreased Risk	Probable Decreased Risk				
Foods containing folate						Probable Decreased Risk			
Foods containing lycopene									
Foods containing selenium <sup>3</sup>									
Red meat									Convincing Increased Risk
Processed meat									Convincing Increased Risk
Cantonese-style salted fish		Probable Increased Risk							
Diets high in calcium <sup>4</sup>									Probable Decreased Risk
Energy-dense foods <sup>5</sup>									
Low energy-dense foods									
Salt, salted and salty foods					Probable Increased Risk				
Arsenic in drinking water				Convincing Increased Risk					
Matè			Probable Increased Risk						
Sugary drinks									
Alcoholic drinks <sup>6</sup>	Convincing Increased Risk		Convincing Increased Risk					Probable Increased Risk	Probable Increased Risk
Beta-carotene <sup>7</sup>				Convincing Increased Risk					
Physical activity									Convincing Decreased Risk
Sedentary living <sup>8</sup>									Convincing Increased Risk
Body fatness			Convincing Increased Risk			Convincing Increased Risk	Probable Increased Risk		Convincing Increased Risk
Abdominal fatness						Probable Increased Risk			Convincing Increased Risk
Adult weight gain									Convincing Increased Risk
Adult attained height						Probable Increased Risk			Convincing Increased Risk
Greater birth weight									Convincing Increased Risk
Lactation									
Being breastfed									

KEY

- Convincing Decreased Risk
- Probable Decreased Risk
- Probable Increased Risk
- Convincing Increased Risk

- 1 Includes evidence on foods containing carotenoids for mouth, pharynx, larynx; foods containing beta-carotene for oesophagus; foods containing vitamin C for oesophagus.
- 2 Includes evidence on foods containing carotenoids for mouth, pharynx, larynx and lung; foods containing beta-carotene for oesophagus; foods containing vitamin C for oesophagus.
- 3 Includes evidence from supplements on prostate.
- 4 Evidence is from milk and studies using supplements for colorectum.
- 5 Includes fast foods.
- 6 Convincing harm for men and probable harm for women for colorectum.
- 7 The evidence is derived from studies using supplements for lung.
- 8 Judgment for physical activity applies to colon and not rectum.
- 9 Includes evidence on television viewing.

This material has been adapted from the 2007 WCRF/AICR Report Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective. World Cancer Research Fund International: [www.wcrf.org](http://www.wcrf.org); American Institute for Cancer Research: [www.aicr.org](http://www.aicr.org)

FIGURE 6.1

World Cancer Research Fund/American Institute for Cancer Research Report:  
Summary of 'Convincing' and 'Probable' Risk

	BREAST PREMENOPAUSE	BREAST POSTMENOPAUSE	OVARY	ENDOMETRIUM	PROSTATE	KIDNEY	SKIN	WEIGHT GAIN, OVERWEIGHT, AND OBESITY
Foods containing dietary fibre								
Aflatoxins								
Non-starchy vegetables <sup>1</sup>								
Allium vegetables								
Garlic								
Fruits <sup>2</sup>								
Foods containing folate								
Foods containing lycopene					■			
Foods containing selenium <sup>3</sup>					■			
Red meat								
Processed meat								
Cantonese-style salted fish								
Diets high in calcium <sup>4</sup>					■			
Energy-dense foods <sup>5</sup>								■
Low energy-dense foods								■
Salt, salted and salty foods								
Arsenic in drinking water							■	
Matè								
Sugary drinks								■
Alcoholic drinks <sup>6</sup>	■	■						
Beta-carotene <sup>7</sup>								
Physical activity		■		■				□
Sedentary living <sup>8</sup>								■
Body fatness	■	■		■		■		
Abdominal fatness		■		■				
Adult weight gain		■						
Adult attained height	■	■	■					
Greater birth weight	■							
Lactation	□	□						
Being breastfed								■

KEY

- Convincing Decreased Risk
- Probable Decreased Risk
- Probable Increased Risk
- Convincing Increased Risk

- 1 Includes evidence on foods containing carotenoids for mouth, pharynx, larynx; foods containing beta-carotene for oesophagus; foods containing vitamin C for oesophagus.
- 2 Includes evidence on foods containing carotenoids for mouth, pharynx, larynx and lung; foods containing beta-carotene for oesophagus; foods containing vitamin C for oesophagus.
- 3 Includes evidence from supplements on prostate.
- 4 Evidence is from milk and studies using supplements for colorectum.
- 5 Includes fast foods.
- 6 Convincing harm for men and probable harm for women for colorectum.
- 7 The evidence is derived from studies using supplements for lung.
- 8 Judgment for physical activity applies to colon and not rectum.
- 9 Includes evidence on television viewing.

This material has been adapted from the 2007 WCRF/AICR Report Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective. World Cancer Research Fund International: www.wcrf.org; American Institute for Cancer Research: www.aicr.org

school students were obese and another 15.6% were overweight.<sup>8</sup> There are no data related to overall obesity rates among Maryland children between ages five and twelve.

Childhood obesity and overweight have not been directly linked to cancer, but obese children are more likely to become obese adults. Children who are obese after age six have a more than 50% chance of being obese as adults. Seventy percent of children overweight at ages 10 to 17 were obese as young adults.<sup>9</sup>

Certain nutrition and physical activity factors have not been linked directly to cancer but are linked to obesity, which is a risk factor for certain cancers.<sup>10</sup> Eating energy-dense foods (see explanation and examples below), drinking sugar-sweetened beverages such as soda, and being sedentary including television-viewing are associated with increased risk for obesity. Eating low-energy-dense foods, being physically active, and having been breastfed as an infant are associated with decreased risk for obesity. Eating low-energy-dense foods such as fruits and vegetables and being physically active are also directly linked with cancer prevention and will be discussed in the following sections.

#### **CALORIES, ENERGY DENSITY, AND INTAKE OF FAT**

**INCREASED CONSUMPTION OF ENERGY-DENSE FOODS** can cause weight gain and, when coupled with a sedentary lifestyle, can lead to overweight and obesity.<sup>11</sup> Foods such as french fries, doughnuts, and fast food burgers and shakes have a relatively small food volume compared to their calorie content; in other words, a high energy density. Many of them also offer few nutrients necessary for good health.

Portion sizes of many foods have also increased over the past 40 years, adding dietary calories that often go unnoticed until they lead to weight gain. The healthiest way to reduce calorie intake is to eat smaller portion sizes, especially for foods with added sugar and fat.<sup>12</sup> These dietary constituents and the foods that provide them are often high in calories but offer few or no essential nutrients.

#### **SUGAR-SWEETENED BEVERAGES**

**INCREASED CONSUMPTION OF SUGAR-SWEETENED BEVERAGES** has been associated with weight gain, overweight,

and obesity.<sup>13</sup> Much of the added sugar in American diets comes from sugar-sweetened beverages such as carbonated soda and fruit drinks. American adults have increased their intake of sodas and fruit drinks by 100% in fewer than 20 years.<sup>14</sup> Children get almost 11% of their total calories from sugar-sweetened beverages.<sup>15</sup> Overweight young people, ages 2 to 19, consume a higher proportion of their calories from carbonated soft drinks than their non-overweight counterparts.<sup>16</sup>

#### **BREASTFEEDING**

**IN ADDITION TO THE ASSOCIATED BENEFIT** of lactation in reducing the risk of developing breast cancer in the mother and the multiple well-known benefits of breastfeeding for an infant, breastfeeding for at least six months is recommended because of probable reduced risk of future obesity for the infant.<sup>17</sup>

#### **SEDENTARY BEHAVIOR**

**SEDENTARY BEHAVIOR HAS BEEN LINKED TO OBESITY.**<sup>18</sup> Sedentary behaviors are those that result in prolonged sitting such as watching television and playing video games. Being sedentary is not the same as lacking physical activity. Evidence suggests that increasing physical activity levels may not be effective if levels of sedentary behavior remain high.<sup>19</sup> Americans are more sedentary than they used to be. Over two-thirds of adults report watching television for more than two hours a day. Another 25% say they use a computer outside of work for more than two hours a day.<sup>20</sup> Television viewing is also related to consumption of calorie-dense foods and drinks, further contributing to weight gain, overweight, and obesity.

### **Nutrition Factors and Cancer**

#### **FRUITS AND VEGETABLES**

**FRUITS AND VEGETABLES** have a relatively large volume compared to their calorie content and are considered low-energy-dense foods. Eating a low-energy-dense diet can help people lower their calorie intake while maintaining feelings of fullness and controlling hunger sensation.<sup>21</sup>

The United States Department of Agriculture (USDA) “2010 Dietary Guidelines Advisory Committee (DGAC) Report” recommends eating a diet mostly of foods of plant origin. Experts have

long promoted consumption of fruits and vegetables to prevent cancer and other chronic diseases, like obesity, diabetes, and cardiovascular disease. One recent study failed to confirm an association between fruit and vegetable intake and overall cancer risk<sup>22</sup> but there is evidence that diets high in vegetables and fruits probably protect against cancers of the mouth, pharynx, larynx, esophagus, and stomach.<sup>23</sup> Allium vegetables (such as onions, garlic, leeks, and shallots), chicory, and Jerusalem artichokes have been shown to protect against stomach cancer, and garlic has been shown to have protective value against colon and rectal cancer.<sup>24</sup>

The wide array of vitamins, minerals, and antioxidants found in fruits and vegetables provide natural defenses for overall cell health and maintenance. Antioxidants such as carotenoids are powerful organic compounds that can protect against cancers of the mouth, pharynx, larynx, and lung. Beta-carotene (found, for example, in carrots and spinach) and lycopenes (abundant in cooked tomatoes), are types of carotenoids thought to enhance the function of the immune system and protect from various cancers such as prostate cancer.<sup>25</sup>

The Centers for Disease Control and Prevention “State Indicator Report on Fruits and Vegetables, 2009” provides information on fruit and vegetable consumption in Maryland. According to the report, about 15% of Maryland adults and even fewer adolescents are consuming the minimum recommended amount of fruits and vegetables every day (Table 6.1).<sup>26</sup> Increasing the proportion of Americans consuming the recommended daily servings of fruit and vegetables is a national health objective, and has been measured as part of the US Department of Health and Human Services Healthy People 2010 Objectives.

#### **DIETARY FIBER**

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**CONSUMPTION OF DIETARY FIBER** may influence cancer risk in two ways. 1) Some, but not all, studies show that consumption of dietary fiber is linked to a probable decrease in colon cancer risk. 2) Foods high in dietary fiber are more often low-energy, nutrient-dense foods. Therefore, high-fiber foods are highly recommended for obesity preven-

tion.<sup>27</sup> Dietary fiber can be found in whole grains, legumes, beans, fruits, and vegetables. In general, foods that are minimally processed will contain more dietary fiber when compared to their processed counterparts. For example, 100% whole grain bread will have more fiber per serving than white bread, and a whole apple will have more fiber per serving than applesauce. Dietary fiber dilutes fecal contents, decreases transit time, and increases stool weight. The exact mechanism of how dietary fiber in the colon may be associated with decreased cancer risk is still unknown.

#### **RED MEAT**

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**SOME STUDIES** have found that the consumption of red meat and the cooking of meat by broiling, grilling, or smoking is associated with a higher risk of some cancers. Red meat is any flesh from animals that have more red than white muscle fibers, such as beef, goat, and lamb.<sup>28</sup>

The mechanism for the association between red meat, high-temperature cooking of meat, and cancer is not completely clear but may be due to the formation of heterocyclic amines and polycyclic aromatic hydrocarbons when protein-rich meat is cooked at high temperature. Both of these compounds are carcinogens in animal studies as well as recent human studies.<sup>29,30</sup>

#### **SALT**

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**UNDERSTANDING THE RELATIONSHIP** of salt consumption and gastric/stomach cancer continues to be an active area of research. Studies have examined the possible correlation between salt intake and the presence of *H. pylori*, the bacterium that is a cause of stomach cancer, stomach ulcers, and chronic gastritis. It has been published that “based on the considerable evidence from ecological, case-control, and cohort studies worldwide and the mechanistic plausibility, limitation on salt and salted food consumption is a practical strategy for preventing gastric cancer.”<sup>31</sup>

#### **PROCESSED FOODS**

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**MANY KNOWN OR SUSPECTED TOXINS AND CARCINOGENS** find their way into the food supply or are created by food processing methods. These toxins and carcinogens include pesticides, heavy metals, and nitrates. These issues are covered in more detail in Chapter 8: Environmental/Occupational Issues and Cancer.

In particular, consumption of processed meats has been linked to colon cancer<sup>32,33</sup> and may cause cancers of the esophagus, lung, stomach, and prostate.<sup>34</sup> Processed meat is commonly defined as meats preserved by smoking, curing, salting, or the addition of chemical preservatives. Processed meats such as hot dogs and bacon are preserved with sodium nitrite to improve their flavor and appearance. Many deli meats and pickled, fried, or smoked foods also contain sodium nitrate. During the digestion process, sodium nitrate is converted to nitrosamine, which is a carcinogen.

Acrylamides are a byproduct of high-temperature cooking methods such as frying, baking, or broiling, and are found at especially high levels in foods such as potato chips and french fries. Studies in rodents have shown that acrylamides pose a risk for several types of cancer. However, the evidence is still incomplete regarding the health risks for humans.<sup>35</sup>

#### NUTRITIONAL SUPPLEMENTS

A COMPREHENSIVE REVIEW OF STUDIES concluded that the strength of the evidence on efficacy for primary prevention of cancer of using multivitamin/mineral supplementation such as vitamin D and vitamin E was “very low.”<sup>36</sup> In fact, a recent report from the National Institutes of Health states that “supernutritional levels of vitamins taken as supplements do not emulate the apparent benefits of diets high in foods that contain those vitamins, and we now know that taking vitamins in supernutritional doses can cause serious harm.” Beta-carotene, which some people take as a supplement, has been shown to increase the number of new cases of lung cancer in study participants with asbestos exposure or smoking history and is associated with a higher death rate.<sup>37</sup> People at higher risk for cancer or those unable to meet the recommended daily intake of certain nutrients from their diet alone should consider talking to their health professional before taking vitamin and/or mineral supplements.

#### ALCOHOL

THE MORE ALCOHOL A PERSON DRINKS, the higher the risk of developing oral, pharynx, larynx, esophagus, liver, and colorectal cancers. Women who drink even a glass or two of alcohol daily have a higher risk of breast cancer.<sup>38</sup> General guidelines advise no more than one drink per day for women and two drinks for men. (The drink-size reference guideline is 12 ounces of beer or wine cooler, 5 ounces of wine, or 1.4 ounces of an 80-proof distilled spirit.)<sup>39</sup>

Tobacco use combined with excessive drinking appears to promote higher rates of oral and head and neck cancers.<sup>40</sup> Researchers are investigating the exact mechanism connecting alcohol consumption and cancer/tumor growth and potential methods of risk reduction, including the relationship of the B-vitamin folate to the alcohol and colon and breast cancer associations.<sup>41</sup>

Because light-to-moderate amounts of alcohol consumption can also have beneficial health effects on heart disease prevention, medical professionals should discuss the risks and benefits of alcohol consumption with their patients and the importance of limiting intake.

#### Physical Activity and Cancer

PHYSICAL ACTIVITY is an important determinant of overall health and specifically of cancer risk.<sup>42</sup>

Evidence supports the role of physical activity in the prevention of many types of cancer.<sup>43,44,45,46</sup> Physically active people have a significantly lower risk of colon, breast, prostate, and endometrial cancers than do inactive people.<sup>47,48</sup> In addition, physical activity is a way to reduce weight and to maintain a healthy weight throughout the lifespan. Because obesity is a known risk factor for the development of cancer, physical activity may also indirectly impact an individual’s risk for cancer by preventing obesity.<sup>49</sup>

Individual recommendations for physical activity are an important part of cancer prevention and can easily be implemented into individual lifestyles. Physical activity is safe for most people and essential for healthy aging. Preexisting medical conditions, disability, or limitations related to aging should be considered when recommending a physical activity program but

almost everyone can be active in some way.<sup>50</sup> While there is no level of physical activity that absolutely reduces cancer risk, evidence does support the substantial health benefits of physical activity. Thirty to 60 minutes of moderate daily physical activity is estimated to reduce the risk of colon, breast, prostate, and endometrial cancer by 20% to 40%.<sup>51</sup>

According to the 2008 Maryland BRFSS, 76% of Maryland adults reported participating in some form of physical activity in the past 30 days, mirroring the national average which has remained steady for ten years. However, only 36% of Maryland adults report participating in moderate physical activity at levels recommended for substantial health benefit (Table 6.1, pages 4-5).

## Prevention of Cancer through Healthy Eating and Physical Activity

**Coordinated action to reduce the nutrition, obesity, and physical activity risk factors related to cancer in Maryland is required.**

**SUCH ACTION HAS BEEN CONDUCTED** in many areas throughout Maryland, and is highlighted in the “Maryland Comprehensive Cancer Control Plan Progress Report,” which can be viewed at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

Marylanders need to make better food and beverage choices, become more physically active, and lose weight. However, individual lifestyle decisions are greatly influenced by the larger social and ecological environment including family and peers. (See the Social Ecological Model on page 10.) This environment can be modified through policies and practices that make healthier choices easier. Everyone who lives and works in Maryland should be able to make healthy life choices about nutrition, physical activity, and attaining and maintaining a healthy weight by having easy, affordable, and equitable access to accurate health information, healthy foods, and safe, enjoyable, and convenient places for physical activity.

To accomplish this, a comprehensive approach is required that engages all levels of the Social Ecological Model, reflects the diverse needs and cultural preferences of communities and populations, and involves collaboration across industry,

community organizations, employers, healthcare providers, health plans, nongovernmental organizations, and local, state, and federal governments. Licensed childcare, schools, workplaces, and communities serve as potential venues that can be modified to improve access to information, healthy food choices, and safe, convenient places for physical activity.

## Institutions and Organizations

### CHILDCARE AND SCHOOLS

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**CHILDREN AND ADOLESCENTS** spend much of their time away from home in childcare or in schools. These settings present opportunities to model normal healthy eating and physical activity behaviors as well as provide age-appropriate health and physical education. The Maryland State Department of Education (MSDE) and the US Department of Agriculture (USDA) have required the development and implementation of wellness policies in all schools since the 2006-2007 school year.<sup>52</sup> Existing Maryland Board of Education nutrition and physical activity policies such as the Management and Operations Memorandum provide guidance for foods of minimal nutritional value (MOM-12). Local compliance with state-level guidance has not been assessed statewide. Further work is still needed in both the school and childcare settings to meet the nutrition and physical activity guidelines for children. Examples of policies and practices to promote healthier behaviors in childcare and school settings include putting nutrition and physical activity parameters in the assessment of childcare quality and requiring schools to provide recommended levels of physical activity for children of all ages through physical education classes or recess, consistent with national and state guidance.<sup>53,54</sup>

### WORKPLACES

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**WORKPLACES PLAY A CRITICAL PART** in the effort to increase opportunities for healthy eating and physical activity. In 2009, there were more than 2.5 million adults employed in Maryland, with the average full-time employee spending 9.2 hours per day at work.<sup>55</sup> Compelling incentives exist for workplace health promotion, as healthy employees are likely to be more productive and

## Social Ecological Model

The **Social Ecological Model** provides a way of thinking about the factors related to preventing cancer. It describes the spheres of influence for interventions from the individual to the much broader level of social structure and policy. Interventions at the individual and interpersonal levels are supported by those implemented at the broader levels of the model.

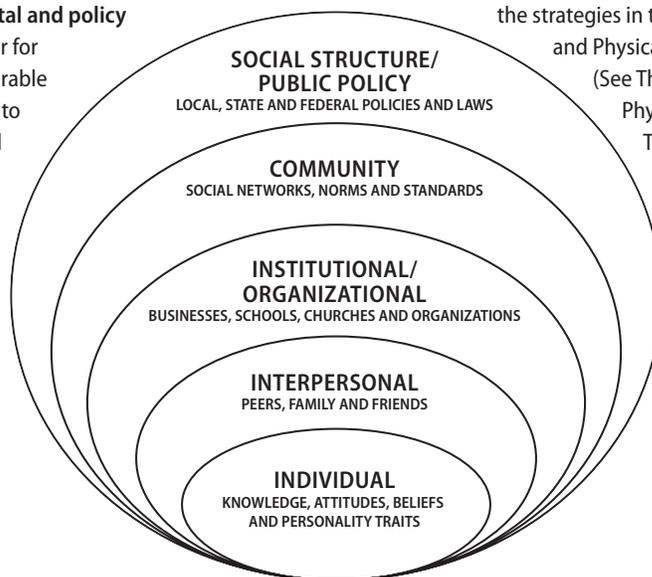
**Implementing environmental and policy interventions** makes it easier for individuals to engage in desirable behaviors and more difficult to engage in behaviors harmful to health.

**Changes in the “built environment,”** such as increasing the availability and accessibility of fresh fruits and vegetables or improving community

infrastructure to promote walking and bicycling, can increase opportunities for healthy eating and physical activity in communities. Achieving these changes requires collaboration among all sectors of society: government, business, media, healthcare and health professionals, public and private organizations, and individuals, as outlined in the model.

The **Social Ecological Model** is also used to organize the strategies in the Maryland Nutrition and Physical Activity Plan 2006-2016. (See The Maryland Nutrition and Physical Activity Plan text box.)

Together these plans can guide efforts to improve the diets and physical activity habits of Marylanders for prevention of cancer as well as other chronic diseases.



incur lower medical costs. There has also been strong evidence that worksite programs are effective to reduce obesity among workers through such measures as providing healthy foods options in the workplace and encouraging physical activity during scheduled breaks.<sup>56</sup>

### HEALTHCARE

**THE HEALTHCARE SECTOR**, including healthcare providers and health plans, has an important role in terms of influencing behavior change. Healthcare providers are often trusted sources of information regarding lifestyle changes to improve health status. In addition, health insurance plan coverage of preventive services (for example, cancer screening tests) has been shown to increase the likelihood of people obtaining these important services.<sup>57</sup> Improving health plan coverage, incentives for risk reduction behaviors, and benefits for other preventive services such

### The Maryland Nutrition and Physical Activity Plan

**Goals and objectives in this chapter** align with the recommendations set forth in the Maryland Nutrition and Physical Activity Plan. In 2003, the state of Maryland was awarded a cooperative agreement from the Centers for Disease Control and Prevention to engage community and state-level stakeholders to develop a comprehensive plan to address obesity across the lifespan of Maryland residents. In 2006, a ten-year framework for action was published. The Maryland Nutrition and Physical Activity Plan focuses on healthy eating and physical activity through changes across the Social Ecological Model in the community, healthcare, school, and worksite settings. The ten-year plan is currently housed within the Maryland Health Eating and Active Lifestyle Coalition, a 501(c)(3) nonprofit and is available for download at [www.healthyactivemaryland.org](http://www.healthyactivemaryland.org). The coalition provides annual plan updates and networking meetings to more than 200 member organizations.

as weight management and behavioral change counseling may increase the number of people who receive these services.

## Communities

### SOCIAL NORMS AND STANDARDS

**CHANGING SOCIAL NORMS AND STANDARDS** to support healthy eating, physical activity, and attaining and maintaining a healthy weight requires Maryland community members to recognize that obesity is a problem and that relatively small changes can be made by making healthier choices. A recent initiative in Maryland aims to create an environment that supports these healthy choices. (See Healthiest Maryland text box).

## Public Policies

**LOCAL, STATE, AND FEDERAL GOVERNMENTS** have a tremendous influence on the environment in which we work, live, and play. Decisions affecting transportation planning, residential and business development, and zoning regulations influence safety, accessibility, and affordability. In addition, governmental health and social programs have an impact on health behaviors. Policies to enhance opportunities for physical activity and decrease sedentary behaviors should be considered. Some examples include implementing the Maryland bike and pedestrian plan, promoting local recreation/parks programs and Safe Routes to Schools (SR2S) initiatives, and embracing Smart Growth principles for planning and development to reduce urban sprawl.<sup>58,59,60</sup> Strategies that could improve retail access to fruits and vegetables include promoting virtual supermarkets and healthy corner stores programs,

### Healthiest Maryland

The Maryland Health Quality and Cost Council, chaired by the Lt. Governor and Secretary of Health, was established by Executive Order in 2007 to develop recommendations for improving healthcare quality and reducing healthcare costs in the state. In 2009, the Health Quality and Cost Council recommended the promotion of Healthiest Maryland, a statewide movement to create a culture of wellness—an environment that makes the healthiest choice an easy choice. The three components of Healthiest Maryland are Healthiest Maryland Businesses, Healthiest Maryland Communities, and Healthiest Maryland Schools. Within each of the sectors, there is a peer-to-peer recruitment campaign to engage leadership and conduct an organizational assessment, referral to resources and technical assistance, and recognition of successful implementation of policies and environmental change. In addition, corresponding state-level policies and environmental changes will contribute to the culture of wellness throughout Maryland.

using incentives for grocery stores to relocate in food deserts, and increasing the use of Electronic Benefits Transfer at local farmers markets.<sup>61,62</sup> Another approach considered by some states and local jurisdictions is enacting an excise tax on sugary beverages or other unhealthy foods, which increases the cost to the consumer. Such policies have a potential to impact individual behaviors, such as implementation of tobacco excise taxes have contributed to decreases in tobacco use.<sup>63</sup>

Focusing attention on policies and programs that impact broader levels of the social ecological model have a greater potential for influencing individual and peer networks. The following goals, objectives and strategies to decrease cancer risks through optimal nutrition, physical activity and achieving a healthy weight strongly emphasize these broader targets.

## GOALS - OBJECTIVES - STRATEGIES

### GOAL

**Reduce the burden of cancer in Maryland by improving the nutrition and physical activity and promoting the healthy weight of Marylanders across the lifespan.**

#### TARGETS (2016)

- **Increase the proportion of Maryland adults consuming at least five fruits and vegetables per day to 32%\* (2008 Baseline: 27%).**  
Source: Maryland BRFSS.
- **Maintain the proportion of Maryland adults engaging in moderate physical activity for 30 minutes or more per day, five or more days per week at 36%\* (2008 Baseline: 36%).**  
Source: Maryland BRFSS.
- **Reduce the proportion of Maryland adults engaging in no leisure time physical activity to 19%\* (2008 Baseline: 24%).**  
Source: Maryland BRFSS.
- **Increase the proportion of Maryland adults who are at a healthy weight (18.0 >= BMI <= 25.0) to 44%\* (2008 Baseline: 35.5%).**  
Source: Maryland BRFSS.
- **Reduce the proportion of low-income children (ages 2-4) who are obese to 14.1% (2008 Baseline: 15.7%).**  
Source: Maryland Pediatric Nutrition Surveillance Survey, 2008.

\*(The target for 2016 is taken from the Maryland Nutrition and Physical Activity Plan, published in May 2006 (<http://fha.maryland.gov/pdf/cdp/npaplan.pdf>).

#### OBJECTIVE 1

**By 2015, ensure that Maryland has a team of personnel and dedicated resources sufficient to implement and evaluate cancer prevention strategies related to nutrition, physical activity, and obesity prevention and treatment.**

#### STRATEGIES

- 1 **EXPLORE MECHANISMS** (including identifying novel funding sources and/or leveraging other public and private initiatives with similar goals) to provide dedicated funding to support nutrition and physical activity policy implementation and environmental changes.

- 2 **IMPLEMENT A STATEWIDE SURVEILLANCE SYSTEM** that can be used to measure the reach and impact of the strategies for Objectives 2-6.

#### OBJECTIVE 2

**By 2015, ensure that at least 25% of Maryland businesses have policies and supports for promoting healthy eating and physical activity.**

#### STRATEGIES

- 1 **ESTABLISH MECHANISMS** for obtaining a baseline and tracking the healthy eating and physical activity policies of workplaces and business, and for providing technical assistance to interested workplaces and businesses on improving workplace policies, programs, and support for nutrition, physical activity, and lactation support for workers.
- 2 **ASSESS AND ADDRESS BARRIERS** for Maryland workplaces and businesses to establish worksite wellness programs that encourage healthier behaviors and meet their workers' health and wellness needs.
- 3 **ENCOURAGE WORKPLACE WELLNESS INITIATIVES** through a recognition program for businesses with model policies and practices.
- 4 **ESTABLISH STATE-LEVEL POLICIES** and supports to promote healthy eating and physical activity for state employees.

#### OBJECTIVE 3

**By 2015, ensure that 50% of Maryland licensed child-care facilities will have policies to promote healthy eating and physical activity.**

#### STRATEGIES

- 1 **INCORPORATE NUTRITION** and physical activity wellness policy standards in the voluntary Quality Rating Improvement System assessment for licensed childcare in order to measure and track the proportion of licensed childcare facilities meeting Objective 3.
- 2 **INCLUDE NUTRITION** and physical activity-related educational requirements in childcare-provider credentialing and continuing education.
- 3 **EXPLORE POTENTIAL STATE POLICIES** for promoting healthy eating and physical activity in licensed childcare, before and after school care programs, and summer camp including maximizing implementation and utilization of the Supplemental Nutrition Assistance Program (SNAP); Supplemental Nutrition Program for Women, Infants, and Children (WIC);

# GOALS - OBJECTIVES - STRATEGIES

Child and Adult Care Food Program; At Risk Afterschool Meals Program; and Summer Food Service Program.

## OBJECTIVE 4

By 2015, ensure that 100% of Maryland public school systems will have policies to promote healthy eating and physical activity.

### STRATEGIES

- 1 RECRUIT SCHOOL LEADERSHIP** to complete an assessment of their wellness policies in order to measure and track the progress of Objective 4.
- 2 ENHANCE THE INFRASTRUCTURE** for providing nutrition and physical activity technical assistance to schools.
- 3 ENCOURAGE THE IMPLEMENTATION** of school wellness policies through a recognition program for schools with model policies and practices.
- 4 ASSESS AND ADDRESS BARRIERS** to implementation of nutrition and physical activity policies in schools.
- 5 PROMOTE MAXIMUM IMPLEMENTATION AND UTILIZATION** of subsidized food programs such as School Breakfast and Lunch, SNAP, WIC, Child and Adult Care Food Program, At Risk Afterschool Meals Program, and Summer Food Service Program.

## OBJECTIVE 5

By 2015, create policies that promote access to healthy food and opportunities for physical activity in 75% of Maryland jurisdictions.

### STRATEGIES

- 1 RECRUIT LOCAL CIVIC LEVEL LEADERS** to complete assessments of current policies that promote community health in order to measure and track progress on Objective 5.
- 2 IMPLEMENT PROGRAMS** to promote access to healthy foods for high-risk communities (ie: virtual supermarkets, healthy corner stores, and use of Electronic Benefits Transfer for WIC, SNAP participants at farmers' markets).
- 3 IMPLEMENT PROGRAMS** to promote opportunities for physical activity in high-risk communities with county park and recreation programs.

- 4 DEVELOP MODELS AND GUIDELINES** for built environment policies that promote nutrition and physical activity through PlanMaryland, the state's comprehensive plan for growth and development.
- 5 ESTABLISH A MECHANISM** to provide nutrition and physical activity technical assistance to local jurisdictions to draft and implement these policies.
- 6 ENCOURAGE LOCAL GOVERNMENT** and community-based nutrition and physical activity promotion through a recognition program for local governments and community organizations with model policies and practices.

## OBJECTIVE 6

By 2015, implement a communications strategy to encourage Marylanders to be aware of their weight status and steps they can take to achieve a healthy weight.

### STRATEGIES

- 1 CROSS-PROMOTE CANCER PREVENTION** and healthy eating, physical activity, and healthy weight messages from public health service providers and community health partnerships.
- 2 EXPLORE A METHOD TO COLLABORATE WITH MARYLAND INSURANCE COMPANIES** and the Maryland Insurance Commission to improve/increase provider reimbursement rates for providing evidence-based prevention, assessment, and treatment for children and adults who are overweight and obese.
- 3 IMPLEMENT A SOCIAL MARKETING CAMPAIGN** targeting at-risk Marylanders to empower them to take advantage of the policies and programs being implemented throughout Maryland and in local communities that make it easier to make healthier choices.

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# 7 · Ultraviolet Radiation and Skin Cancer



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# 7

## ULTRAVIOLET RADIATION AND SKIN CANCER

Skin cancer is the most commonly diagnosed cancer in the United States, affecting more than 1 million Americans annually and accounting for about 2% of all cancer deaths.<sup>1</sup> There are three major types of skin cancer: basal cell carcinoma, squamous cell carcinoma, and malignant melanoma.

### TERMS TO KNOW

There are three major types of skin cancer.

#### **BASAL CELL CARCINOMA**

Usually develops on sun-exposed areas of the body, especially the head and neck.

#### **SQUAMOUS CELL CARCINOMA**

Commonly appears on sun-exposed parts of the body such as the face, ear, neck, lip and back of the hands.

#### **MELANOMA**

Develops in the cells of the skin that give it color (melanocytes).

**BASAL CELL CARCINOMA** usually develops on sun-exposed areas of the body, especially the head and neck. Squamous cell carcinoma also commonly appears on sun-exposed parts of the body such as the face, ear, neck, lip, and back of the hands, although it can also appear in the genital area.

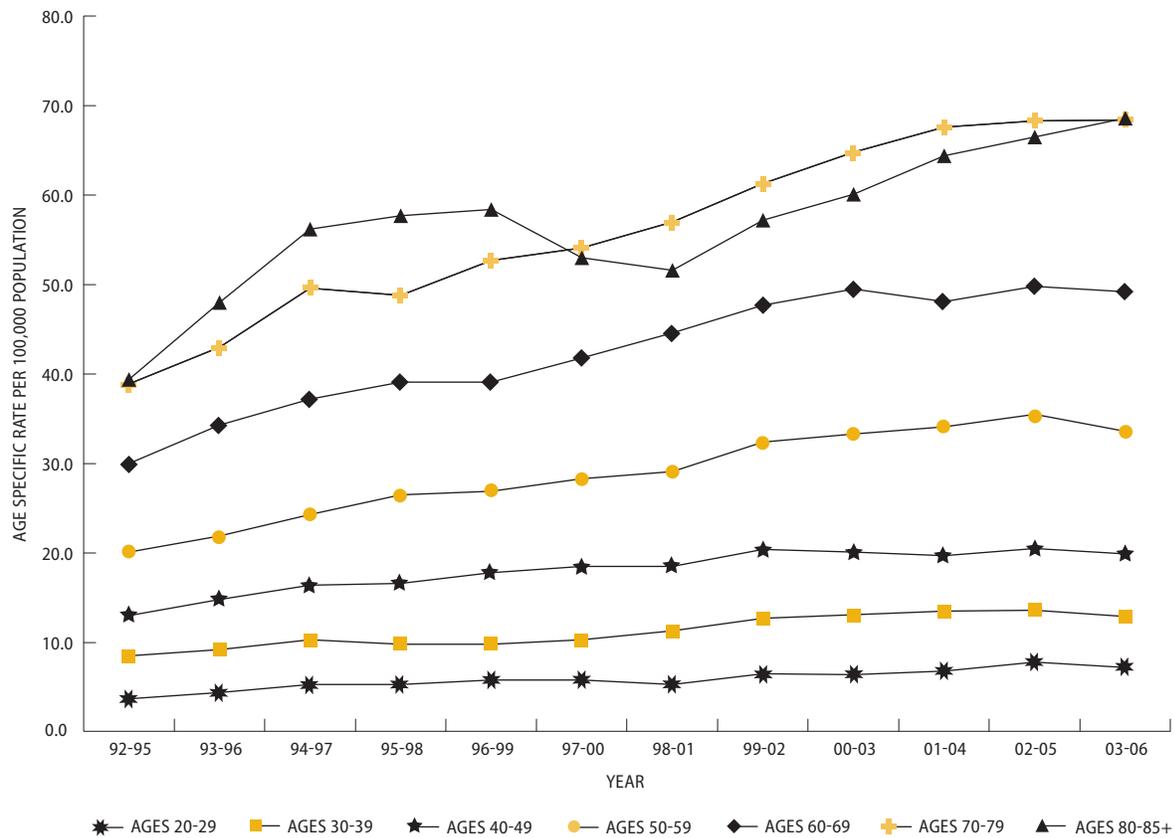
Current estimates are that one in five Americans will develop skin cancer during the course of a lifetime.<sup>2</sup> Basal cell carcinoma makes up 75% of all skin cancers, and squamous cell carcinoma accounts for another 20%. Both basal and squamous cell carcinoma have high cure rates if treated early but can cause considerable disfigurement and occasionally death if treatment is delayed. Melanoma, while only accounting for 5% of all skin cancer, is the most deadly form of skin cancer and is responsible for 75% of all deaths from skin cancer. Melanoma develops in the cells of the skin that give it color (melanocytes) and is associated with high mortality if not diagnosed and treated at an early stage.

Medical professionals agree that exposure to the sun's ultraviolet rays appears to be the most important factor in the development of skin cancer. Ultraviolet radiation (UVR) is commonly divided into three bands: UVA, UVB, and UVC. UVC is completely absorbed in the stratosphere before reaching the earth's surface. The rays of UVB are shorter and are the primary cause of tanning and sunburn. The longer rays of UVA penetrate the skin more

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FIGURE 7.1

Melanoma Age-Specific Incidence Rates, Maryland, 1992-2006



Source: Maryland Cancer Registry, 1992-2006.

deeply and contribute to wrinkling of the skin as well as tanning. Besides sunburn, skin cancer, and wrinkling, other negative effects of UVR include cataracts, macular degeneration, and immune system depression.<sup>3</sup>

## Risk Factors

Risk factors for nonmelanoma and melanoma cancers are not the same; each is described below.<sup>4</sup>

### Nonmelanoma skin cancer

- Being exposed to natural sunlight (ultraviolet radiation or UVR) or artificial sunlight (such as from tanning beds) over long periods of time.
- Having a fair complexion, which includes the following:
  - Fair skin that freckles and burns easily, does not tan, or tans poorly.

- Blue or green or other light-colored eyes.
- Red or blond hair.
- Having actinic keratosis.
- Having past treatment with radiation.
- Having a weakened immune system.
- Being male.

### Melanoma skin cancer

- Having a fair complexion, which includes the following:
  - Fair skin that freckles and burns easily, does not tan, or tans poorly.
  - Blue or green or other light-colored eyes.
  - Red or blond hair.
- Being exposed to natural sunlight or artificial sunlight (such as from tanning beds) over long periods of time.
- Having a history of many blistering sunburns as a child.
- Having several large or many small moles.

- Having a family history of unusual moles (atypical nevus syndrome).
- Having a family or personal history of melanoma.
- Being white and male.

**IN ADDITION**, skin cancer is the most common cancer in solid organ transplant patients (especially transplants that require more immune suppression such as kidney and heart).<sup>5</sup>

## Burden of Skin Cancer in Maryland

### Melanoma

The incidence and mortality of melanoma skin cancer has been increasing in Maryland over the last ten years. In certain years Maryland’s melanoma incidence rates have exceeded the national rate. Figure 7.1 demonstrates how the incidence rates have continued to climb over the past decade and how each increasing decade of life is associated with an increased risk of skin cancer.

Maryland has a unique challenge: more than 50% of Maryland counties exceed the national melanoma incidence rate for the time period 2002-2006 by 25% or more (Figure 7.2). Some of these counties surround the Chesapeake Bay and are known to have economies based on farming, fishing, and tourism, which can be associated with prolonged sun exposure. The Eastern Shore (representing the eastern Maryland peninsula of the Chesapeake Bay) has high rates of melanoma mortality (Figure 7.3) even in areas with lower rates of melanoma incidence (for example, Dorchester and Somerset Counties).

### Nonmelanoma

**PER RECOMMENDATIONS** from the National Program of Cancer Registries, cancer registries in the US collect data on new cases of malignant melanoma and some cases of nonmelanoma carcinomas. However, these registries do not collect basal and squamous cell carcinomas. Nonmelanoma skin cancer comprises 95% of skin cancers; therefore, they pose a healthcare problem in the state of Maryland.<sup>6</sup>

Mortality from nonmelanoma skin cancer is mostly from Merkel cell and squamous cell

carcinoma. Advanced disease is often associated with high morbidity in the instance of nonmelanoma skin cancer because the vast majority of cases occur on sun-exposed sites such as the head, neck, and hands such that surgery and postoperative radiation may produce severe morbidity with often permanent debilitation.

Maryland has several major hospitals that perform solid organ transplantation. These transplant patient populations are known to have an increased incidence of aggressive squamous cell cancers. The incidence of nonmelanoma skin cancers increases over time of immunosuppression and is the most common cancer in transplant patients. Skin cancers in these patients have more accelerated growth, recur locally, and more rapidly become metastatic.<sup>7</sup>

## Disparities

- Many counties in Maryland have incidence and mortality rates greater than 25% above the US rate (Figure 7.2, Figure 7.5). These heightened rates may be attributed to Maryland’s diverse geography, ranging from coastlines to mountains, which allows residents to partake in a wide variety of outdoor activities and sun-exposure-based occupations.
- The melanoma mortality rate for Maryland males is more than twice as high as for females. In 2006, the male mortality rate was 4.8 per 100,000 population compared with 1.8 per 100,000 for females (Table 7.1).
- Maryland continues to have a lower percentage of melanoma cases diagnosed at the local stage relative to US data. In 2006, 84.3% of all melanoma cancer cases in the US were diagnosed at the local stage.<sup>8</sup> In contrast, only 59.1% of melanoma cases in Maryland were diagnosed at the local stage. This disparity may be partially due to the large number of Maryland melanoma cases that remain unstaged at diagnosis, which measured 27.5% in 2006, an improvement from 38.9% unstaged in 2002.<sup>9</sup>
- Blacks or African Americans have lower five-year survival rates than whites after diagnosis of melanoma (US data only). For 1999-2006, five-year survival rates by race and gender were: 89.0% for white men, 93.7% for white women, 70.0% for black or African

FIGURE 7.2

Maryland Melanoma Incidence Rates by Geographical Area:  
Comparison to US Rate, 2002-2006

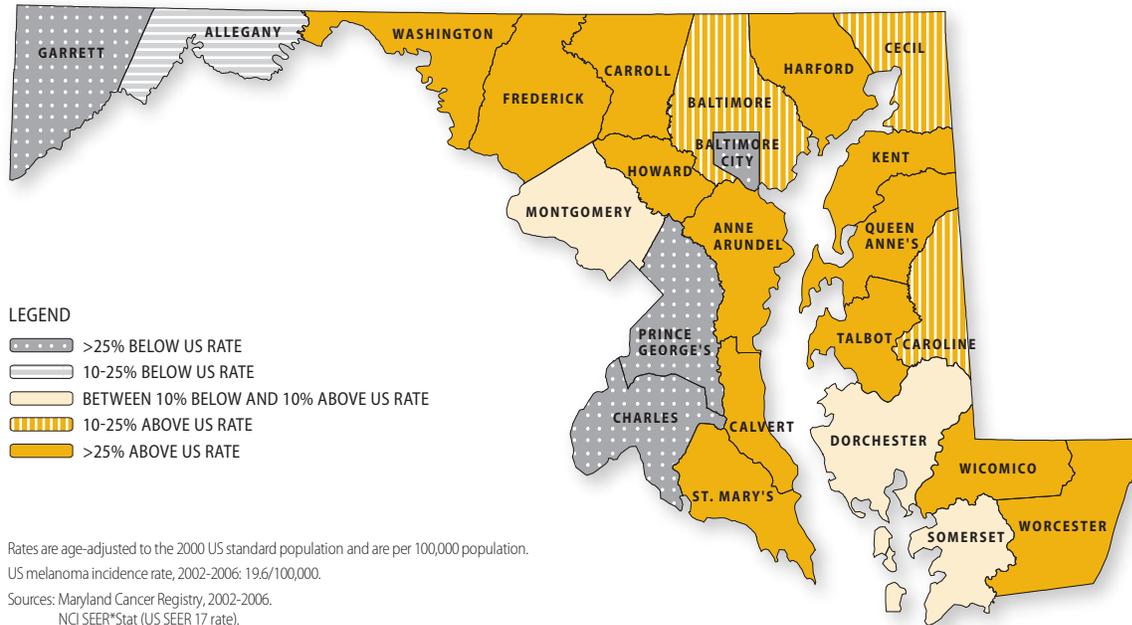
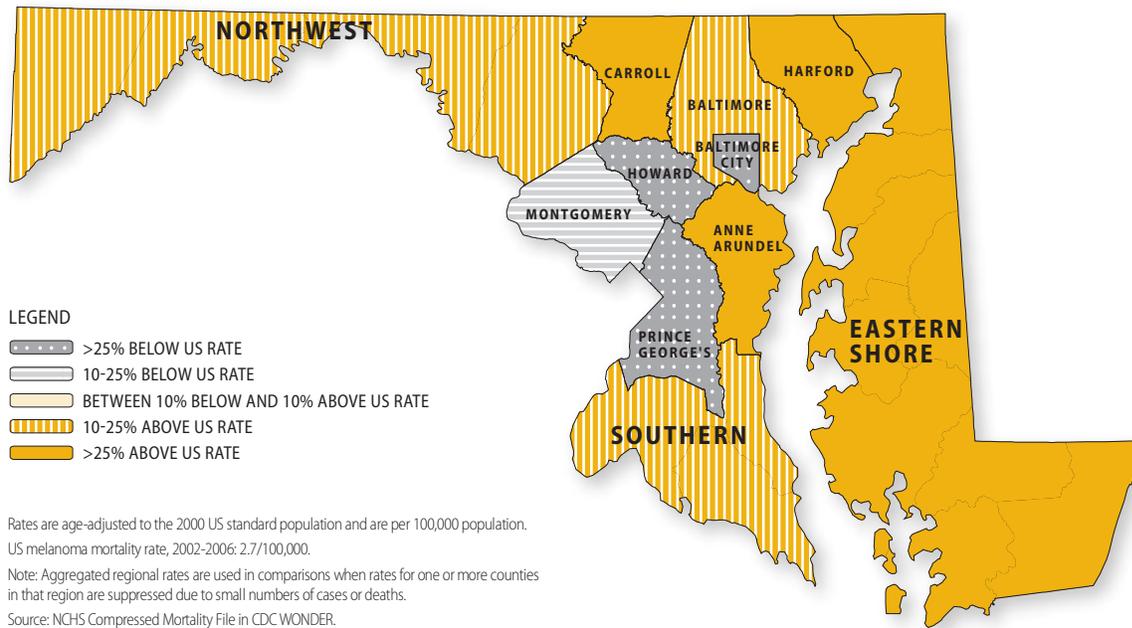


FIGURE 7.3

Maryland Melanoma Mortality Rates by Geographical Area:  
Comparison to US Rate, 2002-2006



**TABLE 7.1**

**Melanoma Incidence and Mortality Rates by Gender and Race, Maryland and the US, 2006**

	TOTAL	MALES	FEMALES	WHITES	BLACKS	OTHER
<b>INCIDENCE 2006</b>						
MD New Cases (count)	1,137	661	473	1,069	15	11
MD Incidence Rate	19.7	26.0	15.3	26.7	**	**
US SEER Rate	19.8	25.2	16.0	23.1	0.9	1.6
<b>Mortality 2006</b>						
MD Deaths (count)	172	113	59	166	s	<6
MD Mortality Rate	3.0	4.8	1.8	4.0	**	**
US Mortality Rate	2.7	4.1	1.7	3.1	0.4	0.5

Incidence and mortality rates are per 100,000 and are age-adjusted to 2000 US standard population. Total includes cases reported as transsexual, hermaphrodite, unknown gender, and unknown race. \*\* MD incidence rates based on case counts of 1-15 are suppressed per DHMH/MCR Data Use Policy; MD mortality rates based on death counts of 0-15 are suppressed per DHMH/CCSC Mortality Data Suppression Policy. <6 = MD death counts of 0-5 are suppressed per DHMH/CCSC Mortality Data Suppression Policy. s = Counts are suppressed in CRF Cancer Report tables to prevent disclosure of data in other cell(s). Sources: Maryland Cancer Registry, 2004-2006. NCI SEER\*Stat. (US SEER 17 rates) NCHS Compressed Mortality File in CDC WONDER.

American men, and 77.9% for black or African American women. The overall five-year survival rate was 91.4%.<sup>10</sup>

## Prevalence of Sun-Safe Behaviors in Maryland

Statistics regarding sun-safe behaviors among Marylanders are from the Maryland Behavioral Risk Factor Surveillance System (BRFSS).

**I**n 2006, 67% of adults age 18 years or older and 70% of those age 40 years or older used at least one of the following measures to protect themselves from UVR: avoiding the sun between 10:00 a.m. and 4:00 p.m., wearing sun-protective clothing, or wearing sunscreen with a sun-protective factor of 15 or higher (Figure 7.4). These numbers are increased from 59% of adults 18 or older and 61% age 40 or older who reported using one or more protective measures in 1998, which may reflect the success of continued state-wide educational efforts emphasizing the importance of sun safety.

However, in 2006 39% of adults stated that they never use sunscreen with an SPF of 15 or higher when outdoors for an hour or more, and in 2005 29% of adults reported having a sunburn within the previous 12 months. In addition, in 2006

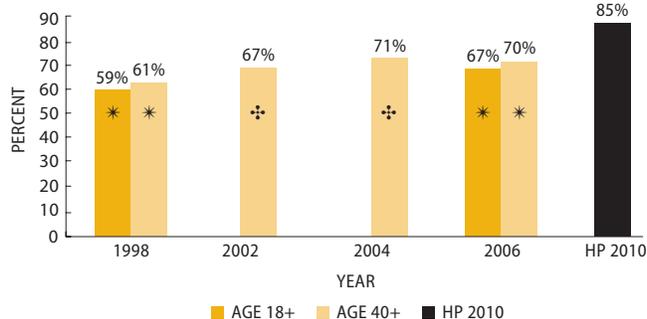
68% of adults reported always or nearly always taking measures to protect their child’s skin from UVR when the child (under age 13) is outdoors on a sunny day for an hour or more, which represents only a slight increase from 65% in 1998. These factors illustrate that there is still considerable room for improvement in sun-safe practices by Maryland adults.<sup>11</sup>

## Primary Prevention

- Both the American Academy of Dermatology and the American Cancer Society strongly recommend sun avoidance and sun protection as forms of primary prevention of skin cancer.
- Sun-protective measures include avoiding midday sun between the hours of 10:00 a.m. and 4:00 p.m., wearing protective clothing, and applying sunscreen within an SPF of 15 or higher.
- Studies have shown that broad-spectrum sunscreen use prevents the occurrence of both squamous cell carcinoma and their precursors, called actinic keratoses.<sup>12,13</sup>
- While there is no evidence that sunscreen use prevents melanoma or basal cell carcinoma, studies looking at this were based on sunscreens that primarily blocked Ultraviolet B (UVB). Future reports will need to be conducted to

FIGURE 7.4

Percentage of Maryland Adults Using Sun-Exposure Protection\* by Age Group, Compared to Healthy People 2010 Target 1998-2006



\* Sun-exposure protection means percentage of adults who report “always” or “nearly always” using one or more of the following measures: a) avoid sun between 10:00 a.m. and 4:00 p.m.; b) wear sun-protective clothing when exposed to sunlight; c) use sunscreen with a sun-protective factor of 15 or higher; and d) wear a hat when outdoors. The BRFSS and MCS do not include questions regarding frequency of exposure to artificial sources of ultraviolet light.

Sources: \* Maryland BRFSS, 1998, 2006.  
 † Maryland Cancer Survey, 2002, 2004.  
 ‡ Healthy People 2010 Midcourse Review, US Department of Health and Human Services, 2006.

assess the efficacy of broader-spectrum agents that protect against both Ultraviolet A (UVA) and UVB.<sup>14,15</sup>

- Primary prevention also includes avoiding artificial sources of ultraviolet radiation produced by tanning beds. Numerous studies support that indoor tanning is a risk factor for both squamous and basal cell carcinoma, and, more recently, melanoma.<sup>16, 17, 18</sup>
- While vitamin D is considered necessary for the development and maintenance of strong healthy bones, the National Council on Skin Cancer Prevention does not recommend intentional exposure to natural or artificial ultraviolet radiation as a way of obtaining vitamin D. Instead, individuals with limited sun exposure can meet their daily vitamin D requirements by supplementing their diet with vitamin D-fortified foods and/or supplements.<sup>19</sup>

**FAST FACT**

Numerous studies support that indoor tanning is a risk factor for both squamous and basal cell carcinoma and, more recently, melanoma.

**Education**

Education efforts are vital for the prevention of skin cancer among Marylanders. Education directed toward the general public should emphasize the importance of the primary prevention measures discussed above.

**I**N ADDITION, advice regarding sunscreen should include; (1) use sunscreen with SPF 15 or higher; (2) apply it 20 minutes prior to exposure; (3) use 1 ounce of sunscreen per application; and (4) reapply sunscreen every two hours or after swimming or excessive sweating.

Several population groups warrant special consideration for educational efforts, including those in occupations requiring outdoor exposure, children and adolescents, school educators, professionals who routinely see the skin of their clients (barbers, hairdressers, cosmetologists, massage therapists, etc.), and solid organ transplant recipients or those who are immune-suppressed.

Currently, Maryland has no licensing requirement for barbers, hairdressers, or cosmetologists to have knowledge of or skills in early detection of skin cancer. This presents an educational opportunity because individuals employed in those professions have direct access to their clients’ skin.

Healthcare provider education in and awareness of skin cancer detection is a key factor in patient survival. Many physicians do not receive sufficient education on skin cancer screening to feel competent in this area. A survey conducted at the Boston University School of Medicine found that 52% of fourth-year students rated

## DID YOU KNOW?

In 2008, a Maryland statewide tanning bed law was passed that required on-site parental consent for minors. Howard County subsequently passed a law in 2009 banning all minors from indoor tanning, becoming the first jurisdiction in the country to do so.

themselves as unskilled in skin cancer examinations.<sup>20</sup> This deficit of skin cancer knowledge was also apparent in a survey of family practitioners; more than 50% of those surveyed stated that they lacked the confidence to recognize melanoma.<sup>21</sup>

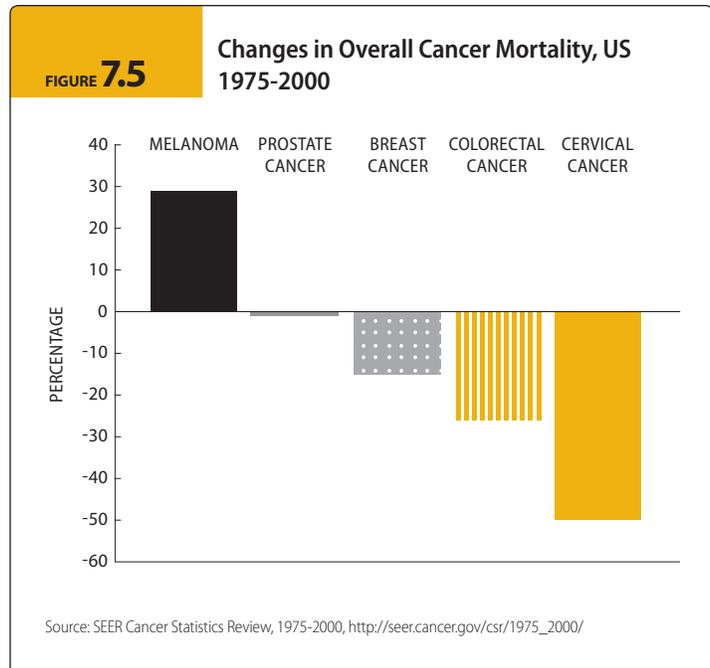
Educational interventions and curriculum enhancement for providers can be effective.<sup>22</sup> While the mortality rates of some cancers over the period 1975-2000 have decreased, the melanoma mortality rates increased during that time period (Figure 7.5). For this reason, it is imperative to provide public and provider education in the early detection of skin cancer, including melanoma.

## Public Policy

**The development of state and national legislation supporting sun-safe behavior plays an important role in enforcing primary prevention recommendations and preventing skin cancer.**

**T**HE MARYLAND SKIN CANCER PREVENTION PROGRAM has been instrumental in influencing policy change by promoting skin cancer awareness among the public, physicians, and school educators as summarized within the Current Efforts section of this chapter.

The Maryland State Department of Education has also played a vital part through its development of numerous guidelines and policies designed to protect students and staff from sun overexposure. One of these policies was supported by a 2006 Maryland law allowing students to carry sunscreen products while in school. However, additional state policy changes may be needed to further encourage sun-safety practices among Maryland schoolchildren, including the integra-



tion of skin cancer prevention education within the curriculum and funding for the building of shaded structures on school property.

Another important area of public policy focuses on regulation of the indoor tanning industry. In 2008, a Maryland statewide tanning bed law was passed that required on-site parental consent for minors. Howard County subsequently passed a law in 2009 banning all minors from indoor tanning, becoming the first jurisdiction in the country to do so.<sup>23</sup> With these new laws Maryland joins at least 31 other states that have enacted legislation addressing youth access to tanning facilities.<sup>24</sup> However, research has shown that many states do not adequately enforce these laws, with low rates of annual inspections and citations for violations.<sup>25</sup> Although progress has been made, additional legislation may be needed to further restrict Maryland minors from indoor tanning businesses and to ensure these policies are enforced.

Policy and implementation efforts in Maryland can be modeled on those in Australia, which is known for implementing some of the most extensive, long-term, and successful skin cancer prevention programs addressing a high incidence of both melanoma and non-melanoma skin cancer.<sup>26</sup> These programs began in 1980 when the Anti-Cancer Council of Victoria developed the Slip! Slop! Slap! Campaign and continued in

1988 when the Victorian Health Promotion Foundation launched SunSmart, a broad-based prevention program focusing on public education in sun-safety behaviors and environmental change in various settings.<sup>27</sup> Recent studies have indicated that basal cell carcinoma, squamous cell carcinoma, and melanoma incidence rates in Australia have begun to stabilize among younger populations, which may reflect the success of these sun-protection behavior efforts over the past 30 years.<sup>28,29</sup> Australia's Cancer Council, together with other organizations, works to continue the favorable trend in skin cancer rates seen in these younger groups.<sup>30</sup>

## Screening Recommendations of Professional Groups

**Prominent professional and governmental groups have developed guidelines for skin cancer screening, but there is a lack of consensus among these groups. There is no clear direction or guidance for healthcare professionals and the public.**

**A** SUMMARY OF THESE RECOMMENDATIONS can be found on the Skin Cancer page of the Maryland Cancer Plan Web site ([www.marylandcancer-plan.org](http://www.marylandcancer-plan.org)). In the absence of research-based evidence for skin cancer screening, however, there is anecdotal data to support the need for skin cancer screening by all primary care providers.

Despite a lack of consensus among groups that issue screening guidelines, the Skin Cancer Committee encourages healthcare providers, especially primary care providers, to perform routine skin exams and to educate patients on skin self exams. The early detection of skin cancer at a local stage and precancerous skin conditions enables less invasive treatment options.

## Dermatologist Availability

**A shortage of dermatologists exists within the United States, with an estimated total of only 10,600 physicians (or 3.6 per 100,000 population).<sup>31</sup>**

**T**HIS HAS TRANSLATED into wait times exceeding one month for new patient appointments, and has resulted in the hiring of physician assistants and nurse practitioners within clinics to aid with the increasing demand for dermatologic services. Despite the continued demand, there has been a lack of significant change in the number of dermatology residency training positions during the past three decades.<sup>32</sup> Telemedicine has been used to supplement the low availability of dermatologists within rural and underserved areas.

## Treatment

**Once a diagnosis of skin cancer is rendered, the following should be done:**

- Appropriate staging is recommended for any cancer. Patients and physicians are referred to the 7th edition 2009 AJCC (American Joint Committee on Cancer) and UICC (Union International Contra Cancer) cancer staging manuals.

- In the United States, the NCCN (National Cancer Center Network) produces annual guidelines for treatment. On the [www.nccn.org](http://www.nccn.org) Web site, there are physician and patient guidelines.

## Current/Ongoing Efforts in Maryland

Several organizations are involved in educating the public and providing skin cancer prevention and sun-safe behavior programs in Maryland.

### The Maryland Skin Cancer Prevention Program

The Maryland Skin Cancer Prevention Program was established in 1997 by the Centers for Disease Control and Prevention and funded 2001-2009 by the Maryland Department of Health and Mental Hygiene. Program activities are carried out through a statewide coalition consisting of more than 90 members representing 65 public and private organizations as well as dedicated individuals. Messages are disseminated to the general public and providers through many vehicles including television/radio/print media, Web sites (<http://www.sunguardman.org>), poster contests, community events, provider outreach through the state medical society, museum exhibits, the SunGuard Your Skin elementary/middle school curriculum, and the SunGuardMan Mascot. Some of these activities are described in greater detail in the “Progress Report on the 2004-2008 Maryland Comprehensive Cancer Control Plan,” which can be found at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

### American Cancer Society

The American Cancer Society (ACS) is involved in providing public education on all aspects of the early detection and prevention of cancer. In addition to providing educational programs and materials to local communities, ACS is engaged in advocacy efforts that may ultimately lead to a decline in the incidence of skin cancer by reducing the exposure of young people to the harmful effects of tanning beds.

### Environmental Protection Agency

The US Environmental Protection Agency has an educational program that targets children in grades K-8. The SunWise Program is an award-winning national environmental and health education program that teaches children and their caregivers how to protect themselves from overexposure to the sun. Organizations that work with children, including schools, camps, museums, and health departments, register online ([www.epa.gov/sunwise](http://www.epa.gov/sunwise)) to receive a free SunWise Tool Kit with more than 50 standards-based, cross-curricular classroom activities for grades K-8; an ultraviolet (UV) sensitive Frisbee for hands-on experiments and fun; story and activity books; posters; a video; policy guidance; and more. As of February 2010, more than 34,000 educators at 28,000 US schools, camps, etc. have registered for SunWise, including more than 1,000 educators representing every jurisdiction in Maryland.

Many other national and governmental organizations promote and support skin cancer awareness and sun-safety education, such as the American Academy of Dermatology, the National Cancer Institute, the National Institutes of Health, and the Ulman Cancer Fund for Young Adults.

## GOALS - OBJECTIVES - STRATEGIES

### GOAL 1

Increase awareness of skin safe behaviors.

#### OBJECTIVE 1

By 2015, increase the proportion of Maryland adults who

- Can name two sources and two dangers of UV radiation.
- Can name three sun-safe behaviors.
- Are aware of early detection options for skin cancer.

#### STRATEGIES

- 1 **CONTINUE TO USE MEDIA OUTLETS** such as Web sites; print, radio, and television PSAs; billboards; and press releases to provide messages on sun-safe behaviors, the dangers of ultraviolet radiation, and early detection.
- 2 **PROMOTE SKIN CANCER PREVENTION AND DETECTION EDUCATION** through community events, health fairs, and continued partnerships with medical, outdoor occupational, and beauty industry members.
- 3 **PROMOTE MULTIDISCIPLINARY AND CONSISTENT AWARENESS** messages when addressing issues of vitamin D, sunscreen use, and nutrition and physical activity recommendations.
- 4 **DEVELOP METHODS** for obtaining baseline measurements and monitoring progress on Objective 1, for example:
  - Promote inclusion of questions on awareness of sun-safe behaviors in the Maryland BRFSS.
  - Create/implement a survey to measure awareness of sun-safe behaviors among Maryland adults.

#### OBJECTIVE 2

By 2015, increase skin cancer prevention and detection education for Maryland healthcare providers and beauty industry providers.

#### STRATEGIES

- 1 **COLLABORATE WITH MARYLAND MEDICAL AND BEAUTY INDUSTRY** providers to offer CMEs or other types of training in skin cancer recognition and education of patients on skin cancer prevention and detection.
- 2 **DISCUSS/PRESENT INFORMATION** on skin cancer prevention and detection at dermatological and other medical and nursing association conferences.
- 3 **FORM PARTNERSHIPS** with researchers to increase the number of written publications on skin cancer prevention and detection.
- 4 **DEVELOP METHODS** to obtain baseline measurement and monitor progress on Objective 2. For example, conduct a statewide assessment of educational opportunities available to and participated in by healthcare providers.

#### OBJECTIVE 3

By 2015, increase the proportion of childcare facilities, schools, and youth-focused organizations that provide education on skin safety to Maryland children and adolescents.

#### STRATEGIES

- 1 **PROMOTE/INTEGRATE THE USE** of sun safety educational curricula in elementary and middle schools through Web sites, mass media, and community events.
- 2 **EDUCATE CHILDCARE PROVIDERS** on sun-safe behaviors and the dangers of ultraviolet radiation for children and adolescents through in-person trainings, Web sites, mass media, and community events.
- 3 **FORM PARTNERSHIPS** with youth service, recreation, and sports organizations such as Girl Scouts, 4H, Little League, swimming leagues, etc. to provide opportunities for education on skin cancer prevention.
- 4 **CREATE/IMPLEMENT SURVEYS** of childcare facilities, schools, and youth-focused organizations regarding their use of educational curricula on sun safety.

# GOALS - OBJECTIVES - STRATEGIES

## GOAL 2

Increase the utilization of skin safe behaviors.

### OBJECTIVE 1

By 2015:

- Increase the percentage of Maryland adults to 44% who always or nearly always do at least two of the following (2006 Baseline: 36%):
    - Limit sun exposure between 10:00 a.m. and 4:00 p.m.
    - Use sunscreen with SPF of 15 or higher when outdoors for an hour or more on a sunny day.
    - Wear a hat with a broad brim when outdoors for an hour or more on a sunny day.
    - Wear sun-protective clothing when outdoors for an hour or more on a sunny day.
- Source: Maryland BRFS.

- Increase the percentage of Maryland children (under age 13) who always or nearly always use sun-protection measures (including sunscreen and protective clothing) to 73% (2006 Baseline: 68%).
- Source: Maryland BRFS.

### STRATEGIES

- 1 **ENCOURAGE FUNDING** for the building of covered structures and implementing signage at public beaches and parks reminding people to wear sunscreen.
- 2 **DEVELOP PROGRAMS** encouraging sun-safe behaviors for outdoor workers.
- 3 **DECREASE THE USE OF TANNING BEDS** while promoting alternate, safe sunless tanning options.
- 4 **INCREASE THE USE OF SUN-PROTECTIVE METHODS** for outdoor activities.
- 5 **REQUEST THE ADDITION OF QUESTIONS** on the Maryland Behavioral Risk Factor Surveillance Survey regarding avoiding artificial UVR, and on the Maryland Youth Risk Behavior Surveillance System regarding the use of sun-safe behaviors (as listed in Objective 1) along with avoiding artificial UVR.

### OBJECTIVE 2

By 2015, decrease the percentage of Maryland minors who use artificial sources of ultraviolet light (i.e., tanning beds).

### STRATEGIES

- 1 **INCREASE AWARENESS** of the Maryland law regarding parental consent for minors' use of tanning beds.
- 2 **ENSURE CONTINUED DISSEMINATION** of the DHMH Parental Consent Form for minors to use tanning booths.
- 3 **MODEL LEGISLATION** in Maryland based on the Howard County policy that prohibits minors from using tanning beds.
- 4 **REQUEST THE ADDITION OF QUESTIONS** on the Maryland Behavioral Risk Factor Surveillance Survey and the Maryland Youth Risk Behavior Surveillance Survey regarding tanning bed use by minors.

### OBJECTIVE 3

By 2015, improve the early detection of skin cancer by increasing the percentage of melanoma cancers in Maryland diagnosed at the local stage to 74.1% (2006 Baseline: 59.1%).

Source: Maryland Cancer Registry.

### STRATEGIES

- 1 **DECREASE THE NUMBER** of unstaged melanoma cases reported in the Maryland Cancer Registry in order to obtain more accurate data of melanoma stage at diagnosis.
- 2 **ENCOURAGE RESEARCH** on skin cancer detection, stage, mortality, and morbidity.

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# 8. Environmental/ Occupational Issues and Cancer



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# 8

## ENVIRONMENTAL/ OCCUPATIONAL ISSUES AND CANCER

This chapter addresses the complex relationship between cancer and environmental and occupational factors.

The chapter’s goals are to:

- Describe the current state of knowledge regarding environmental and occupational hazards and cancer, especially related to these factors in Maryland.
- Describe specific environmental and occupational hazards that may be related to cancer, stressing ways in which exposures can be decreased or eliminated.
- Talk about the role of cancer surveillance in helping us understand these questions, especially when investigating possible cancer clusters.
- Address research needs that would specifically contribute to either improved understanding or improved management/prevention of cancer related to environmental and occupational factors.

### Environmental Factors

The Maryland Comprehensive Cancer Control Plan takes a specific view of “environmental factors.” The term “environmental factor” in this chapter specifically refers to chemicals, physical agents such as radiation (including ultraviolet radiation), and other non-biological agents that could potentially be reduced or eliminated. Also, while most attention to environmental and occupational hazards has usually been on those that cause (initiate) cancer, the focus in this chapter is more comprehensive. Some hazards included in this chapter may not necessarily cause cancer, but may instead promote cancer (that is, make it easier for a cancer to grow). This chapter, however, does not include viruses or other biological agents linked to cancer, which may be covered in specific disease chapters (for example, human papilloma virus is covered in Chapter 15 on Cervical Cancer). Finally, tobacco smoke, which is the most important environmental factor in cancer, is briefly addressed here in the section on indoor air, but is addressed primarily in Chapter 5: Tobacco-Use Prevention/Cessation and Lung Cancer.

**WHAT IS THE “RISK” OF CANCER?**

There is often confusion about terms like the “risk” of cancer, “risk analysis,” and “risk assessment.” When we speak of “risk” in this chapter, we mean the probability (not certainty) of developing a case of cancer. A “risk” of 1 in a million means the probability that there would be one extra case of cancer in a million people. Risk assessment is a formal process for estimating risk, using mathematical models.

Why use risk assessment? It is not possible to completely eliminate exposures to potential environmental carcinogens; therefore, we assess the risk of exposures and use “acceptable levels of cancer risk” to set environmental standards. These cancer risk levels estimate how many cases of cancer attributable to a hazard would be expected to occur in a population of a given size. For example, a cancer risk level for a chemical in drinking water of 1 in 100,000 means that, for every 100,000 people exposed, one extra case of cancer would be expected to occur because of exposure to the contaminant in drinking water in a given period of time (usually either over a lifetime or per year).

**Occupational Factors**

This chapter also discusses workplace or occupational factors and cancer. Workers exposed to chemicals are often exposed to higher concentrations than are found outside the workplace, and there are different regulations and different regulatory agencies involved in controlling occupational exposures. However, the line between occupational and environmental exposures may be blurred. For example, there are so-called “para-occupational” exposures, in which the hazard is brought out of the workplace (typically by the worker without his or her knowledge) and into the home. One example of this is when asbestos workers unknowingly brought asbestos into the home. In this chapter, we recognize that the difference between the workplace and other environments is somewhat artificial, and when considering the cumulative exposure of an individual one should consider all possible sources of exposure.

**Environmental and Occupational Factors of Concern to Marylanders**

Some clues to which environmental and occupational factors are of concern to Marylanders come from questions that have come to the Department of Health and Mental Hygiene or local health departments over the years; some clues come from the kinds of industries in Maryland today or in the past. Types of chemicals considered range from asbestos (used in steelmaking, shipbuilding, and insulation), to naturally occurring radioactivity in drinking water, organic solvents that have been found in groundwater leaching from underground storage tanks or hazardous waste sites, environmental chemicals found in consumer products, and low-level electromagnetic

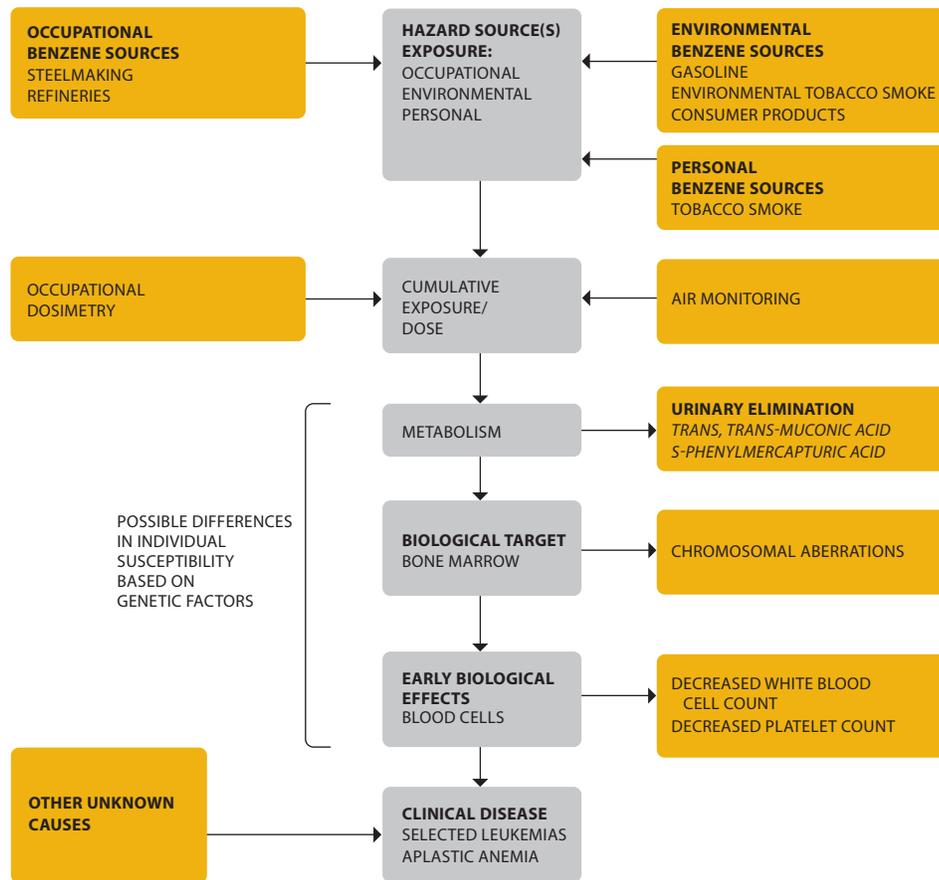
fields. While some of these represent well known causes of cancer, in other cases, the relationship between exposure and any specific type of cancer, or cancer at all, may be very much in question. This can make it very challenging—for individual patients with questions, for their healthcare providers, and for the public health community—to offer specific guidance or conclusions about the significance of specific exposures to cancer, as shown in the example of benzene in Figure 8.1.

As Figure 8.1 shows, in the case of a compound like benzene there may be more than one source of exposure, including occupational, environmental, and personal (tobacco smoke) sources. Furthermore, in most cases of aplastic anemia or certain leukemias, the cause is not exposure to benzene, but remains unknown. Typically only in the case of individuals with significant occupational exposures is there enough confidence to conclude that the cause was probably specific exposure to benzene.

Another issue related to environmental/occupational factors and cancer concerns health disparities and vulnerable populations. Most discussions of health disparities concern access to care, but in the world of environmental factors, disparities may also involve disparities in exposure. We have come to understand that while it is not always possible to “prove” that a specific cancer is linked to a specific exposure, it

FIGURE 8.1

Exposure-Dose-Effect Model for Benzene



is not uncommon for different groups (separated by race, gender, age, socioeconomic status, or occupation) to have differences in both exposures and in rates of cancer, as well as cancer outcomes. The policy questions may then be both how to reduce elevated exposure and elevated cancer rates, while not necessarily assuming that a reduction in exposure will inevitably lead to a reduction in cancer rates.

CASE STUDY

Occupation, Gender, Race, and Lung Cancer in Maryland

A recent study by Amr et al. examined possible racial and gender differences in non-small cell lung cancer rates among participants in the Maryland Lung Cancer Study in various industries. This is an example of the type of analysis, using surveillance and other data, that can be used to identify opportunities for workplace educational interventions, disparities in health status among different occupational cohorts, and, potentially, diseases associated with different occupational exposures.

Amr S, Wolpert B, Loffredo CA, Zheng YL, Shields PG, Jones R, Harris CC. Occupation, gender, race, and lung cancer. *J Occup Environ Med.* 2008 Oct;50(10):1167-75.

## Types of Hazards

### Occupational Hazards

One important determinant of risk is the occupational profile of the population. Employment patterns in Maryland have shifted over the past 30 years, changing the patterns of exposure and, probably, of disease. In past decades, Maryland's industry was a mix of manufacturing, agriculture, services, education, research, and government. The 2002 economic census showed that the largest employers in Maryland were state and local government (combined); retailing; healthcare and social assistance; and professional, scientific, and technical services.<sup>1,2</sup>

Maryland's current cancer profile is, in part, a product of past occupational exposures. For example, it typically takes two to three decades for some cancers related to asbestos exposure (found in Maryland's shipbuilding and steelmaking industries, among others) to develop. The decline of those industries as major employers, which occurred several decades ago, means that their contribution to the overall cancer rate should begin to decline as well. At the moment, however, there is no discernible decline in number of cases of mesothelioma annually (Figure 8.2). There has been improvement in the control of many occupational chemical exposures. However, there are still significant opportunities for exposures to carcinogens in many industries. This points to the need for surveillance of and research into occupa-

tional contributions to cancer, as well as the need for collection and analysis of information about both current and former employment as potential risk factors.

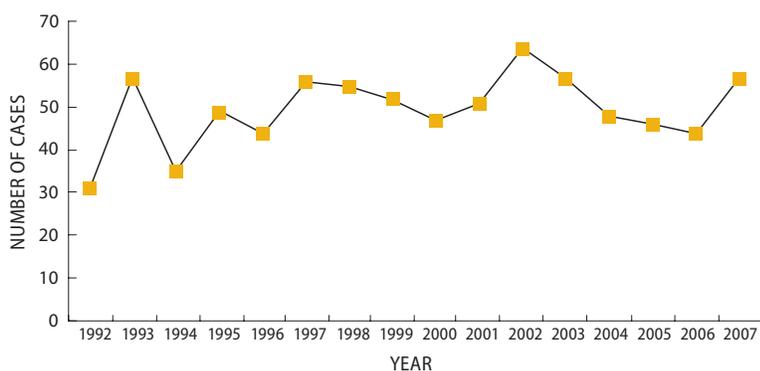
### Outdoor Air Pollution: Airborne Toxics

Air pollution is a complex mixture of chemicals, many of which are known to cause cancer. These chemicals may be present as gases, or bound to small, inhalable particles known as particulate matter (PM). Air PM is generally divided into categories based on the size of the particles. The smaller particles—"fine particulate matter," or those of 2.5 micrometers or less in diameter (PM<sub>2.5</sub>)—are the particles that can be inhaled deeper into the lungs and are generally considered the particles more likely to be related to health problems.

The relationship between exposure to airborne chemicals and cancer risk is a significant public health concern because even if the associated risk of cancer is low, the number of people exposed to air pollutants is large and people may be exposed to poor air quality for their entire lifespan. Although not all air pollutants cause cancer, 187 hazardous air pollutants (HAPs), some of which are known causes of cancer, were defined under the 1990 Clean Air Act Amendments.<sup>3</sup>

FIGURE 8.2

Mesothelioma Cases in Maryland by Year, 1992-2007



N=793

Source: SeerSat Static Data as of December 01, 2009, Maryland Cancer Registry.

### TERMS TO KNOW

#### PM

Particulate matter (PM) refers to particles that can be inhaled. The smaller particles (those of 2.5 micrometers or less in diameter [PM<sub>2.5</sub>]) can be inhaled deeper into the lungs.

#### HAPs

The 1990 Clean Air Act Amendments identified 187 hazardous air pollutants (HAPs), some of which are known to cause cancer.

### 1990 Clean Air Act Amendment Hazardous Air Pollutants (HAPs)

- The HAPs list contains 187 chemicals that are known or suspected to cause cancer or other serious health effects.
- Examples of HAPs known or suspected to cause cancer are:
  - Benzene
  - 1,3 Butadiene
  - Dioxin
  - Polycyclic Aromatic Hydrocarbons (PAHs)
  - Metals, such as cadmium (Cd), Hexavalent Chromium (Cr+6) and nickel (Ni)

Many chemicals on the HAPs list are known human carcinogens, including benzene. A primary source of benzene in ambient air is gasoline. Therefore, depending on the number of gas stations and “mobile sources” (moving gas-powered vehicles, cars, trucks, etc.) in an area, inhalation of outdoor air can be the primary exposure pathway to benzene for many people. More information on the health effects of specific hazardous air pollutants can be found at <http://www.epa.gov/airtoxics/hlthef/hapindex.html>.

Exposure to carcinogenic air toxicants is a problem nationally as well as in the state of Maryland. The Environmental Protection Agency’s 2002 National-Scale Assessment Program has estimated that:<sup>4</sup>

- More than 284 million people in the US live in areas with cancer risks greater than 10 in a million due to exposure to HAPs (this is a lifetime risk of cancer—defined by EPA as the “plausible upper limit to the true probability that an individual will contract cancer over a 70-year lifetime as a result of a given hazard”).
- More than 2 million people in the US live in areas with HAPs-associated cancer risks of greater than 100 in a million.

In Maryland, cancer risks associated with exposure to HAPs range from:<sup>5</sup>

- 1 to 25 in a million in rural areas.
- As high as 100 in a million in the Baltimore City area.

Many epidemiological studies have begun to examine the role of individual HAPs in the initiation of cancers, but have found it difficult to identify specific chemicals of greatest concern.

Results of two studies suggest that benzene is one of a number of chemicals associated with excess cancer risk.<sup>6,7</sup> Also, the strong association of PM<sub>2.5</sub> levels with excess cancer is most likely due to the many chemicals bound to the fine PM<sub>2.5</sub> particles. The fact that Baltimore does not meet EPA’s standards for PM<sub>2.5</sub> concentrations in ambient air makes this an important target for lowering Maryland’s cancer burden.

### SOURCES OF OUTDOOR AIR CARCINOGENS

Most HAPs, like other common air pollutants, are produced by mobile sources (mainly vehicles) and stationary sources (factories). Mobile sources include highway vehicles and on-road and off-road equipment that release engine exhaust or evaporative emissions. Industrial emissions have been better characterized for larger industries through information gathered as part of EPA’s Toxic Release Inventory (TRI) Program.<sup>8</sup>

On a national level, vehicle exhaust is thought to be the dominant source of most HAPs, followed by industrial emissions;<sup>9</sup> however source distributions differ for different areas depending on vehicular traffic patterns and the types of industries located within an area. Modeling results suggest that as much as 60% of ambient concentrations of benzene, 1,3-butadiene, and POM are attributable to mobile sources.<sup>10</sup>

Although EPA’s National-Scale Air Toxics Assessment (NATA) results for Maryland provide a general view of cancer risks associated with inhalation of ambient air carcinogens in our state, monitoring data for air toxics in Maryland are sparse, both in terms of the number of air toxics measured and the low number of monitoring sites present in the Eastern and Western Maryland areas. The extent to which NATA results accurately predict the concentrations of HAPs in Maryland’s ambient air is not known; nor do we know which of the industrial chemicals are the most important of the reported cancer risks. This makes it difficult to identify specific sources and develop effective control measures. In addition, the NATA data do not account for small local sources; thus, it is desirable to cross-validate NATA-modeled data with monitoring data for Maryland. Without local data, it is difficult to reliably quantify the temporal as well as spatial variability in HAPs across Maryland. For instance,

due to lower volumes of traffic in Western Maryland, non-vehicular sources of carcinogenic pollutants may be of greater relative significance in this area of the state compared to the urban Baltimore-Washington corridor.

It is also important to consider the impact of multiple chemical exposures on health. To date, both EPA's and Maryland's research and regulatory focus has been on individual pollutants, as exemplified by the National Ambient Air Quality Standards (NAAQS). However, in reality, people are exposed to many chemical pollutants simultaneously. Therefore, increased emphasis should be given to determining how chemical mixtures can be collectively regulated and their health risks quantified. In addition, the impact of other co-exposures, such as smoking and occupational exposures, needs to be taken into consideration when assessing health risks to determine how they might interact synergistically. It also remains unknown how cancer risks associated with HAPs may be modified by genetics and other conditions such as nutritional deficiencies, chronic pulmonary inflammation, and other pre-existing health problems.

### Waterborne Exposures

All Marylanders consume and use water every day. Because of this, preventing exposure to waterborne contaminants that pose a cancer risk is a significant public health issue. Water may contain contaminants from various sources. Contaminants may occur naturally, can be manmade, or may be formed when water is disinfected to make it suitable for drinking. Contaminants that were originally released into the air or soil can make their way into water. In addition, some contaminants can accumulate in fish that are consumed by Marylanders.

In order to protect Marylanders from waterborne carcinogens, water standards are developed and enforced by the Maryland Department of the Environment. Standards are used for surface waters under the Clean Water Act and for publicly supplied drinking water under the Safe Drinking Water Act. Maryland adopts drinking water standards for public water supplies that have been established by the US Environmental Protection Agency, although Maryland-specific standards could be developed if a national

standard does not exist for a given contaminant. Table 8.1 lists examples of waterborne carcinogens that are regulated in Maryland under water quality standards. It is important to recognize that the drinking-water quality standards and required periodic testing for water quality do not apply to private wells. This means that people who drink from private wells cannot be certain about the possibility of carcinogenic chemicals in their drinking water unless they test the water themselves.

TABLE 8.1

Examples of Regulated Waterborne Carcinogens

Contaminant	Category
Benzene	organic chemical
Dioxin	organic chemical
Vinyl chloride	organic chemical
Chlordane	organic chemical/pesticide
Haloacetic acids	byproduct of disinfection
Uranium	radioactive element

Consumption of fish caught in Maryland waters is another route of exposure to water contaminants that pose a cancer risk. Mercury and PCBs (polychlorinated biphenyls) are contaminants that can accumulate in fish. PCBs are suspected to cause cancer in humans. The level of mercury and PCBs in Maryland fish has prompted the Maryland Department of the Environment to issue fish consumption advisories. The advisories recommend how often certain fish from a given location can be eaten so that health risks are minimized ([www.mde.state.md.us](http://www.mde.state.md.us)).

### Foodborne Hazards

The United States possesses one of the safest and most nutritious food supplies in the world. Unlike countries in which the risk of malnutrition is high, in Maryland and the United States there is growing concern about overconsumption leading to obesity and its related health consequences. However, food as a source of exposure to carcinogens remains a concern to many. Broadly speaking, the sources of carcinogens in food may be considered to be naturally occurring (such as mycotoxins; that is, toxins from fungi) or related to human

**Examples of Foodborne Carcinogens Related to Human Activities**

- Industry: environmental dioxins entering into fish, meat, dairy products, etc.
- Agricultural practices: pesticides and feed additives.
- Food cooking methods: acrylamides and furans.
- Introduction of food additives and dyes.
- Food preservation: nitrosamines.
- Lack of food preservation: e.g., growth of fungi-producing mycotoxins.
- Chemical migration from packaging into food and water: bisphenol A.

**Federal Agency Responsibilities Regarding Foodborne Hazards**

**Environmental Protection Agency (EPA)**

- Regulation, control, mitigation of toxic substances in the environment.

**Food and Drug Administration (FDA)**

- Regulation of food and milk processing.
- Monitoring foods for contaminants including pesticide residues.

**United States Department of Agriculture (USDA)**

- Regulation of meat and meat products, shellfish, eggs, poultry, and farm-raised fish.
- Surveys of pesticide usage.

activity (See the text box “Examples of Foodborne Carcinogens Related to Human Activities”). The vast majority of chemicals found in food remain unevaluated as to their potential as carcinogens.

A number of known human and animal carcinogens have been detected in food. Technology continues to improve, allowing the detection of ever-smaller concentrations of chemicals. The biological activity of extremely low concentrations of these chemicals is not calculable with our current level of knowledge. Food is also known to have compounds and properties that reduce the risk of cancer, including such chemicals as antioxidants, flavinoids, omega-3 fatty acids, and plant fiber.

Research on the carcinogenicity of foods is often conducted using experiments involving animals, particularly rodents. Dosages for exposure (amount of chemical per unit of body weight) are often far in excess of exposures that might be reasonably encountered by humans in the course of ordinary activities. Extrapolation of animal data to humans for estimation of exposure dose and risk is difficult. Current data do not allow the estimation of cumulative risks posed by exposure to extremely low levels of multiple chemicals in food. However, these cumulative low-level risks do not appear to substantively contribute to the overall lifetime risk of cancer on a population basis.

The Food and Drug Administration (FDA) is responsible for the protection of processed foods, produce, imported foods, and milk and dairy

products. The Federal Food, Drug, and Cosmetic Act governs FDA regulatory activities. In 1958, the law was amended to prohibit any known animal or human carcinogen as a food additive (the Delaney Clause). The Food Quality Protection Act of 1996 repealed the Delaney Clause and replaced it with a strict standard regarding pesticide chemical residues in foods as discussed above. The safety standard now requires that the administrator determine “that there is a reasonable certainty that no harm will result from aggregate exposure to pesticide chemical residue, including all anticipated dietary exposures and all other exposures for which there is reliable information” (Title 4, Section 408, 21 U.S.C. 346a). In addition, this statute requires coordination between USDA, EPA, and FDA in the collection of adequate data on food consumption patterns of infants and children and provides for an additional tenfold margin of safety for exposures for infants and children. (See the text box “Federal Agency Responsibilities Regarding Foodborne Hazards”).<sup>11</sup>

**Physical Agents**

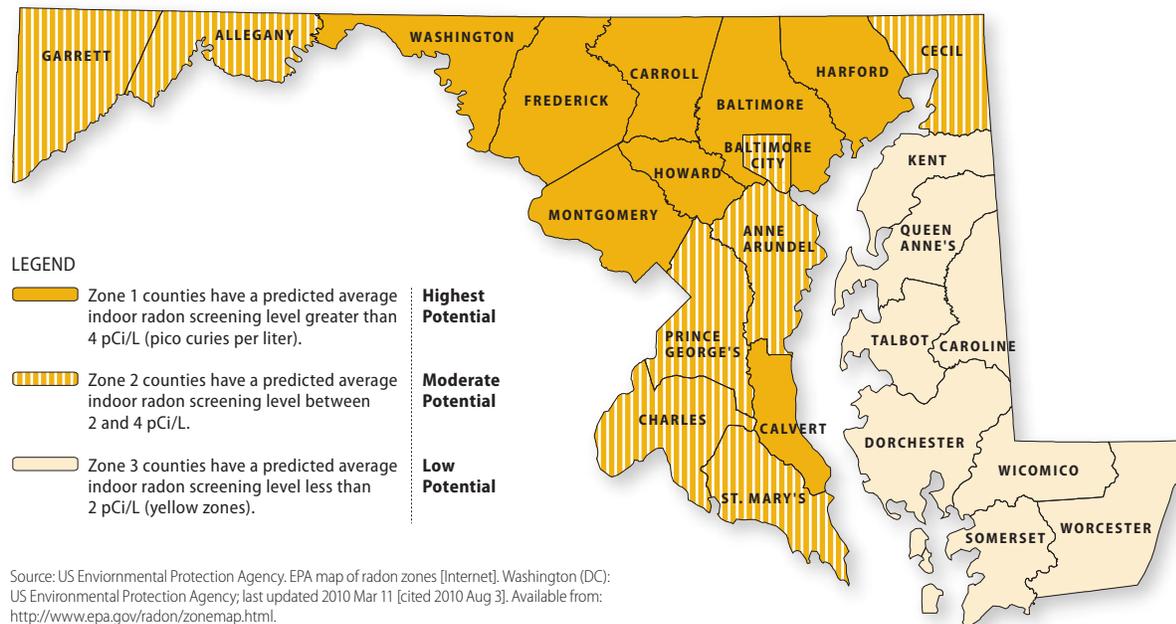
Physical agents include radiation (both ionizing and non-ionizing) and particles such as asbestos. These agents are known carcinogens, and information about them has been changing significantly in the past few years, especially regarding radiation.

Ionizing radiation exists everywhere. Until recently, most of the radiation exposure that a person in Maryland received was due to natural sources (also known as “background” radiation).

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FIGURE 8.3

Predicted Radon Concentrations in Maryland



The main sources of background radiation in the environment are cosmic rays from space, naturally occurring radioactivity given off by radioactive elements in the earth, and small amounts of radiation given off by naturally occurring radioactive elements in our own bodies. This naturally occurring background radiation historically has accounted for more than 80% of the average radiation dose to someone living in the United States.<sup>12</sup>

**RADON**

The most important preventable source of background radiation for people in Maryland is radon. Radon is an invisible, odorless radioactive gas produced as a decay product of uranium in the ground. The radon is able to enter a home through cracks and holes in a foundation, but because it is heavy, it generally stays at ground level (in the basement). When inhaled (and only when inhaled), the radioactivity given off by the radon can increase the risk of lung cancer, both in smokers and in non-smokers. Fortunately, an inexpensive and simple radon test kit can be used to measure radon levels. If the radon is above recommended levels, the solution is also usually simple and relatively inexpensive, typically requiring increased ventilation of the basement space. The US Environmental Protection Agency estimates that radon is the most important risk factor for lung cancer in people who do not smoke, so measuring and eliminating radon is very important.

Figure 8.3 is a map developed by the EPA that shows predicted radon concentrations for Maryland. The map was developed using five factors to determine radon potential: indoor radon measurements, geology, aerial radioactivity, soil permeability, and foundation type.<sup>13</sup>

**DID YOU KNOW?**

The most important preventable source of background radiation for people in Maryland is radon.

## PERSONAL RADIATION

Recently, studies suggest that an increasing fraction of personal radiation doses come from the use of medical imaging technologies. In particular, the increasing use of computed tomography (CT) scans has been pointed out as a significant challenge and has caused the US Food and Drug Administration (FDA) to focus on the problem.<sup>14,15</sup>

## ULTRAVIOLET (UV) RADIATION

Ultraviolet radiation is a known carcinogen. There is increasing concern about cancers related to sunlight exposure, including melanoma and basal and squamous cell carcinomas. Groups at increased risk include outdoor workers, teenagers (especially teens who use artificial ultraviolet tanning beds), and people with certain medical conditions.<sup>16</sup> More information on ultraviolet radiation can be found in Chapter 7: Ultraviolet Radiation and Skin Cancer.

### Household/Personal Exposures

Americans spend most of their time indoors. Indoor air pollution can be a significant source of exposure to carcinogens, depending on the location of a home, how it is constructed and maintained, and activities within the home. Indoor air pollution is a mixture of pollutants entering from the outdoors and those from sources within the home.<sup>17</sup> More information on indoor air pollution can be found at <http://www.epa.gov/ap4/course422/ap4.html>.

Potential indoor sources include building materials, furniture, household cleaning products, and sources that release combustion gases such as wood stoves and fireplaces. The toxicants that are of particular concern from cancer risk perspectives include formaldehyde, p-dichlorobenzene, chloroform, acetaldehyde, benzene, naphthalene, dichloromethane, and asbestos. In addition, environmental tobacco smoke and radon are two important carcinogens that are present in the indoor environment. These pollutants are covered in other sections within this chapter.

In addition to airborne agents, drinking water can be a source of carcinogens. Chemical contaminants in drinking water are discussed in the section on Waterborne Exposures. Chemical contaminants may be of particular concern in homes with private wells, as these wells generally

have fewer requirements for testing than public water supplies.

## Sources of Data for Environmental/Occupational Cancer

**F**OR GENERAL INFORMATION about cancer surveillance data and the Maryland Cancer Registry (MCR), see Chapter 2 on Cancer Surveillance.

In this section we discuss the specific challenges and opportunities for using surveillance data to investigate possible links between environmental conditions and cancer. Use of cancer surveillance data, including the MCR data, for evaluating environmental causation or association is challenging for a number of reasons, including:

- Cancer is usually caused by more than one factor, including a combination of genetics, environment, and personal lifestyle factors.
- Cancer has a long incubation period (latency) from initiation (the starting event) to the development symptoms and disease.
- Cases are classified by their address at diagnosis, rather than where they lived when they might have been exposed to particular environmental agents. The address at diagnosis may or may not reflect where the person lived before the cancer diagnosis.
- Environmental exposures may occur at a place of work; however, the person's occupational information (and therefore potential exposure information) is often missing in cancer registries, including the MCR.
- Personal risk factors such as tobacco use, body mass index, diet source/composition, water source/intake, exercise, UV exposure, prior screening for cancer, etc., are typically not collected by cancer surveillance systems, including the MCR.
- Some cancers are often diagnosed in an outpatient setting, particularly skin cancer and urologic cancers. This limits the reporting of full data on these cancers to state registries.

“Ecologic associations” between cases of cancer and certain environmental factors can be investigated by examining the relationship between rates of all or certain types of cancer and various environmental factors. Such analyses usually are most useful for raising possible avenues for

**TABLE 8.2**

**Data Sources for Environmental and Occupational Factors**

DATA SOURCE	CONTENTS	COMMENTS
<b>OCCUPATIONAL</b>		
Maryland Occupational Safety and Health	No provision for occupational cancer reporting.	Maryland DHMH has received a grant from National Institute for Occupational Safety and Health for occupational health surveillance. Cancer reporting should be a priority.
<b>AIR</b>		
Toxics Release Inventory (TRI) Program ( <a href="http://www.epa.gov/tri/#hts1">http://www.epa.gov/tri/#hts1</a> )	Toxic chemical releases and waste management activities reported annually by specific types of industries and federal facilities.	Downloadable TRI data files are available for individual states, including Maryland ( <a href="http://www.epa.gov/tri/tridata/current_data/index.html">http://www.epa.gov/tri/tridata/current_data/index.html</a> ). Mobile source data available (compounds emitted from standard gasoline and diesel engines and alternative fuels such as ethanol, biodiesel, and compressed natural gas) ( <a href="http://www.epa.gov/otaq/regs/toxics/420b06002.pdf">http://www.epa.gov/otaq/regs/toxics/420b06002.pdf</a> ).
Air monitoring program for Criteria Air Pollutants	23 monitoring stations across the state of Maryland collect data on Criteria Air Pollutants: ozone, PM10, PM2.5, carbon monoxide (CO), nitric oxides (NOX) and sulfur dioxide (SO2).	Most monitoring sites located in Central Maryland, with a single monitoring site in Millington on the Eastern Shore and two in Western Maryland in Hagerstown and Piney Run. Not all Criteria Air Pollutants measured at all sites ( <a href="http://www.mde.state.md.us/Programs/AirPrograms/Monitoring/monitnetwork/index.asp">http://www.mde.state.md.us/Programs/AirPrograms/Monitoring/monitnetwork/index.asp</a> ).
Air monitoring for Hazardous Air Pollutants	Carbonyls, volatile organic chemicals, and heavy metals are measured at three sites between Baltimore and Washington ( <a href="http://www.epa.gov/reg3artd/airquality/toxmon3.htm">http://www.epa.gov/reg3artd/airquality/toxmon3.htm</a> ).	Since many carcinogens on EPA's HAPs list are bound to fine PM2.5, inhalation of PM2.5 particles may be a good surrogate measure of exposure to carcinogenic HAPs.
National-Scale Air Toxics Assessment (NATA) ( <a href="http://www.epa.gov/ttn/atw/natamain">http://www.epa.gov/ttn/atw/natamain</a> )	Uses national emissions inventory data from outdoor sources for 180 of the 187 Clean Air Act HAPs plus diesel PM to model ambient concentrations of air toxics in the United States and population exposure at the census tract level.	Results from this modeling have been used to calculate cancer risks associated with 80 known carcinogens within the 180 chemicals examined at national and regional levels ( <a href="http://www.epa.gov/ttn/atw/nata2002/tables.html">http://www.epa.gov/ttn/atw/nata2002/tables.html</a> ).

further investigation rather than demonstrating cause and effect because there is usually limited case information on other factors known to affect cancer, such as smoking, diet, family history, or previous environmental or occupational exposures.

Table 8.2 describes different data sources available for environmental and occupational factors.

Prevention of environmental and occupational cancer relies primarily on the identification and reduction of exposures to carcinogens. In the occupational setting this has been accomplished through regulations that reduce or eliminate exposures. In many cases environmental

exposures cannot be completely eliminated, so the goal is to reduce them as much as possible.

### Cluster Investigations

Evaluating small geographic areas (such as a neighborhood or a census tract) for increased cancer risk is difficult. Often a citizen is concerned about cancer cases in a neighborhood or worksite. For neighborhood evaluations, the cases diagnosed in the area may not yet have been reported, may not be completely reported, or may be inaccurately reported. Identifying the denominator or “population at risk” in a neighborhood

**TABLE 8.2 CONT.** Data Sources for Environmental and Occupational Factors

DATA SOURCE	CONTENTS	COMMENTS
<b>WATER</b>		
Drinking water data MDE	Local water quality reports.	
<b>FOOD</b>		
Food and Drug Administration <a href="http://www.fda.gov/downloads/Food/FoodSafety/FoodContaminantsAdulteration/TotalDietStudy/UCM186204.pdf">http://www.fda.gov/downloads/Food/FoodSafety/FoodContaminantsAdulteration/TotalDietStudy/UCM186204.pdf</a>	The FDA collects several hundred samples of food from grocery stores and food distribution centers each year to test for pesticide residues, contaminants, and nutrients in foods.	<a href="http://www.fda.gov/downloads/Food/FoodSafety/FoodContaminantsAdulteration/TotalDietStudy/UCM186204.pdf">http://www.fda.gov/downloads/Food/FoodSafety/FoodContaminantsAdulteration/TotalDietStudy/UCM186204.pdf</a> FDA may also conduct targeted sampling of food and animal feed ( <a href="http://www.cfsan.fda.gov/">http://www.cfsan.fda.gov/</a> ).
US Department of Agriculture <a href="http://www.fsis.usda.gov">http://www.fsis.usda.gov</a> and <a href="http://www.foodsafety.gov">http://www.foodsafety.gov</a>	The USDA's Food Safety and Inspection Service (FSIS) monitors and regulates domestically produced meat, farm-raised fish, eggs, and poultry.	USDA collects state/regional pesticide use data for all crops including food crops.
<b>INDOOR ENVIRONMENTS</b>		
No national or state data source for indoor environmental monitoring.		
<b>HUMAN EXPOSURE</b>		
EPA's Human Exposure Database System (HEDS)	Maryland data available.	HEDS is an integrated database system that contains chemical measurements, questionnaire responses, documents, and other information related to EPA-supported research studies of the exposure of people to environmental contaminants. These data are available to the public for exposure and risk assessment modeling.

relies on ten-year census information and intercensus estimates. Population data are often not available below the ZIP code or census tract level. ZIP codes also change with time. Identifying the “population at risk” at a worksite for rate calculation and comparison is very difficult, requiring a research study to obtain personnel records and to track individuals forward in time to assure complete denominator information and complete case identification on those who moved out of the surveillance area. Additionally, each of these evaluations requires having a population rate of the cancer of interest in a comparison group, which is often difficult to identify. Conveying these

limitations of cancer concern investigation and cancer surveillance to individuals who seek the cause of a cancer diagnosis and to the media is challenging yet necessary.

Maryland has recently adopted a strategy to manage investigations where concerns are raised regarding possible relationships between cancer and some environmental factor. Annually, there are about a dozen cancer concerns reported to DHMH, MDE, or local jurisdictions. Cancer concerns are primarily reported to state and local health departments, but also can be directed to local and state environmental agencies, academic institutions, and healthcare facilities. Residents

concerned about potential “clustering” of cancer cases reach out to public health professionals:

- For input into, consultation about, and clarification over the complex set of diseases known collectively as cancer.
- To report cases of cancer that appear unusual or atypical to the resident.
- To get a comprehensive analysis on observed patterns in number or type(s) of cancer.
- To learn plausible explanations for their own cancer diagnosis or diagnoses among neighbors, loved ones, colleagues, or other acquaintances.

Responsiveness to these concerns in a sensitive and timely manner with accurate information and appropriate level of detail is critical.

Adequate responses to reported cancer concerns involve coordination among local health departments as the lead contact to concerned communities, state cancer registries as the guardian of the most current and accurate cancer data, and overarching coordination by the state lead for cancer and environmental health as the agency with oversight. Most concerns are adequately addressed by providing timely information and directing the resident to additional resources for more information from trusted organizations; providing transparency in the process through which the concerns are addressed; recognizing the fear, anger, and frustration of anyone coping with a cancer diagnosis; assisting in navigating the individual through the multitude of information available to best enable him or her to better understand the complexity of the disease; and maintaining accessibility for follow-up and future assistance should it be needed. DHMH provides many resources to assist concerned residents with information, additional resources, and local contact information to further respond to cancer concerns in individual communities. Links to these resources can be found at [http://fha.maryland.gov/pdf/cancer/mcr\\_combined\\_cancer\\_cluster.pdf](http://fha.maryland.gov/pdf/cancer/mcr_combined_cancer_cluster.pdf).

## Research

**R**ESearch AND DATA COLLECTION are essential for understanding and reducing cancer from exposure to carcinogens in the environment and workplace. Environmental and occupational cancer research has historically been very challenging for several reasons. First, the

time between exposure to a carcinogen and the development of cancer (latency) can take years or decades, making it very difficult to determine what exposures occurred in the past and to measure them. Second, in order to understand what level of exposure poses a cancer risk, it is important to measure the amount of a carcinogen that enters the body when exposures occur. Because it is often difficult or impossible to eliminate all exposures, we need to determine what level of exposure can be considered acceptable or “safe.” The best way to measure the dose we receive from exposure to a carcinogen is with biological sampling (i.e., blood samples); however, this is labor intensive and expensive. Third, the biological process that occurs when someone is exposed to a carcinogen in the environment is often very complicated and may vary from individual to individual. In other words, two people exposed to the same amount of a carcinogen may not have the same response. And finally, because we are exposed to many different chemicals and agents in the environment and workplace simultaneously, it is often difficult to determine which exposure is causing cancer.

Research will help us answer many of the questions about the biological mechanisms that determine the ultimate health impact of carcinogens in our environment. Other important questions include:

- What carcinogens are we exposed to?
- How much is getting into our bodies?
- What dose will cause cancer?
- What exposure can be considered “safe” or acceptable?
- How can we reduce or eliminate our exposures to carcinogens?

In addition to research, data collection and cancer surveillance are critical pieces to reducing environmental and occupational cancer. We must collect data on exposure to carcinogens in the environment (air, water, soil, food) and workplace and conduct cancer surveillance in the workplace as well as within communities if we are going to understand what our cancer risks are and how to reduce them.

# GOALS - OBJECTIVES - STRATEGIES

## GOAL 1

Reduce cancer incidence in Maryland by minimizing exposures to known environmental and occupational carcinogens.

### OBJECTIVE 1

By 2015, identify a limited set of up to five priority hazards to address during the course of the cancer plan.

#### STRATEGIES

- 1 **UTILIZE EXISTING DATA** on environmental hazards from multiple sources to identify the priority hazards based on the following criteria: known hazards, population potentially exposed, public health impact, vulnerability of the exposed populations, environmental justice considerations.
- 2 **DEVELOP A STRATEGY** to reduce exposures to these priority hazards by 2015.

### OBJECTIVE 2

By 2015, develop and implement within state regulatory agencies a coordinated approach to reduce the priority hazards.

- 1 **INVENTORY STATUTES, REGULATIONS, AND NON-REGULATORY MECHANISMS** related to the priority hazards and examine them for regulatory gaps and non-regulatory opportunities available to Maryland.

### OBJECTIVE 3

By 2015, create state policies that address levels of risk, disparities, community vulnerability, and the precautionary principle\* when addressing environmental and occupational factors in cancer.

#### STRATEGIES

- 1 **COLLABORATE WITH APPROPRIATE AGENCIES** and councils to establish specific goals within existing state agencies to move the agencies to explore relationships between environment, occupation, and cancer.
- 2 **PUBLIC HEALTH AND ENVIRONMENTAL AGENCIES** will develop educational messages and outreach, in conjunction with academic partners, targeted towards improving public understanding of the complex relationship(s) between environmental/occupational factors and cancer.

## GOAL 2

Improve Maryland-specific data and strengthen research and education related to environmental and occupational factors and cancer.

### OBJECTIVE 1

By 2015, create more integrated state systems for the surveillance and prevention of environmental and occupational carcinogen exposures and outcomes.

#### STRATEGIES

- 1 **COLLABORATE WITH APPROPRIATE AGENCIES** and councils to develop a strategy related to how healthcare reform and the institution of health information exchanges may affect current surveillance efforts.
- 2 **COLLABORATE WITH APPROPRIATE AGENCIES** and councils to identify priorities for data related to environmental and occupational factors and cancer in all of its surveillance systems including vital records, the Maryland Cancer Registry, death certificates, and the new occupational disease surveillance program at DHMH.

### OBJECTIVE 2

By 2015, develop a state strategy on education and outreach associated with environmental and occupational factors and cancer.

#### STRATEGIES

- 1 **IMPROVE AND PROMOTE THE USE OF DATA PRESENTATION TOOLS** such as Environmental Public Health Tracking, the Maryland Assessment Tool for Community Health, and other systems that allow the public and decision-makers to better understand the complex relationship(s) between environmental and occupational factors and cancer.
- 2 **PROMOTE STATE AGENCY EDUCATION** and outreach aimed at improving public understanding of relationships between exposures and associated health outcomes.

*\*Precautionary Principle: When an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically. (1998 Wingspread Consensus Statement on the Precautionary Principle)*

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# 9. Colorectal Cancer



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# 9

## COLORECTAL CANCER

Cancer of the colon and rectum, called colorectal cancer (CRC), is the second leading cause of cancer deaths and the third most common cancer in both men and women in Maryland and in the US. CRC incidence and mortality rates have decreased over the past eight years in Maryland and CRC screening has increased.

Significant progress has been made due in part to local, state, and national efforts. These include:

- Promotion of CRC screening.
- Assuring health insurance coverage for CRC screening.
- Providing coverage for CRC screening for Marylanders with low income and without insurance coverage with linkage to, or payment for, CRC treatment. (See Progress Report: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).)

### The Disease

**CRC IS CAUSED** by a complex interaction of inherited susceptibility and environmental factors.<sup>1</sup> Within the large intestine, genetic changes alter the growth of normal cells to form adenomas (benign tumors). Adenomas are common; they are found in approximately 25% of people by age 50 years and the prevalence increases with age.<sup>2</sup> Seventy to 90% of CRC is believed to arise from these adenomas.<sup>3</sup> Overall, about 10% of adenomas will progress to CRC; however, the rate of progression depends on the size and the type of adenoma: 50% of large adenomas (over two centimeters) will progress to cancer; adenomas with villous features are more likely to progress to cancer than tubular adenomas. (An estimated 20% of villous adenomas

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TABLE 9.1

CRC Incidence and Mortality by Race and Gender in Maryland and the US, 2006

INCIDENCE 2006	TOTAL	MALES	FEMALES	WHITES	BLACKS	OTHER
New Cases (#)	2,322	1,161	1,156	1,640	568	95
Incidence Rate	41.3	48.1	36.2	40.2	42.7	37.5
US SEER Rate	45.9	52.8	40.5	45.3	56.2	38.0

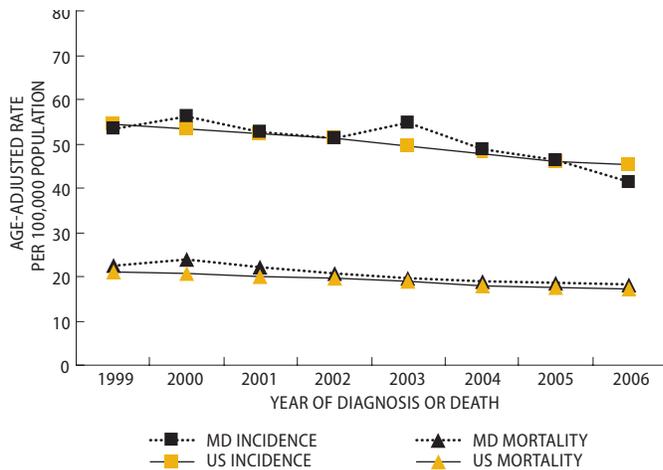
  

MORTALITY 2006	TOTAL	MALES	FEMALES	WHITES	BLACKS	OTHER
MD Deaths (#)	1,015	495	520	719	274	22
MD Mortality Rate	18.4	21.8	16.1	17.6	22.7	9.5
US Mortality Rate	17.1	20.4	14.6	16.6	24.1	10.9

Rates are per 100,000 and are age-adjusted to the 2000 US standard population.  
 Sources: Maryland Cancer Registry, 2006.  
 NCI SEER\*Stat (US SEER 17 rates).  
 NCHS compressed Mortality File in CDC WONDER, 2006.

FIGURE 9.1

Colorectal Cancer Incidence and Mortality Rates by Year of Diagnosis or Death, Maryland and US, 1999-2006



Rates are per 100,000 and age-adjusted to 2000 US standard population.  
 Sources: Maryland Cancer Registry, 1999-2006.  
 NCI SEER\*Stat (US SEER 13 rates).  
 NCHS Compressed Mortality File in CDC WONDER.

and 4% of tubular adenomas will progress.) Adenomas with “high grade dysplasia” are at high risk of progression to CRC. Adenomas that are sessile, flat, or depressed lesions may be at high risk for progression to CRC and are more difficult to detect or to remove than elevated/polyp-like adenomas. The average time between the development of an adenoma and its progression to CRC is estimated to be 10 to 15 years in people who are at average risk.<sup>4</sup>

**FAST FACT** The typical time between the development of an adenoma and its progression to CRC is estimated to be 10 to 15 years in people who are at average risk.

Hyperplastic polyps are another type of growth in the colon and rectum. Most hyperplastic polyps are thought to be relatively benign and not to confer increased risk of CRC. A very small number of people develop a condition called hyperplastic polyposis (that is, large and multiple hyperplastic polyps distributed in various parts of the colon) and are at increased risk of developing CRC.<sup>5,6</sup>

A small number of hyperplastic polyps may undergo genetic changes to become adenomatous lesions which are at higher risk for becoming a carcinoma. Serrated adenomas, sessile serrated adenomas, or sessile serrated polyps are found much less frequently in the colon than either hyperplastic polyps or tubular adenomas.

Ninety-five percent of CRC is carcinoma, and 95% of the carcinomas are adenocarcinoma.<sup>7</sup> Other malignant tumors of the colon and rectum include carcinoid tumors, lymphomas, gastrointestinal stromal tumors, adenosquamous cancer, squamous cancer, and melanomas. The extent of the tumor at the time of diagnosis, or

stage, is the most important factor in predicting survival. For cases diagnosed between 1999 and 2006, survival rates for CRC at five years after diagnosis are 90.4% for tumors diagnosed at local stage, 69.5% for regional, and 11.6% for distant stage. Therefore, earlier diagnosis means longer survival.<sup>8</sup> For all CRC stages combined, the five-year survival rate for whites (67.9%)

exceeded the rate for blacks or African Americans (56.7%) during the same time period.<sup>9</sup>

## Risk Factors

Certain risk factors increase the chance of developing CRC, including the following.

### Age

**AGE IS THE BIGGEST RISK FACTOR** for CRC.

Of the 2,322 cases of CRC diagnosed in Maryland in 2006, 88.3% were diagnosed in people ages 50 years or older.

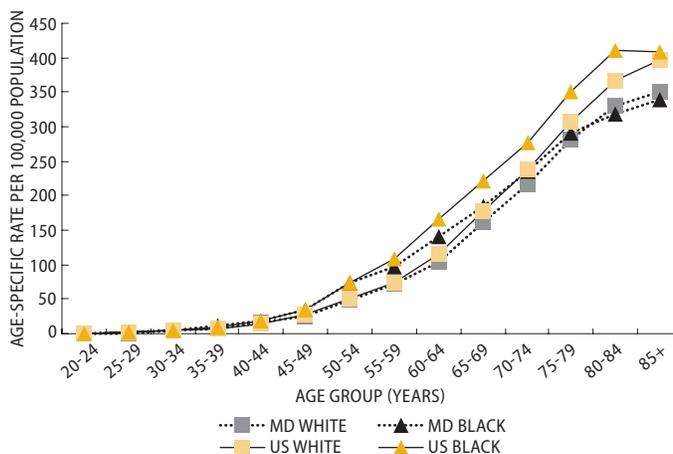
### Family History

**FAMILY HISTORY OF CRC** or adenomas increases a person's risk of CRC.<sup>10</sup> People with familial adenomatous polyposis (FAP) have a mutation in the APC tumor-suppressor gene and their risk of CRC is almost 100%.<sup>11</sup> Those with hereditary non-polyposis colon cancer (HNPCC), or Lynch syndrome, have mutations of human mismatch repair genes and have an 80% or higher risk of CRC by age 70 as well as increased risk of cancer of the endometrium, stomach, ovary, brain, kidney, biliary tract, and gallbladder.<sup>12</sup>

People with two or more first-degree relatives of any age or one first-degree relative diagnosed with CRC at less than 50 years of age have three to four times the risk of CRC than people without first-degree relatives with CRC. Those with one first-degree relative diagnosed with CRC at 60 years or older have almost twice the risk of those without a close family history of CRC.<sup>13, 14</sup> It is estimated that 1% of all CRC occurs in people with FAP, 4-7% with HNPCC, 15-20% with other family history, 1% in other uncommon conditions (e.g., inflammatory bowel disease or Peutz-Jeghers syndrome), and approximately 75% are "sporadic" cases occurring in people with no family or personal history of CRC or adenomas and no personal history of inflammatory bowel disease (IBD).<sup>15, 16</sup>

FIGURE 9.2

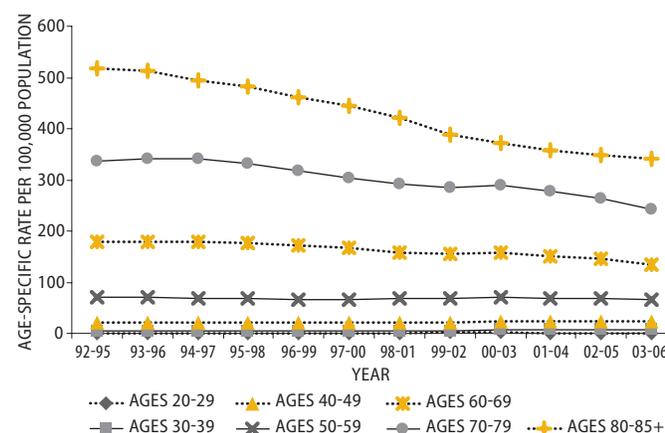
Colorectal Cancer Age-Specific Incidence Rates by Race, Maryland and US, 2002-2006



Sources: Maryland Cancer Registry, 2002-2006. NCI SEER\*Stat (US SEER 17 rates).

FIGURE 9.3

Colorectal Cancer Age-Specific Rates, All Races, Maryland, 1992-2006



Source: Maryland Cancer Registry, 1992-2006.

### Personal History

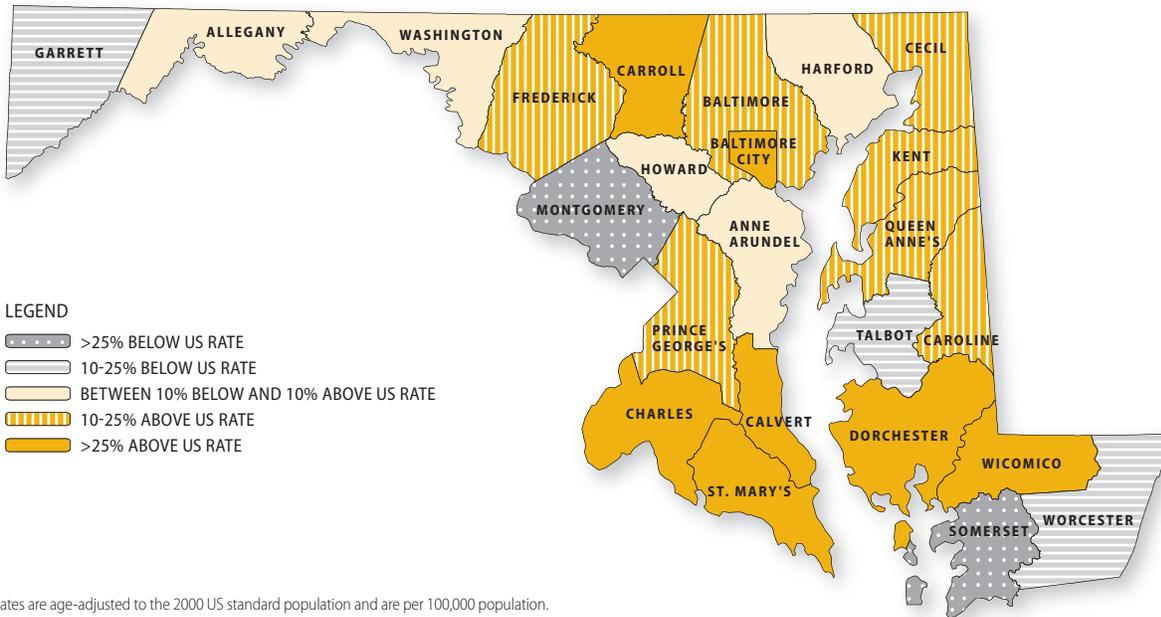
**THE FOLLOWING PEOPLE** are at increased risk of CRC: those with a history of CRC, FAP, HNPCC, adenomas, hyperplastic polyposis, inflammatory bowel disease (ulcerative colitis or Crohn's colitis), or women with prior ovarian or endometrial cancer before age 50. The risk of CRC in people with a history of IBD is approximately 30% after ten years of diagnosis of IBD.

### Other Lifestyle Risks

**OTHER RISK FACTORS** that increase the risk of CRC include: diets high in total fat and meat, sedentary

FIGURE 9.4

Maryland Colorectal Cancer Mortality Rates by Geographical Area: Comparison to US Rate, 2002-2006



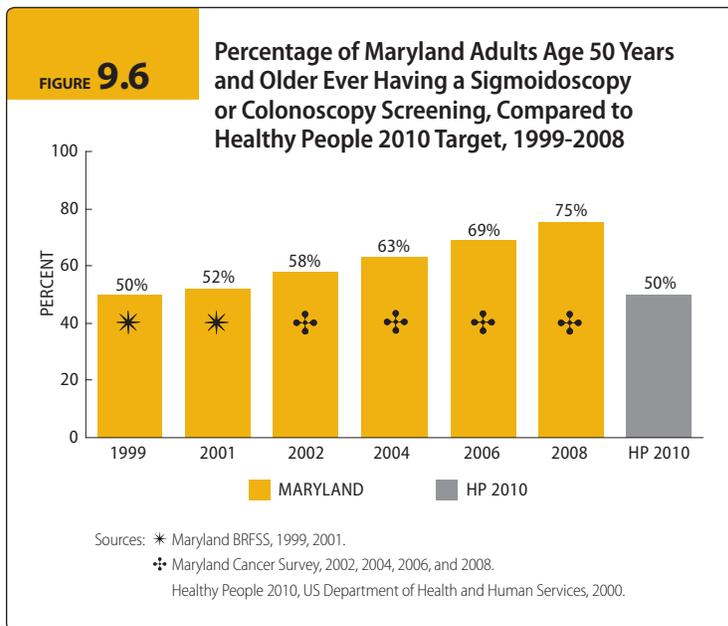
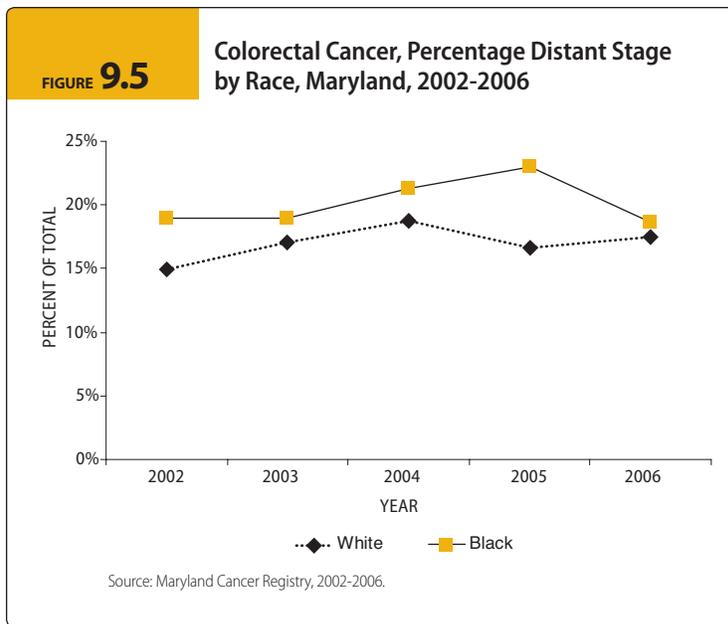
Rates are age-adjusted to the 2000 US standard population and are per 100,000 population. US colorectal cancer mortality rate, 2002-2006: 18.2/100,000. Source: NCHS Compressed Mortality File in CDC WONDER.

lifestyle, and physical inactivity (some studies). Cigarette smoking is associated with an increased tendency to form adenomas and to develop CRC. Obesity is associated with a two-fold risk increase in CRC in premenopausal women. There is inadequate evidence to suggest that a diet low in fat and high in fiber, fruits, and vegetables decreases the risk of CRC; however, there are no known harms from dietary modification. A lower risk of CRC has been seen in women using postmenopausal hormones and people who use aspirin, but the harms of these may outweigh the benefits of lowered CRC risk.<sup>17</sup>

## Burden of CRC in Maryland

**CRC is the second leading cause of cancer deaths among men and women in Maryland (following lung cancer) and the third leading cause of new cancer cases (following lung cancer, breast cancer in women, and prostate cancer in men, and excluding non-melanoma skin cancer).<sup>18</sup>**

**I**n 2006, 2,322 Marylanders were diagnosed with CRC and 1,105 persons died of CRC (Table 9.1). Figure 9.1 shows the declining trends in age-adjusted incidence and mortality rates from 1999 through 2006 compared to US rates. From 2002 to 2006, Maryland had an average annual 5.8% decrease in incidence and 2.8% decrease in mortality.<sup>19</sup> Incidence and mortality rates are higher among men than women, and higher among blacks or African Americans than whites or those of other races (Table 9.1). However, incidence rates have declined among men and women of both races in Maryland. (See data at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).) Black or African American men had the highest CRC mortality rates in 2006, almost twice the rate among white women (27.8 per 100,000 in 2006 vs. 15.4



per 100,000, respectively). (See data at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).)

CRC incidence rates increase markedly with age (Figure 9.2), essentially doubling every decade after the age of 50 years. For those ages 50 to 79 years, blacks or African Americans had a higher incidence rate than whites in Maryland from 2002 to 2006. Between 1992 and 2006, the greatest decrease in CRC incidence in Maryland occurred among those 80 years and older, followed by those 70 to 79 years of age (Figure 9.3). Figure 9.4 shows a map of CRC mortality rates from 2002 to 2006 in Maryland's 24 jurisdictions: four jurisdictions had rates 10% or

more below the US rate and 14 jurisdictions had rates 10% or more above the US rate.

In 2006, 36.9% of CRC cases in Maryland were reported as local stage at the time of diagnosis, 34.2% were regional stage, 17.4% were distant stage, and 11.5% were unstaged. There is a suggestion from the data from 2002 to 2006 that localized CRC has increased and regional stage CRC has decreased among both blacks or African Americans and whites. (See data at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).) Longer time intervals are needed to evaluate this suggested trend. Blacks or African Americans had a higher percentage of their tumors diagnosed in distant stage than did whites over the period (Figure 9.5).

## Primary Prevention

**Primary prevention of CRC requires adopting behaviors that are believed to lower the risk of CRC.**

**C**ERTAIN RISK FACTORS FOR CRC are not modifiable (age, family history, and personal history) while other factors can be modified (e.g., diet, physical inactivity, weight, and smoking). Additionally, having a colonoscopy with removal of adenomas is primary prevention for CRC because it takes away the early growth that may develop into CRC. (Rates of screening

by colonoscopy are described in Figure 9.6.)

The current prevalence of CRC lifestyle risk factors in Maryland, including overweight and obesity, inadequate intake of fruits and vegetables, and physical inactivity, are shown in Chapter 6 on Nutrition, Physical Activity, and Healthy Weight. Recommendations for primary prevention for CRC parallel those recommended for prevention of other cancers, cardiovascular disease, diabetes, and other chronic diseases. These include not smoking; being physically active; eating vegetables and fruits; limiting intake of fats, meat, and alcohol; and achieving and maintaining a healthy weight.<sup>20</sup>

**FAST FACT** Maryland has made great progress in CRC screening in the past ten years. The percentage of Marylanders age 50 years and older who report having ever had a sigmoidoscopy or colonoscopy has increased from 58% in 2002 to 75% in 2008.

## Screening and Surveillance (Secondary Prevention)

**Currently, screening to detect CRC consists of either visualizing the inside of the colon or testing for blood in the stool.**

**THE COLON** can be viewed directly with either a colonoscope (a fiber-optic, lighted instrument that views the entire colon) or a flexible sigmoidoscope (a similar, shorter instrument that views the last third of the colon), or visualized by computerized tomography (CT) or a double-contrast barium enema (DCBE) x-ray exam. During a colonoscopy or sigmoidoscopy, any polyp or other suspicious area can be removed entirely or biopsied and sent to the laboratory for diagnosis. Another type of testing is the fecal occult blood test (FOBT) that identifies hidden blood in feces. For CRC screening, the FOBT is done using a home test kit with stool samples taken over two to three days. Two types of FOBT kits are available: guaiac-based and fecal immunochemical tests (FIT). The two most frequently used screening tests are colonoscopy and FOBT.

The United States Preventive Services Task Force (USPSTF) recommends screening for CRC using FOBT, sigmoidoscopy, or colonoscopy in average-risk adults beginning at age 50 years and continuing until age 75 years (“A” recommendation).<sup>21</sup> The benefits, risks, and screening intervals depend on the type of test chosen for screening. The American Cancer Society, the US Multi-Society Task Force on CRC, the American College of Radiology,<sup>22</sup> and the American College of Gastroenterology have similar recommendations.<sup>23</sup> It is recommended that people at higher risk for developing CRC because of personal or family history undergo earlier and/or more frequent colonoscopy screening, at the direction of their medical providers.

The Maryland Department of Health and Mental Hygiene (DHMH) Medical Advisory Committee concurs and recommends either colonoscopy or FOBT with sigmoidoscopy as the two most effective means of screening people at average risk.<sup>24</sup> For those at increased risk of CRC, the Medical Advisory Committee recommends screening with colonoscopy. All of the above-mentioned groups agree that any form of CRC screening is preferable to no screening. Colonoscopy achieves both early detection of cancers and also primary prevention.

Two screening tests are not currently recommended for routine use by the USPSTF but are on the list of available options by the Multi-Society Task Force guidelines. These include CT of the colon, called “virtual colonoscopy,” and genetic testing of feces to identify genetic changes common in adenomas and CRC.<sup>25</sup> Abnormalities found with either of these tests need to be followed up with colonoscopy.

Factors that influence patient and provider choice of CRC screening test include the risks associated with the test and the test’s accuracy, convenience, and cost.<sup>26</sup>

CRC screening tests are widely available in Maryland. Medicare Part B pays for screening by FOBT, flexible sigmoidoscopy, DCBE, and colonoscopy for those at average risk. Maryland Medical Assistance also covers the cost of screening when ordered by a provider. Maryland law (effective June 30, 2001) mandates that healthcare plans include coverage for CRC screening according to American Cancer Society guidelines.

Maryland has made great progress in CRC screening in the past ten years. Figure 9.6 shows the change in the percentage of Marylanders age 50 years and older who report having ever had a sigmoidoscopy or colonoscopy. The rate has increased from 58% in 2002 to 75% in 2008.<sup>27</sup> While all races increased in their screening rates, the lower rates among blacks or African Americans and other races compared to whites (70%, 70%, and 76%, respectively) persisted in 2008. (See data at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).) Those never tested for CRC decreased from 26% to 18% in the same period. In 2008, of the 18% of people who reported never having been screened for CRC, 80% reported having had a physical

examination in a provider’s office within the preceding two years. Therefore, CRC screening opportunities are still being missed.

## Disparities

### Disease Disparities

**RACIAL DISPARITIES** in CRC incidence, mortality, and stage are highlighted above: blacks or African Americans have a higher rate of disease, higher mortality, and a higher percentage of their tumors reported in late stage and a shorter five-year survival rate after diagnosis than do whites. Other disparities that need investigation but may be more difficult to quantify include differences due to socioeconomic status, geographic region of the state, and access to healthcare.

### Screening Disparities

**ALTHOUGH MARYLAND CRC SCREENING RATES** are high, one of the major differences is whether the person had healthcare insurance and had a healthcare provider. The Maryland Cancer Survey has found that Marylanders who are ages 50 to 64 years and those with low income, less education, or without health insurance are less likely to be up-to-date with CRC screening by any method. (See data at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).)

## Ideal Model for CRC Control

The Ideal Model for CRC Control, detailing primary, secondary, and tertiary prevention, is available at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

**CENTRAL TO THIS MODEL** is screening those who are ages 50 years and older and those of any age who are at increased risk. Health education and promotion, community-based participatory research, basic CRC research, availability of screening, payment for outreach, and payment for healthcare must be combined to promote and support CRC screening. Primary care providers (internists, family physicians, and gynecologists) play a key role in the Ideal Model by recommending and referring patients for screening and by helping to change patient attitudes and behaviors in a culturally sensitive

manner. Recently passed national healthcare legislation may improve access to care.

New to the Model since the last Comprehensive Cancer Control Plan is the importance of every endoscopist meeting reporting standards for colonoscopy (Colonoscopy Reporting and Data System or CO-RADS<sup>28</sup>) and setting appropriate intervals for recall colonoscopy based on the preparation of the bowel, the cecum being reached, and the findings.<sup>29</sup> (If the interval is set inappropriately long, an interval cancer may develop. If the interval is too short, the patient is put at additional risk and expense, and the capacity of endoscopists to perform colonoscopy on others needing the procedure will be limited.)

## Barriers to CRC Screening

Many of the barriers to screening for CRC may be overcome through evidence-based strategies that have been demonstrated as effective.

**THE RISE IN SCREENING RATES** over the last decade is an illustration of how useful these strategies can be to address barriers. There are several categories of barriers: patient barriers, clinician barriers, and system-wide barriers that may confront patients and/or providers. A detailed discussion of barriers to screening and possible strategies is included online ([www.marylandcancerplan.org](http://www.marylandcancerplan.org)). Listed below are some of the major barriers to screening.

### Patient Issues

- Lack of knowledge about CRC risk factors and screening recommendations.
- No source of routine medical care (lack of a “medical home”).
- Failure of a healthcare provider to recommend CRC screening.
- Cost of screening for the uninsured or cost of co-pays and deductibles for those with insurance.
- Inability to take time off from work or lack of transportation.
- Fear of the procedure or fear of knowing the screening results.
- Misconception that cancer is a uniformly fatal diagnosis and that screening is therefore not useful.

### Physician/Healthcare Provider Issues

- Lack of consistent message by provider about the screening recommendations and follow-up.
- Lack of provider knowledge about best-practices of CRC screening, for example:
  - Digital rectal exam (DRE) is no longer recommended as a screening method for CRC.
  - A single in-office FOBT following a DRE is not recommended as a screening method for CRC.
  - A positive test for fecal occult blood is an indication for colonoscopy and should NOT be followed up with another FOBT.
- Insufficient number of providers for sigmoidoscopy or colonoscopy in some areas of Maryland.
- Language and cultural barriers in some provider offices.
- Limited number of providers who accept uninsured patients or patients who have Medical Assistance or Medicare.

### Healthcare System Issues

- Lack of access to medical care.
  - Not having sufficient numbers of primary care providers.
  - Not having universal health insurance.
  - Having high co-pays or deductibles for those with insurance.
- Insufficient funding to pay for diagnosis and treatment for all people with CRC who do not have health insurance coverage.
- Limited availability of endoscopists in underserved areas.

Great efforts have been made in Maryland to address barriers to CRC screening at the state and local levels through mandated insurance coverage, patient and provider education, and access to CRC screening for low-income uninsured patients through the Cigarette Restitution Fund (CRF), the Centers for Disease Control and Prevention funding, and the Maryland Cancer Fund public health programs.

### Current/Ongoing Efforts

**In 1998, as part of Maryland’s portion of the multi-state Master Settlement Agreement with the tobacco industry, the Cigarette Restitution Fund Program (CRFP) was created by the Maryland General Assembly and signed into law by the Governor.**

**U**NDER THIS FUNDING, 23 of Maryland’s 24 jurisdictions developed CRC education programs and screening programs for people with low income who were uninsured or underinsured for CRC screening. Baltimore City and its Community Health Coalition (CHC), on the other hand, elected to focus on prostate, oral, breast, and cervical cancer screening rather than CRC.

In fiscal year 2001, locally controlled programs, designed in conjunction with their local community health coalition, began outreach and education for all residents and started CRC screening for those who met local income and insurance eligibility guidelines.

In the absence of funding for a public health CRC screening program in Baltimore City, the CRC Committee of the Baltimore City CHC focused on CRC education. The CRC Committee was led by a representative of the American Cancer Society, and representatives of the state and Baltimore City health departments and major Baltimore City hospitals were part of the “collaborative.” City CRC Committee representatives served on the CRC Chapter Committee of the Maryland Comprehensive Cancer Plan 2004-2008 and added to the plan an objective stating: “Increase funding for CRC screening among uninsured, low-income Maryland residents, especially in Baltimore City.”

The DHMH and the City CRC Collaborative had the support of the Comprehensive Cancer Plan coordinator for their application to the Centers for Disease Control and Prevention for the CRC Screening Demonstration Program (SDP) grant in April 2005. The successful Maryland application built on the strength and experiences of its CRFP CRC screening program and brought additional funds to the state health department. The SDP contracted with five Baltimore City hospitals for CRC screening services, case management, data entry, and bill paying.

Between 2001 and December 31, 2009, local programs and CRC SDP hospitals hired staff and partnered with numerous community-based and faith-based organizations for outreach and with providers for colonoscopy services. Collectively, these programs in Maryland have provided CRC education or outreach to nearly 497,000 members of the public, more than 30,000 healthcare providers, and nearly 4,400 trainers. Additionally, Marylanders were informed about CRC and screening through CRF-funded television, radio, newspapers, public service announcements, distribution of printed materials, billboards, and health fairs, and through other national campaigns (American Cancer Society, CDC Screen for Life, Katie Couric, etc.).

By December 31, 2009, the public health screening programs had screened 8,345 people with fecal occult blood tests (7% were positive). For low-income, uninsured, or underinsured residents, the programs contracted with providers and paid for 163 sigmoidoscopies and 16,244 colonoscopies. Forty-eight percent of those screened were racial and/or ethnic minorities. Adenomatous polyps were found on 3,599 (22%) of these colonoscopies, and 174 cases of CRC and 64 high-grade dysplasia cases were identified.

Maryland recognized the need for additional funding for its cancer programs. In 2004, the Maryland General Assembly established the Maryland Cancer Fund (MCF) within the DHMH. The MCF funds—donated through an income tax check-off on the Maryland annual tax return or through other direct donations—are targeted for cancer prevention, screening, treatment, and research in Maryland. Additional CRC screening in Maryland has been made available through grants funded by the Maryland Cancer Fund; MCF funds have been used to pay for treatment for patients found to have CRC in the Maryland screening programs.

The successes of the Maryland CRC education, outreach, and screening programs have been documented through population-based surveys. The Maryland Cancer Survey showed that CRC screening with endoscopy (ever having had a sigmoidoscopy or colonoscopy) of Marylanders ages 50 years and older has risen from 58% in 2002 to 75% in 2008. Disparities in screening rates between blacks or African Americans and whites have also narrowed in this time period. In 2009, the successes of the ongoing CRFP and the CRC SDP led to Maryland’s new funding under the federal CRC Control Program, an initiative that focuses more on population-based strategies, including policy changes, to increase screening.

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# GOALS - OBJECTIVES - STRATEGIES

## GOAL 1

**Reduce colorectal cancer incidence and mortality.**

### TARGETS (2015)

<b>INCIDENCE</b>	<b>29.4 per 100,000</b> (2006 Baseline: 41.3 per 100,000) Source: Maryland Cancer Registry.
<b>MORTALITY</b>	<b>11.0 per 100,000</b> (2006 Baseline: 18.4 per 100,000) Source: CDC WONDER.

### OBJECTIVE 1

By 2015, increase the percentage of Marylanders ages 50 years and older who are up-to-date with screening per ACS/Multi Society Task Force guidelines to 80%. (2008 Baseline: 73%)

Source: Maryland Cancer Registry.

### STRATEGIES

- 1 PROVIDE TARGETED EDUCATIONAL INFORMATION** to the public regarding CRC screening recommendations (including but not limited to primary care provider offices, pharmacies, public locations).
- 2 CONVENE A "BENEFITS UTILIZATION" WORKGROUP/ SUBCOMMITTEE** to devise and oversee implementation of a plan for CRC screening benefits utilization, including encouraging insurers in Maryland to promote benefit utilization and the insured to utilize their benefits.
- 3 INCREASE THE PROPORTION OF PRIMARY CARE PROVIDERS** and specialists who utilize evidence-based approaches such as physician recommendation for screening, client reminders, and chart review to identify patients appropriate for screening (recalling patients for screening and surveillance testing to increase CRC screening in their practices).
- 4 REDUCE BARRIERS TO CRC SCREENING** by utilizing strategies that
  - Facilitate primary care referral to specialists for screening.
  - Facilitate screening by use of patient navigators, community health workers, or lay health advisors.
  - Encourage improved coordination between primary care providers and specialists to increase patient convenience, assure completion of endoscopy screening, and promote sharing of results with primary care practitioners.

- 5 MAINTAIN PUBLIC HEALTH FUNDING** for CRC screening for low-income and uninsured Marylanders (e.g., funding from the Cigarette Restitution Fund, the Maryland Cancer Fund, and the Centers for Disease Control and Prevention).

### OBJECTIVE 2

By 2015, increase the percentage of Marylanders receiving site- and stage-appropriate treatment for CRC.

Source: Maryland Cancer Registry.

### STRATEGIES

- 1 EDUCATE PRIMARY CARE PROVIDERS** to refer patients initially diagnosed with CRC to high-volume surgeons and centers that have multidisciplinary cancer treatment teams, when possible.
- 2 DECREASE THE NUMBER OF UNSTAGED CRC CANCER REPORTED** to the Maryland Cancer Registry (MCR).
- 3 DEVELOP METHODS** to measure "site- and stage-appropriate treatment."
- 4 ANALYZE EXISTING MCR DATA** and present findings to the DHMH CRC Medical Advisory Committee to arrive at a consensus definition of "site- and stage-appropriate treatment."
- 5 MEASURE THE PERCENTAGE** of all CRC patients reported to the MCR who are reported from hospitals with multidisciplinary teams.

### OBJECTIVE 3

By 2015, improve provider adherence to the following recommendations:

- **Colonoscopists: Follow national guidelines for colonoscopy CRC screening intervals.**
- **Colonoscopists: Report colonoscopy results using Colonoscopy Reporting and Data Standards (CoRADS).**
- **Pathologists: Report colon/rectum pathology results (including high-grade dysplasia, serrated lesions, number of nodes, and positive nodes on resection specimens) according to national guidelines.**

### STRATEGIES

- 1 DEVELOP METHODS** to measure adherence to standards and national guidelines.
- 2 EDUCATE ENDOSCOPISTS** through nurse managers at endoscopy centers/units on national guidelines for CRC screening/surveillance colonoscopy intervals and on the use of the Colonoscopy Reporting and Data System (CoRADS).

# GOALS - OBJECTIVES - STRATEGIES

- 3 **EDUCATE PRIMARY CARE PROVIDERS** (PCPs) about CoRADs so that PCPs expect to receive colonoscopy reports on their patients that follow CoRADs.
- 4 **ENCOURAGE QUALITY ASSURANCE MONITORING** of colonoscopy by hospitals and ambulatory surgical centers.
- 5 **EDUCATE PATHOLOGISTS** on national guidelines and consensus standards for identifying lymph nodes in CRC surgical specimens and for reading neoplastic lesions in the colon and rectum.

## OBJECTIVE 4

By 2015, among those 18 years and older in Maryland, decrease the prevalence of risk factors for cancer, including CRC, such as smoking, obesity, low physical activity, and diets low in vegetables and fruits.

*See the Nutrition, Physical Activity, and Healthy Weight, Tobacco-Use Prevention/Cessation, and Lung Cancer chapters for specific objectives and strategies.*

## GOAL 2

**Reduce disparities in the incidence and mortality of CRC.**

### INCIDENCE TARGETS (2015)

<b>WHITE</b>	<b>29.5 per 100,000</b> (2006 Baseline: 40.2 per 100,000)
<b>BLACK</b>	<b>32.0 per 100,000</b> (2006 Baseline: 42.7 per 100,000)
<b>MALE</b>	<b>31.2 per 100,000</b> (2006 Baseline: 48.1 per 100,000)
<b>FEMALE</b>	<b>28.2 per 100,000</b> (2006 Baseline: 36.2 per 100,000)

Source: Maryland Cancer Registry.

### MORTALITY TARGETS (2015)

<b>WHITE</b>	<b>11.1 per 100,000</b> (2006 Baseline: 17.6 per 100,000)
<b>BLACK</b>	<b>13.5 per 100,000</b> (2006 Baseline: 22.7 per 100,000)
<b>MALE</b>	<b>13.8 per 100,000</b> (2006 Baseline: 21.8 per 100,000)
<b>FEMALE</b>	<b>9.0 per 100,000</b> (2006 Baseline: 16.1 per 100,000)

Source: CDC WONDER.

## OBJECTIVE 1

By 2015, increase the rates of up-to-date CRC screening for the following groups age 50 and older:

<b>BLACK OR AFRICAN AMERICAN FEMALE</b>	<b>80% or higher*</b> (2008 Baseline: 75%)
<b>WHITE FEMALE</b>	<b>80% or higher*</b> (2008 Baseline: 73%)
<b>BLACK OR AFRICAN AMERICAN MALE</b>	<b>80% or higher*</b> (2008 Baseline: 68%)
<b>WHITE MALE</b>	<b>80% or higher*</b> (2008 Baseline: 76%)

Source: MD BRFSS.

\* Target of 80% was determined based on the overall goal of 80% CRC screening rates in the CDC Colorectal Cancer Control Program.

### STRATEGIES

- 1 **ENCOURAGE HEALTHCARE PROVIDERS** and health departments to present and distribute targeted age/literacy/culturally appropriate information regarding CRC screening recommendations.
- 2 **LINK POPULATIONS** without primary care providers to sources of preventative care.
- 3 **SUPPORT UNIVERSAL HEALTH CARE COVERAGE** that includes the benefit of CRC screening.
- 4 **EDUCATE TARGET POPULATIONS** by working through primary care providers that serve the uninsured, emergency departments, as well as faith-based, community, and civic/social/service organizations (e.g., sororities, fraternities, Rotary Club).
- 5 **UTILIZE NONTRADITIONAL METHODS** such as navigators, community health workers, and lay health advisors to educate target populations.
- 6 **ENCOURAGE PRIMARY CARE PROVIDERS** to refer insured patients for screening and to refer uninsured patients to publicly funded CRC screening programs.

## OBJECTIVE 2

By 2015, produce an epidemiology report of CRC data highlighting CRC disparities including differences in histology, site in the colon, stage at diagnosis, and treatment by race, gender, and age.

### STRATEGIES

- 1 **OUTLINE THE CONTENT** of the report and the sources of data.
- 2 **PRODUCE AND DISTRIBUTE** the report.

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# 10 • Breast Cancer



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# 10

## BREAST CANCER

The goal for Maryland is to reduce the incidence, mortality, and morbidity from breast cancer through prevention, early detection, treatment, and effective survivorship care.

**BREAST CANCER IS A BROAD TERM** for many different types of breast cancer but the most common type is ductal carcinoma which makes up 70% to 80% of the breast cancer that occurs, followed by lobular carcinoma. Breast cancer may present as in situ cancer, meaning that the cells do not invade the local tissue, or invasive forms of breast cancer where the cancer cells have invaded the local breast tissue.

Among women, the average lifetime risk of developing either invasive or in situ breast cancer is about 14.5%; the lifetime risk for developing invasive breast cancer is about 12%.<sup>1</sup> Breast cancer may rarely occur among men who have, on average, a 0.03% lifetime risk of developing breast cancer, although the risk is higher among those men who carry a genetic predisposition to cancer. Due to advances in early detection and treatment, the average risk of dying from breast cancer is only 2.8%.<sup>1</sup>

### Risk Factors

**BREAST CANCER PREVENTION AND SCREENING** can be tailored for women based on their specific risk factor profile. Table 10.1 outlines some of the established risk factors for breast cancer. For complete information on breast cancer risk factors, see the National Cancer Institute Breast Cancer Prevention Physician Data Query (PDQ) at [www.cancer.gov](http://www.cancer.gov).<sup>2</sup> Additional information can also be found at Susan G. Komen for the Cure ([www.komen.org](http://www.komen.org)) and the American Cancer Society ([www.cancer.org](http://www.cancer.org)).

Research continues to identify factors that may alter an individual's risk of developing breast cancer, such as environmental exposures. Statistical models have been developed that help to determine if women fall into high-risk groups for developing breast cancer. Women should know where they fall on the spectrum of risk for developing breast cancer because screening and prevention recommendations may vary according to risk.

TABLE 10.1

## Established Risk Factors for Breast Cancer

RISK FACTOR
• Age.
• Family history of breast cancer, especially in close relatives with an early age at diagnosis.
• Nodular densities on the mammogram involving most of the breast tissue (dense breast tissue often described as “heterogeneously dense”).
• Breast biopsy showing atypical hyperplasia.
• Early age at menarche.
• Late age at menopause.
• Late age at first birth (>30).
• Radiation to chest, especially at early ages.
• Being overweight or obese after menopause.
• High socioeconomic status
• Drinking one to two alcoholic beverages every day.

Some models are appropriate for the general population of women, and others are specifically designed for individuals with a strong family history of cancer. Any model that is used should be validated (tested for accuracy of prediction). Choosing the correct model is very important in order to appropriately estimate a woman’s risk, and women should consult with their healthcare provider to determine which model best applies to their situation.

One of the most widely used models is the Breast Cancer Risk Assessment Tool, also known as the Gail model.<sup>3</sup> This model is appropriate for use among women from the general population who are regularly screened. The Gail model has been widely validated and has been used to determine eligibility for two breast cancer prevention trials: the Tamoxifen Prevention Trial and the Study of Tamoxifen and Raloxifene (STAR).<sup>4,5</sup> The Gail model does not include an extensive family history and thus is not appropriate to use for women with a strong family history who are suspected to be at high genetic risk. Models such as the BRCAPro model have been developed to estimate the likelihood that a major genetic factor,

such as a mutation in BRCA1 or BRCA2 genes, is present in the family.<sup>6</sup> These models incorporate only age and family history into their risk-prediction models. Because only 20% to 30% of women have a family history of breast cancer and in general only about 10% of women develop breast cancer due to a strong inherited susceptibility factor, the models that use only family history in risk estimation are not appropriate for most women in the general population.

Another model, the Tyrer-Cuzick Model, was developed in the United Kingdom (UK) and combines both genetic and other risk factors to estimate the risk of developing breast cancer.<sup>7,8</sup> Because it was developed in the UK, the model is based on rates of breast cancer in the UK, which vary from those in the United States. This model differs from the Gail model in that it includes an expanded family history, body mass index, and use of hormone therapy. This model also produces estimates of both the probability of developing breast cancer as well as the likelihood of carrying a mutation in either BRCA1 or BRCA2. It has been validated among a population of women with a family history of breast cancer, and did perform better in that population than the Gail model.<sup>9</sup> However, the Gail model was developed and validated for the general population of women who are undergoing routine screening. Thus, the most appropriate model to use depends on the population being evaluated.

**D**ECREASING MORBIDITY AND MORTALITY from breast cancer requires interventions across the continuum of care from prevention through end-of-life care (see Figure 10.5). The risk of developing breast cancer can be reduced. Regular exercise is associated with a reduced risk of breast cancer. Exercise is good at any age for multiple health benefits, but exercise during early adolescence and adulthood may be especially beneficial.<sup>10,11</sup> Maintaining a healthy weight after menopause may also help to lower the risk of breast cancer.<sup>12</sup> Weight can be managed through healthy eating as well as regular exercise. Breast-feeding has been shown in some studies to be associated with a lower risk of breast cancer, but study results are not consistent.<sup>13</sup> Recommendations to increase rates of breastfeeding are

supported by known benefits to the infant and the potential for long-term benefit to women through reduced risk of breast cancer. For women at high risk, it has been shown in clinical trials that treatment with Tamoxifen or Raloxifene can cut the risk of developing breast cancer in half.<sup>14,15,16</sup>

The goal of screening is to detect breast cancer early when it is most easily treated. The treatment of breast cancer depends on the stage of the disease at diagnosis as well as other characteristics of the tumor. The stage is determined by the size of the tumor, whether or not the local lymph nodes are involved, and whether there is evidence that the cancer has spread beyond the breast or the lymph nodes to other parts of the body (metastasis). Treatment also depends on characteristics of the tumor such as whether or not estrogen receptors or other markers such as HER2neu receptors are present. More detailed information about breast cancer and its treatment can be found at <http://www.cancer.gov/cancer-topics/pdq>.<sup>17</sup>

Survivorship care with the goal of minimizing morbidity from cancer and its treatment should begin at the time of diagnosis. Prevention and prompt treatment of short- and long-term side effects of the cancer as well as its treatment are needed to optimize quality of life. Dr. Fitzhugh Mullan, a cancer survivor, said: “The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly, but also to map the middle ground of survivorship and minimize its medical and social hazards.”<sup>18</sup> The Institute of Medicine’s 2006 report “From Cancer Patient to Cancer Survivor: Lost in Transition” emphasizes the need to improve the long-term care of cancer survivors. Survivorship care, like other healthcare, should embrace the holistic concept of treating mind, body, and spirit.

Through application of effective measures across the continuum of breast cancer control—prevention, early detection, effective treatment, survivorship care, palliative care, and hospice care—the goal of reducing the burden of and from breast cancer in the state of Maryland can be achieved. The report’s recommendations for interventions across the continuum of care have been shown to be effective and have pointed out

those areas where more research may be needed before action can be taken.

## Current Burden of Breast Cancer and Progress Made

**B**REAST CANCER IS THE MOST COMMON CANCER diagnosed in women, excluding cancers of the skin, and is the second leading cause of cancer death after lung cancer.<sup>19</sup> Breast cancer accounts for about 30% of all cancer diagnosed among women in Maryland.<sup>20</sup> Although men are at risk to develop breast cancer, this is a rare cancer among men, except for those who carry a genetic mutation in BRCA1 or BRCA2 who have up to a 6% lifetime risk of breast cancer. Because male breast cancer is rare, the data cited below focus on women in Maryland.

The number of women who are long-term survivors of breast cancer continues to grow nationally and in Maryland due to advances in both early detection and screening. The National Cancer Institute estimates that approximately 2.9 million US women and approximately 58,600 Maryland women with a history of breast cancer are alive in 2010.<sup>21</sup>

Approximately 3,500 women in Maryland are diagnosed with breast cancer each year (Table 10.2). Maryland’s overall age-adjusted breast cancer incidence rate, as well as the specific rates for white and black or African American women, are similar to the SEER rates for the nation (Figure 10.1). The overall age-adjusted breast cancer incidence rate for Maryland in 2006 was 112.8 per 100,000 women compared to 120.8 per 100,000 women nationally. As seen in Figure 10.2, since 1999, breast cancer incidence rates have declined in Maryland as well as nationally among all races. The decline in incidence observed since 2002 is primarily attributed to change in patterns of use of postmenopausal combined hormone therapy, but declines in screening mammography rates may also contribute to the observed decrease in incidence.<sup>22,23</sup>

**T**HE RISK OF BREAST CANCER increases with age for all women (Figure 10.3) up to age 75. White women age 45 and over have consistently higher age-specific incidence rates than black or African American women (Figure 10.3).

TABLE 10.2

Female Breast Cancer Incidence Data by Race, MD and the US, 2004-2006

2004	TOTAL	WHITES	BLACKS	OTHER
MD New Cases (count)	3,850	2,767	915	129
MD Incidence Rate	124.2	127.4	114.0	90.2
US SEER Rate	123.0	126.7	118.3	88.8
2005	TOTAL	WHITES	BLACKS	OTHER
MD New Cases (count)	3,712	2,637	896	153
MD Incidence Rate	118.6	121.1	108.7	101.2
US SEER Rate	122.1	126.2	114.8	88.1
2006	TOTAL	WHITES	BLACKS	OTHER
MD New Cases (count)	3,580	2,509	921	124
MD Incidence Rate	112.8	115.0	109.7	76.9
US SEER Rate	120.8	124.3	116.8	86.9

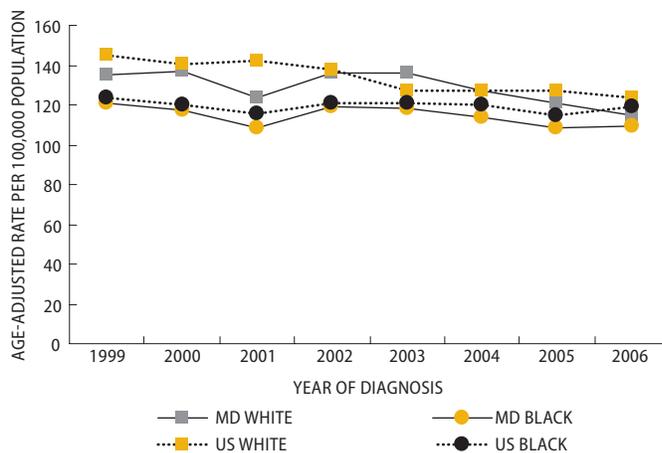
\*Rates are per 100,000 and are age-adjusted to 2000 U.S. standard population.

Total includes cases reported as unknown race.

Sources: Maryland Cancer Registry, 2004-2006.  
NCI SEER\*Stat (US SEER 17 rates).

FIGURE 10.1

Female Breast Cancer Incidence Rates by Race, Maryland and US, 1999-2006



Source: Maryland Cancer Registry, 1999-2006.

However, between the ages of 20 and 44, black or African American women have higher age-specific incidence rates than white women. This trend is similar to the national age-specific incidence rate.

For Maryland women of all races, stage of breast cancer at diagnosis is similar to national SEER data; however, Maryland has a higher proportion of cases that are not staged compared

**FAST FACT** Mortality rates from breast cancer have been decreasing nationally as well as in Maryland.

to SEER data (Figure 10.4). Staging is an important factor in determining the most appropriate treatment for women with breast cancer. In addition, early stage disease is associated with better outcomes than more advanced stage disease. The stage of disease depends on the size of the tumor at diagnosis and whether or not it has spread to local lymph nodes or to other parts of the body (metastasis). The proportion reported unstaged could be due to either lack of staging or lack of reporting of staging data.

Mortality rates from breast cancer have been decreasing nationally as well in Maryland (Figure 10.2) due to screening as well as improved treatment.<sup>24</sup> Although breast cancer mortality is declining in Maryland among all race groups, black or African American women continue to have significantly higher breast cancer mortality rates compared to white women, both nationally and in Maryland.<sup>19,20</sup> Because Maryland has a larger proportion of blacks or African Americans compared to the nation, the breast cancer mortality rate will likely remain high in Maryland until the gap between white and black or African American breast cancer mortality rates narrows.

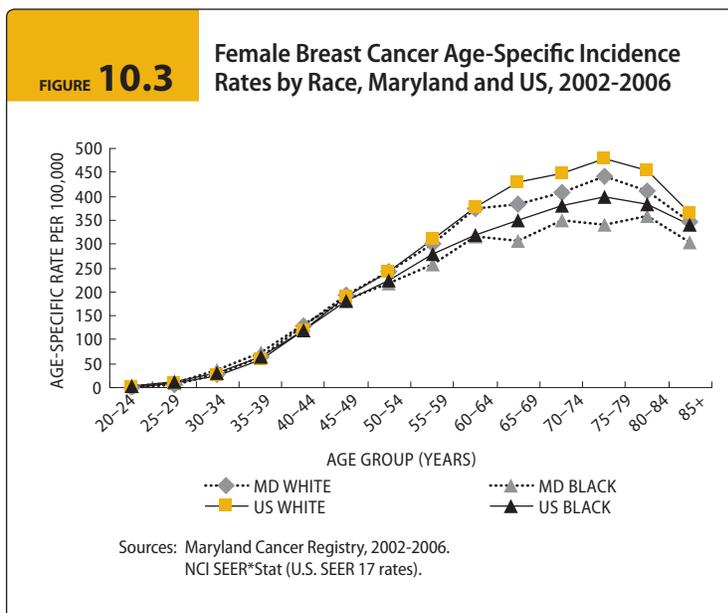
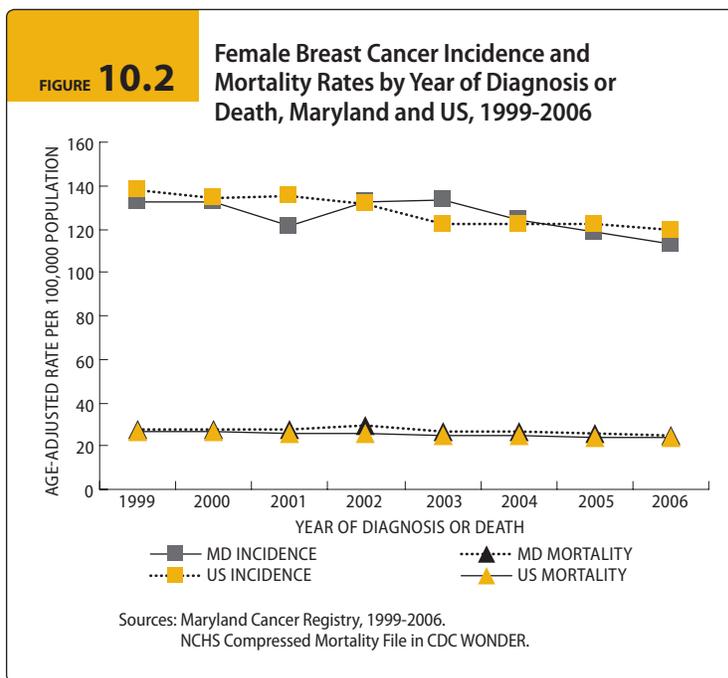
The National Cancer Institute estimates that approximately 2.9 million US women and approximately 58,600 Maryland women with a history of breast cancer are alive in 2010.<sup>21</sup> With advances in detection and treatment, the numbers of breast cancer survivors will continue to increase and their long-term medical needs will continue to be addressed.

## Current/Ongoing Breast Cancer Control Efforts in Maryland

**P**ROGRESS IN BREAST CANCER CONTROL has been accomplished with the assistance of many individuals and organizations throughout Maryland. Some of these efforts are highlighted below.

The Maryland Department of Health and Mental Hygiene (DMHM) Breast and Cervical Cancer Program (BCCP) is a statewide program that provides breast and cervical cancer screening

services to uninsured or underinsured, low-income (less than 250% of the federal poverty level) women 40 to 64 years of age. Across the state, the DHMH awards funds to each jurisdiction to coordinate the provision of breast and cervical cancer outreach, patient and public education, and screening, referral, follow-up, and case management services for its residents. Annually, the BCCP provides about 13,000 mammograms to Maryland women. The proportion of black or African American and Hispanic or Latina clients who have received services under the BCCP is greater than the proportion of these groups in the Maryland population.



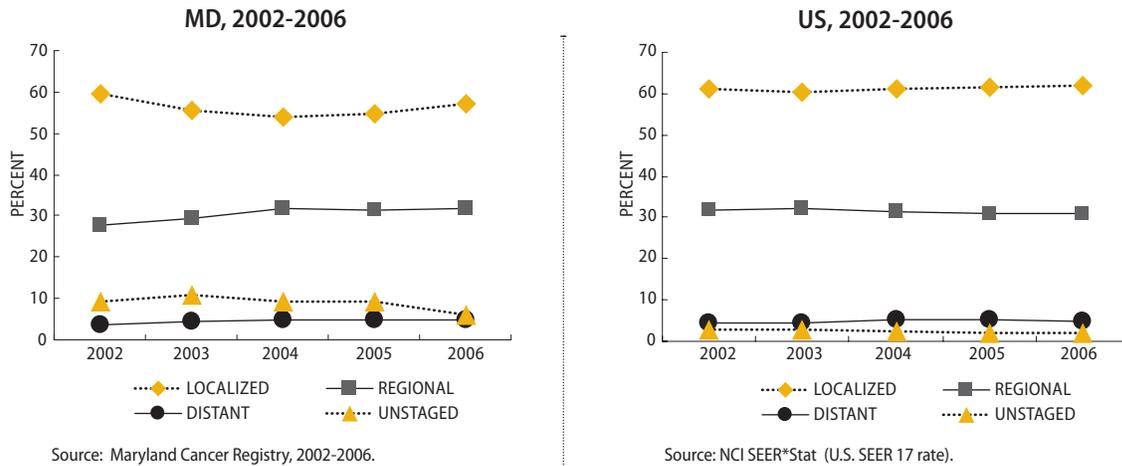
The DHMH formed a Breast Cancer Medical Advisory Committee, which developed guidelines titled Minimal Clinical Elements for Breast Cancer Screening. The Minimal Clinical elements provide guidance for public health programs that screen for breast cancer.

In addition, funding from the Cigarette Restitution Fund Program has been awarded to the University of Maryland Medical System/University Care to provide breast and cervical cancer screening for low-income, uninsured, or underinsured women who live in Baltimore City.

Several hospitals offer free breast cancer screening to high-risk or symptomatic women who do not qualify for state programs. Funding for these programs, usually from donations and private foundations, tends to vary from one year to the next. Patients needing a work-up or treatment are referred to the Maryland Breast and Cervical Cancer Diagnosis and Treatment Program.

**FAST FACT** The Maryland Breast and Cervical Cancer Diagnosis and Treatment Program covers diagnostic and treatment services for eligible Maryland residents diagnosed with either breast or cervical cancer.

FIGURE 10.4 Female Breast Cancer by Stage at Diagnosis



The Maryland Breast and Cervical Cancer Diagnosis and Treatment Program is a state-funded program that covers diagnostic and treatment services for Maryland residents who are diagnosed with either breast or cervical cancer, meet income guidelines (250% of the poverty level), and are either uninsured or underinsured for these services. The Women's Breast and Cervical Cancer Health Program provides Medicaid coverage to women who were screened under the BCCP and who have been diagnosed with either breast or cervical cancer. Women in this program are eligible for full Medical Assistance while they are undergoing treatment for breast or cervical cancer.

In addition to the state programs, nonprofit foundations provide a wide variety of programs for breast cancer patients, providers, and caregivers. These organizations provide support for clinical services, educational programs for patients and providers, counseling and support programs, community grants and research grants, and help to meet basic needs such as transportation, housing, and other basic services. Information about services and links to many of these organizations is available at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

Numerous laws related to breast cancer have been passed in Maryland. These laws address issues related to provision of screening services and treatment, including access to clinical trials. Additional information on laws relevant to breast

cancer control can be found in the text box, Maryland Law Related to Breast Cancer on page 11.

## Disparities

### Factors That Contribute to Disparities Across the Continuum of Breast Cancer Control

**CANCER IS AN EQUAL OPPORTUNITY DISEASE:** It affects men and women of all socioeconomic levels, races, and ethnicity, across age groups and regions of the state and country. Unfortunately, access to prevention, screening, diagnosis, treatment, and after-cancer care for breast cancer is not uniformly accessible or provided. Disparities across the continuum of cancer control persist by factors such as urban/rural location, age, race, ethnicity, insurance, and socioeconomic status.<sup>25</sup> Programs in Maryland have helped to address barriers to breast cancer care, but there is much more to do to address these disparities.

Even if universal healthcare is achieved, there will be individuals with gaps in health insurance coverage and therefore populations who lack access to consistent healthcare. Even if insured, not all would have adequate coverage from prevention through survivorship care. Although Maryland helps to fill some of these gaps through the Breast and Cervical Cancer Screening Program, the Cigarette Restitution Fund Program, and the Breast and Cervical Cancer Diagnosis and Treatment Program, funds are not sufficient to cover all in need.

Those in rural communities may have limited access to primary care providers and state-of-the-art diagnosis and treatment facilities. Lack of employment opportunities, lack of health insurance, and lack of public transportation compounds the access issues. Women in rural settings have lower screening rates compared to women in urban settings.<sup>26</sup> These differences result in differential effects for care across age, race, and socioeconomic groups.

Ethnic and racial differences in breast cancer outcomes are due to a combination of factors, such as screening rates, access to treatment, and prompt treatment. However, there may be underlying biological factors that also contribute to disparities in outcomes. In general racial and ethnic minority groups tend to be diagnosed with more advanced stage disease compared to white women, and some differences persist even within healthcare settings that provide similar access to care among the groups.

Age also influences screening and treatment. Older women are less likely than younger women to be offered the opportunity to take part in clinical trials and to receive optimum treatment as defined by accepted standard-of-care treatment guidelines.<sup>27,28</sup> Often multiple factors—such as older age, race, and language barriers—are present that contribute to disparities in prevention, screening, diagnosis, and treatment.

Efforts to overcome disparities need to be aimed at multiple levels: patient, provider, and the health system. Breaking down cultural and language barriers is critical for both the health-care consumer and the provider. Providers should be equipped to provide culturally sensitive resources and services that have been proven effective at all stages of the cancer control continuum from prevention to survivorship care.

Participation in clinical trials should be encouraged. Healthcare systems should facilitate care by making system changes that ensure preventive and screening services are offered when appropriate and that diagnosis and treatment are done promptly and efficiently, offering the optimum standard of care per accepted treatment guidelines established by organizations such as the National Comprehensive Cancer Network.

## Continuum of Cancer Control

**INTERVENTIONS ACROSS THE CONTINUUM** of breast cancer control, as outlined in Figure 10.5, are needed to achieve the goals of reduced incidence, morbidity, and mortality from breast cancer. Cancer control encompasses prevention, screening and early detection, effective treatment, survivorship care, and end-of-life care.

### 1. Prevention

**CLINICAL TRIALS HAVE PROVEN** that among women at increased risk to develop breast cancer (defined as a five-year risk of breast cancer greater than 1.67%), taking Tamoxifen or Raloxifene for five years reduces the risk of breast cancer by about 50%.<sup>29</sup> Evidence also supports that regular moderate exercise at any age, but especially during adolescence, is associated with a lower risk of developing breast cancer. After menopause, being overweight is associated with an increased risk of breast cancer, so maintaining a healthy weight through diet and exercise is an important lifestyle factor that may help to reduce the risk of developing breast cancer. In addition, breast-feeding has been shown in some studies to be associated with a reduced risk of developing breast cancer.

Avoiding factors such as radiation exposure, especially during adolescence when breasts are developing, can help to minimize risk. In addition to maintaining a healthy weight, data suggest that minimizing alcohol intake to fewer than three to four drinks a week may help lower the risk of breast cancer.

Following the report of results from the Women's Health Initiative (WHI) that confirmed results from cohort studies showing an increased risk of breast cancer with use of combined estrogen and progestin hormone therapy after menopause, use of combination hormone therapy plummeted.<sup>30,31</sup> Subsequent to the publication of these results, breast cancer incidence rates were noted to be decreasing in the United States and elsewhere with the decline largely attributed to changes in use of postmenopausal hormone therapy.<sup>32,33</sup> Avoiding long-term use of combined hormone therapy after menopause would be a prudent action to minimize breast cancer risk. It is important to note, however, that a companion arm

of the Women’s Health Initiative trial that tested the use of estrogen-only hormone therapy among women who had a hysterectomy observed a nonstatistically significant decreased risk of breast cancer associated with estrogen use compared to a placebo.<sup>34</sup> Estrogen-only hormone therapy is only indicated for women who have had a hysterectomy due to the increased risk of endometrial cancer when using estrogen unopposed by progestin.

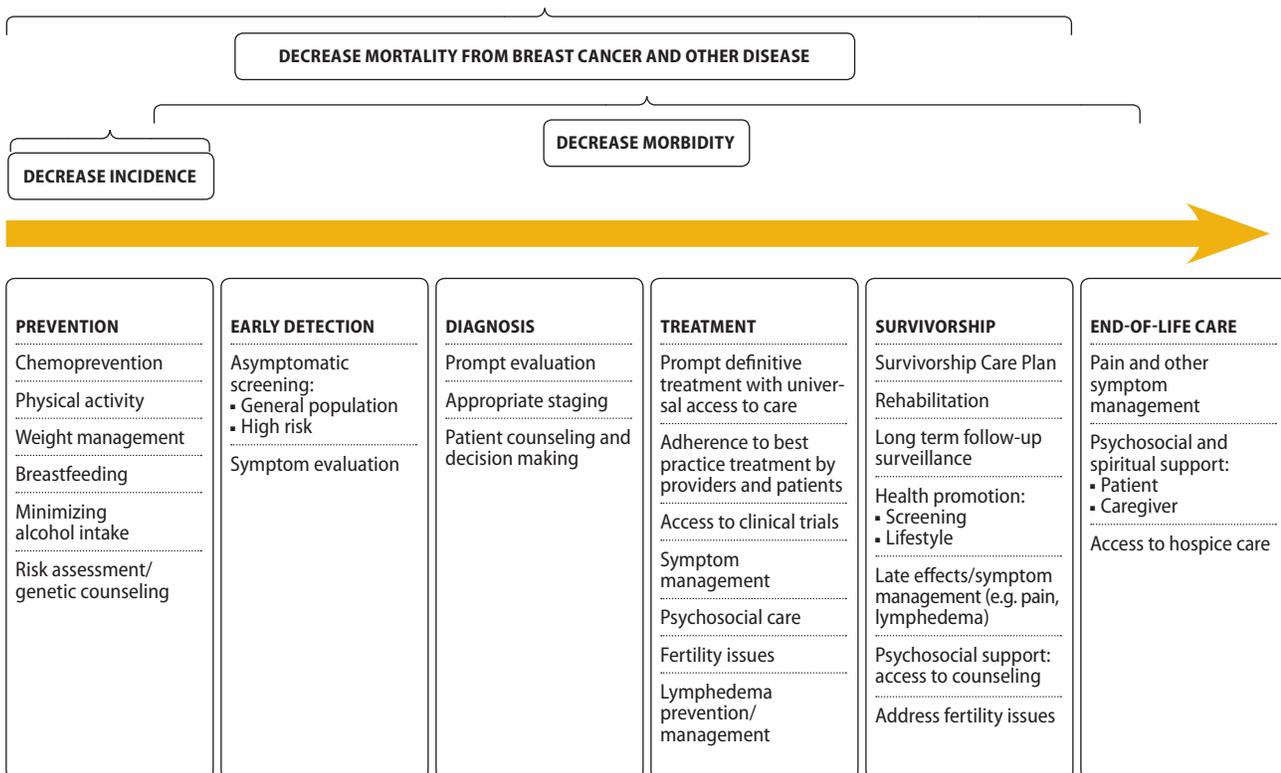
Evaluating a woman’s risk factor profile and estimated risk to develop breast cancer should be a part of routine primary care. Individuals at very high risk of developing breast cancer—such as women who carry mutations in the BRCA1 or BRCA2 genes or other genes known to be associated with an increased risk of breast cancer (e.g., PTEN and p53), women with a strong family history of breast cancer unexplained by known genetic changes, and women with prior high-dose radiation exposure—should receive counseling regarding prevention and screening management options.

## 2. Early Detection

**MAMMOGRAPHY AND CLINICAL BREAST EXAMINATION** are the primary methods of screening for breast cancer for the general population of women 40 years and older.<sup>35,36</sup> A mammogram is a dedicated x-ray of the breast that can often find tumors that are too small to be felt. The ability of mammography to detect cancer depends on factors such as the size of the tumor, the age of the woman, breast density, and the skill of the radiologist. Presently, it is the only screening exam that has been shown to reduce mortality from breast cancer. The degree of benefit with regularly mammography varies by age with more benefit observed at higher ages. One reason is that the breast tissue is easier to examine as a woman ages. Based on evidence from clinical trials clinical breast examination is recommended along with routine mammography in the United States.<sup>37,38,39</sup> Studies have been conducted to examine whether or not instructing women in breast self-examination is beneficial in reducing mortality from breast cancer.<sup>40</sup>

FIGURE 10.5

Interventions Across the Continuum of Breast Cancer Control



Adapted from: Institute of Medicine "From Cancer Patient to Cancer Survivor: Lost in Translation" (2005) and National Cancer Institute.

The studies showed that more breast biopsies were done, but there was no benefit in reducing mortality from breast cancer.

Since 1987, the United States has seen a rapid increase in reported use of mammography. The percentage of women ages 40 and older reporting a mammogram in the past two years jumped from 39.1% in 1987 to 70% in 2000.<sup>41</sup> Maryland followed the same trend; the percentage of Maryland women ages 40 and older reporting a mammogram within the previous two years increased from 75% in 1990 to about 82% in 2000. However, since 2000, mammography rates have stabilized and in some cases declined.<sup>42,43</sup> In 2008, the percentage of Maryland women ages 40 and older who reported having a mammogram in the past two years dropped to 77%, but this change in screening rates is not statistically significant. Maryland's rates are similar to the national rates for women ages 40 and older reporting a mammogram within the previous two years; the Healthy People 2010 goal was 70% and was met by the state of Maryland.

Among women at high risk of developing breast cancer (>20% lifetime risk), additional tests such as ultrasound and magnetic resonance imaging (MRI) of the breasts may be indicated. Personalizing screening plans for women is dependent on assessing their risk profile.

### 3. Diagnosis

**ONCE AN ABNORMALITY IS DETECTED** either by physical examination or screening mammography, additional testing is needed to make the appropriate diagnosis.<sup>44</sup> A first step in evaluating an abnormality noted on a screening mammography is to conduct a more detailed mammographic examination (diagnostic mammogram) with additional views such as magnification and compression views of the specific area in question. This may clearly show that the finding on the initial mammogram was benign and no additional testing may be needed. Sometimes additional testing with breast ultrasound or MRI is required and ultimately a breast biopsy may be indicated.

Ultrasound is useful for evaluating breast masses identified on mammogram and physical exam. Ultrasound can differentiate between cysts versus benign/suspicious masses that may require

further tissue sampling. Ultrasound is also useful in evaluating axillary lymph nodes for possible metastasis in known breast cancer patients. Advancements in ultrasound technology now offer three-dimensional capability, which may improve its sensitivity for detecting cancer.

Magnetic resonance imaging (MRI) may be indicated but its role in screening and diagnosis is still being evaluated. MRI has a high sensitivity (ability to detect) an invasive breast cancer but it also has more false positives than mammography, which may cause unnecessary anxiety or biopsies. However, sensitivity of MRI to detect the in situ breast disease is less than with mammography.

Abnormalities that are suspicious from either the tests described above or physical examination should be biopsied to determine if these abnormalities are cancer. The majority of breast cancer abnormalities can be evaluated with a needle core biopsy. To make sure there is adequate sampling, a core biopsy should be performed with imaging guidance even if the lesion can be felt. Based on the results of the needle biopsy, surgical excision may be needed.

### 4. Treatment Options

**DETECTING BREAST CANCER AT AN EARLY STAGE OF DISEASE** and completing treatment are essential to maintaining the best outcomes. Treatment options for breast cancer are continually evolving and are tailored to the individual patient and breast cancer biology. Choosing the optimum treatment is best achieved by a multidisciplinary approach including surgery, medical oncology, radiation oncology, genetics, nursing, with consideration for the individual patient. The multi-modality approaches should be in line with recommended treatment guidelines. Participation in clinical trials is very important to make further advances in prevention, treatment, and survivorship. Up-to-date treatment algorithms are detailed by the National Comprehensive Cancer Network (NCCN) ([www.nccn.org](http://www.nccn.org)) and other organizations such as the American Cancer Society ([www.cancer.org](http://www.cancer.org)), American Society of Clinical Oncology (ASCO) ([www.asco.org](http://www.asco.org)), and American College of Surgeons ([www.facs.org](http://www.facs.org)). Advances in treatment include surgical advances such as the use of sentinel lymph node biopsies (which is a major advance in helping to reduce the incidence of

lymphedema); new methods to deliver radiation safely, effectively, and efficiently; and new types of chemotherapy and hormonal therapy.

Patients benefit from culturally sensitive information, which can be obtained from the Cancer Information Service, National Cancer Institute, American Cancer Society, and Susan G. Komen for the Cure. Patients should be aware of their treatment options and understand potential side effects. A follow-up plan should be reviewed with each patient to ensure monitoring for recurrences and long-term complications. These guidelines are available through the NCCN and ASCO. Diagnostic work-up and treatment services are available through the Maryland Breast and Cervical Cancer Diagnosis and Treatment Program; however, funds are currently insufficient to serve all uninsured and underinsured women diagnosed with breast cancer in Maryland.

## 5. Survivorship

**A GOAL FOR ALL PATIENTS WITH CANCER** is to successfully complete treatment with minimum treatment-associated acute and long-term adverse health consequences. The acute consequences of treatment are well documented but less is known about long-term consequences. More research is needed to determine how best to reduce both short- and long-term adverse effects of breast cancer treatment.

To improve the health-related quality of life of cancer patients, the Institute of Medicine's report "From Cancer Patient to Cancer Survivor: Lost in Transition"<sup>45</sup> calls for all patients to have a survivorship care plan as part of the standard of care. The essential elements of survivorship care include: prevention of recurrent and new cancers and other late effects, surveillance for cancer and assessment of medical and psychosocial late effects, intervention for effects of cancer and its treatment, and coordination of care between specialists and primary care providers. These elements should be incorporated into the ongoing care of all cancer patients. See Chapter 4 for goals related to survivorship care for cancer patients.

## 6. Palliative and Hospice Care

**WOMEN WITH METASTATIC BREAST CANCER** have a wide array of potential chemotherapy options for treatment. While metastatic breast cancer is not curable, long-term survival is still possible with treatment. Treatment is available with the goals of both relief of symptoms and extension of life. At some point in the course of the disease, life extension is no longer possible, and the first and foremost goals are symptom relief and quality of life. Although breast cancer patients may have specific challenges at this point in care compared to other cancer patients, many of the challenges of end-of-life care are shared among cancer patients. End-of-life care is critical for both the patient and their family members. Chapter 15 provides the overall goals for palliative and hospice care for patients in the state of Maryland.

## Maryland Laws Related to Breast Cancer

### THESE LAWS REQUIRE HEALTH INSURERS AND HEALTH MAINTENANCE ORGANIZATIONS TO:

Provide coverage for routine mammography screening without a deductible charge.

- SB 445 <http://www.michie.com/maryland>  
(See Maryland Insurance Code Title 15 Section 814)

Provide coverage for reconstructive breast surgery following a mastectomy and include surgery to the non-diseased breast to establish symmetry with the diseased breast.

- HB 1267 Applies to the Breast Cancer Diagnosis and Treatment Program:  
<http://mlis.state.md.us/PDF-Documents/2001rs/bills/hb/hb1267e.PDF>
- HB119/SB181 Applies to health insurers and health maintenance organizations:  
<http://mlis.state.md.us/PDF-Documents/1996rs/bills/hb/hb0119t.PDF>

Provide coverage for patient costs incurred as a result of treatment provided in a clinical trial for: (1) a life-threatening condition; or (2) prevention, early detection, and treatment studies on cancer.

A carrier must provide coverage for costs incurred by patients for FDA-approved drugs and devices, whether or not the FDA has approved the drug or device for treating the enrollee's particular condition.

- HB45/SB137 <http://mlis.state.md.us/PDF-Documents/1998rs/bills/hb/hb0045t.PDF>

Pay for a minimum of 48 hours of inpatient care following a mastectomy or cover costs of one home visit within 24 hours following discharge.

- SB173/HB41 <http://mlis.state.md.us/2009rs/bills/sb/sb0173t.pdf>

Provide coverage for a breast prosthesis.

- SB 181 <http://mlis.state.md.us/PDF-Documents/1999rs/bills/sb/sb0181e.PDF>

Reimburse patients (up to \$350) for the cost of a hair prosthesis when the loss of hair is due to chemotherapy or radiation treatments for cancer.

- HB45/SB386 <http://mlis.state.md.us/PDF-Documents/2000rs/bills/sb/sb0386e.PDF>

### THESE LAWS ARE FOR PHYSICIANS:

Physicians who treat breast cancer patients are required to provide them with a written summary (to be provided by DHMH) describing various breast cancer treatments.

<http://www.dsd.state.md.us/comar/comarhtml/10/10.14.03.03.htm>

Physicians who perform breast implantations are required to provide patients with a standardized written summary (provided by DHMH) describing the advantages, disadvantages, and risks associated with breast implantation.

<http://www.dsd.state.md.us/comar/comarhtml/10/10.14.03.03.htm>

## GOALS - OBJECTIVES - STRATEGIES

### GOAL 1

Reduce the incidence of breast cancer in Maryland.

#### TARGETS (2015)

OVERALL	96.5 per 100,000 (2006 Baseline: 112.8 per 100,000)
BLACK OR AFRICAN AMERICAN	97.7 per 100,000 (2006 Baseline: 109.7 per 100,000)
WHITE	97.7 per 100,000 (2006 Baseline: 115.0 per 100,000) Source: Maryland Cancer Registry.

#### OBJECTIVE 1

By 2015, improve healthy behaviors of Marylanders including decreasing the number of women who are overweight or obese and increasing physical activity.

See the *Nutrition, Physical Activity, and Healthy Weight* chapter for specific objectives and strategies.

#### OBJECTIVE 2

By 2015, increase the proportion of Maryland women breastfeeding to reach the following targets:

- Increase the percentage ever breastfed to 85% (2006 Baseline: 75%).
  - Increase the percentage breastfeeding at six months to 67% (2006 Baseline: 46%).
  - Increase the percentage breastfeeding at 12 months to 42% (2006 Baseline: 26%).
- Source: CDC National Immunization Survey.

#### STRATEGIES

- 1 **SUPPORT WORKPLACE INITIATIVES** to encourage continued breastfeeding after return to work.
- 2 **INCREASE AWARENESS AND SUPPORT** the implementation of legislation requiring employers with more than 50 employees to provide break time and facilities (other than the bathroom) for breast pumping at work.
- 3 **ENCOURAGE THE ADOPTION** of the Ten Steps to Successful Breastfeeding (outlined by UNICEF/WHO) by Maryland hospitals.

#### OBJECTIVE 3

By 2015, incorporate breast cancer risk assessment as a part of routine healthcare for all women and conduct appropriate risk-based counseling for breast cancer prevention and screening.

#### STRATEGIES

- 1 **ASSESS THE NUMBER OF WOMEN COUNSELED** regarding their risk of breast cancer through surveys such as the Behavioral Risk Factor Survey or Maryland Cancer Survey to establish a baseline and appropriate target goals.
- 2 **DISSEMINATE AVAILABLE TOOLS** for cancer risk assessment to primary healthcare providers to assist in determining who is at risk.
- 3 **PROMOTE COVERAGE** for and increase awareness of individual counseling for risk reduction strategies (lifestyle factors such as weight management and exercise, genetic counseling and testing when appropriate, chemoprevention, avoiding or reducing combination hormone therapy after menopause, risk-reducing surgery, minimizing radiation exposure, and other strategies as they develop).

### GOAL 2

Reduce the morbidity and mortality from breast cancer in Maryland.

#### MORTALITY TARGETS (2015)

OVERALL	22.0 per 100,000 (2006 Baseline: 25.0 per 100,000)
BLACK OR AFRICAN AMERICAN	25.1 per 100,000 (2006 Baseline: 30.3 per 100,000)
WHITE	20.7 per 100,000 (2006 Baseline: 23.7 per 100,000) Source: CDC WONDER.

#### OBJECTIVE 1

By 2015, increase the percentage of females in Maryland ages 40 and above who have received a mammogram in the past two years to greater than 77% (2008 baseline: 77%).

Source: MD BRFSS.

#### STRATEGIES

- 1 **PROMOTE ADEQUATE FUNDING** for screening mammography:
  - Support universal healthcare that includes breast cancer screening services.

## GOALS - OBJECTIVES - STRATEGIES

- Maintain the Breast and Cervical Cancer Program for uninsured and underinsured women.
- Maintain mandatory insurance coverage and no co-pays for screening mammography.
- 2 INCORPORATE SYSTEM CHANGES** in healthcare provider settings that automatically order annual mammography for women 40 and older.
- 3 SUPPORT POLICIES** that allow work-time release to obtain cancer-screening services (as was done for Baltimore City employees).
- 4 REMOVE BARRIERS TO SELF-REFERRAL** for women 40 and older to obtain annual mammography and employ strategies such as direct-to-consumer advertising, mobile mammography services, and others to reach underserved individuals and ensure adequate follow-up.

### OBJECTIVE 2

**By 2015, ensure that all individuals are promptly diagnosed within 60 days of abnormal screening and receive appropriate surgical (including breast reconstruction) options and adjuvant therapy treatment according to national guidelines (e.g., CDC, NCCN guidelines).**

#### STRATEGIES

- 1 ESTABLISH THE BASELINE RATES** of individuals receiving diagnosis within 60 days and adherence to guidelines for prescribed treatment, and monitor/report primary treatment patterns using Maryland Cancer Registry and/or hospital tumor registries.
- 2 REDUCE THE NUMBER OF BREAST CANCERS** that are reported as unstaged in the Maryland Cancer Registry:
  - Decrease the number of death-certificate-only and/or lab-only reports.
  - Determine and support the use of sentinel node biopsy as part of the staging procedure.
  - Ensure that all women undergo appropriate staging procedures per national guidelines (e.g., American College of Surgeons guidelines).
- 3 INCLUDE “AMOUNT OF TIME TO DIAGNOSIS”** and “breast cancer treatment” as part of quality indicators that are publicly reported.

- 4 ENCOURAGE THE DEVELOPMENT** of patient navigator/ case manager programs to serve all patients, especially low-income populations, in order to ensure that patients have access to necessary services.
- 5 IMPROVE THE NUMBER OF PATIENTS** participating in clinical trials by improving access throughout the state and increasing the provider network offering clinical trials.

### OBJECTIVE 3

**By 2015, ensure that all patients have a survivorship care plan as part of routine care and have adequate access to supportive care for pain and other symptom management for those living with, through, and beyond cancer.**

#### STRATEGIES

- 1 ASSESS THE NUMBER OF PATIENTS** who receive survivorship care plans and supportive care for pain/symptom management through patient and provider survivors in order to establish a baseline and measure progress.
- 2 ESTABLISH MINIMAL CLINICAL ELEMENTS** for survivorship, pain management, and palliative and hospice care.
- 3 IMPROVE THE ASSESSMENT AND TREATMENT** of pain and other symptom management by including assessments at each follow-up visit and incorporating systemic methods to trigger appropriate follow-up and treatment (including access to psychological services and palliative and hospice care if needed).

*See the Patient Issues and Cancer Survivorship, Pain Management, and Palliative and Hospice Care chapters for additional specific objectives and strategies.*

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# 11 · Prostate Cancer



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## 11

## PROSTATE CANCER

The prostate is a small gland located beneath the bladder and in front of the rectum. It surrounds the urethra, which is the tube that empties urine from the bladder (Figure 11.1).

Only men have a prostate. It is part of the reproductive system.

**PROSTATE CANCER** is the uncontrolled growth and invasion of malignant prostate cells. Not all prostate conditions are cancer. Common non-cancerous conditions of the prostate include benign prostatic hyperplasia and prostatitis.

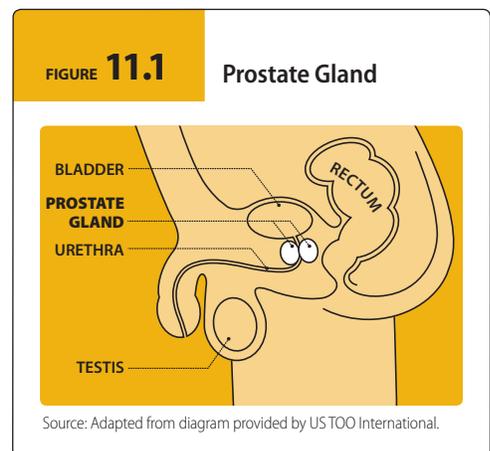
### Burden of Prostate Cancer

**Prostate cancer is the most commonly diagnosed non-skin cancer and it is the second cause of cancer death after lung cancer in US men. One in six men (17%) is diagnosed with prostate cancer during his lifetime, whereas the lifetime risk of dying from this cancer is only 3%.**

**DETAILS** on the number of prostate cancer cases and rates in the US may be found on these Web sites:

- National Cancer Institute: Surveillance Epidemiology and End Results: <http://seer.cancer.gov/>.
- American Cancer Society: <http://www.cancer.org/>.

**PROSTATE CANCER** is also the most commonly diagnosed cancer in men living in other economically developed countries, although the incidence rate is lower because the PSA test (see Prostate Cancer Early Detection section) is



not routinely used for prostate cancer screening elsewhere. In developing countries, prostate cancer is not as common, but in some countries the rate is increasing. See the American Cancer Society Web site for more information: <http://www.cancer.org/>.

Similar to US men as a whole, prostate cancer is the most commonly diagnosed non-skin cancer among men in Maryland. In 2006, 3,897 Maryland

men were diagnosed with prostate cancer. The age-adjusted prostate cancer incidence rate in Maryland in 2006 is 153.9 per 100,000 men; this rate is similar to the 2006 US SEER age-adjusted prostate cancer incidence rate of 154.0 per 100,000 men (Table 11.1).

Similar to US men as a whole, prostate cancer is the second most common cancer cause of death in Maryland men. In 2006, 531 Maryland men died of prostate cancer. The age-adjusted mortality rate in Maryland in 2006 is 26.3 per 100,000 men; this rate is slightly higher than the US SEER age-adjusted prostate cancer mortality rate of 23.5 per 100,000 men (Table 11.2). Prostate cancer mortality rates have been declining in the US, including in Maryland, since the mid-1990s (Figure 11.2).<sup>1</sup>

Additional details on prostate cancer in Maryland, including rates by county, stage at diagnosis, and survival may be found on this Maryland Department of Health and Mental Hygiene Web site ([http://fha.maryland.gov/cancer/surv\\_data-reports.cfm](http://fha.maryland.gov/cancer/surv_data-reports.cfm)). Additional details for the US may be found on these Web sites:

- National Cancer Institute: Surveillance Epidemiology and End Results: <http://seer.cancer.gov/>.
- American Cancer Society: <http://www.cancer.org/>.

## Disparities

Similar to US men as a whole, black or African American men in Maryland are more likely to be diagnosed with prostate cancer (Table 11.1) and more likely to die of prostate cancer (Table 11.2) than white men in Maryland.

**I**N THE US, the lifetime risk of developing prostate cancer for black or African American men is one in five as opposed to one in six for white men (<http://www.cancer.org/>). However, when comparing black or African American men in Maryland to the US

TABLE 11.1

Prostate Cancer Incidence Data by Race, Maryland and the US, 2004-2006

	TOTAL	WHITES	BLACKS	OTHER
<b>2004</b>				
MD New Cases (count)	3,579	2,381	1,051	106
MD Incidence Rate	148.0	132.0	202.7	112.9
US SEER Rate	158.4	151.9	242.7	93.7
<b>2005</b>				
MD New Cases (count)	3,649	2,418	1,042	150
MD Incidence Rate	147.2	131.7	193.3	149.5
US SEER Rate	146.2	140.2	222.5	83.3
<b>2006</b>				
MD New Cases (count)	3,897	2,554	1,032	206
MD Incidence Rate	153.9	137.3	186.3	191.2
US SEER Rate	154.0	147.7	217.5	85.2

Rates are per 100,000 and are age-adjusted to 2000 US standard population.  
Total includes cases reported as unknown race.  
Sources: Maryland Cancer Registry, 2004m-2006.  
NCI SEER\*Stat (US SEER 17 rates).

TABLE 11.2

Prostate Cancer Mortality Data by Race, Maryland and the US, 2004-2006

	TOTAL	WHITES	BLACKS	OTHER
<b>2004</b>				
MD Deaths (count)	560	368	186	6
MD Mortality Rate	28.6	24.1	52.9	**
US Mortality Rate	25.4	23.4	55.5	12.1
<b>2005</b>				
MD Deaths (count)	519	328	178	13
MD Mortality Rate	25.7	20.9	47.7	**
US Mortality Rate	24.5	22.6	53.3	11.5
<b>2006</b>				
MD Deaths (count)	531	341	s	<6
MD Mortality Rate	26.3	21.7	51.2	**
US Mortality Rate	23.5	21.7	50.5	10.4

Rates are per 100,000 and are age-adjusted to 2000 US standard population.  
\*\*MD mortality rates based on death counts of 0-15 are suppressed per DHMH/CCSC Mortality Data Suppression Policy.  
s = Counts are suppressed in CRF Cancer Report tables to prevent disclosure of data in other cell(s).  
<6 = MD death counts of 0-5 are suppressed per DHMH/CCSC Mortality Data Suppression Policy.  
Source: NCHS Compressed Mortality File in CDC WONDER.

as a whole, the prostate cancer incidence rate is lower in Maryland (Table 11.1).

Why black or African American men have a higher risk of prostate cancer is unknown. Fortunately, prostate cancer mortality rates in the US, including in Maryland, have been declining in both black or African American and white men (Figure 11.3 and <http://www.cancer.org/>).

## Prostate Cancer Risk Factors and Primary Prevention

**It has long been known that older men, men who have other relatives with prostate cancer, and black or African American men (including other men of African ancestry) have a higher risk of prostate cancer compared to white men.**

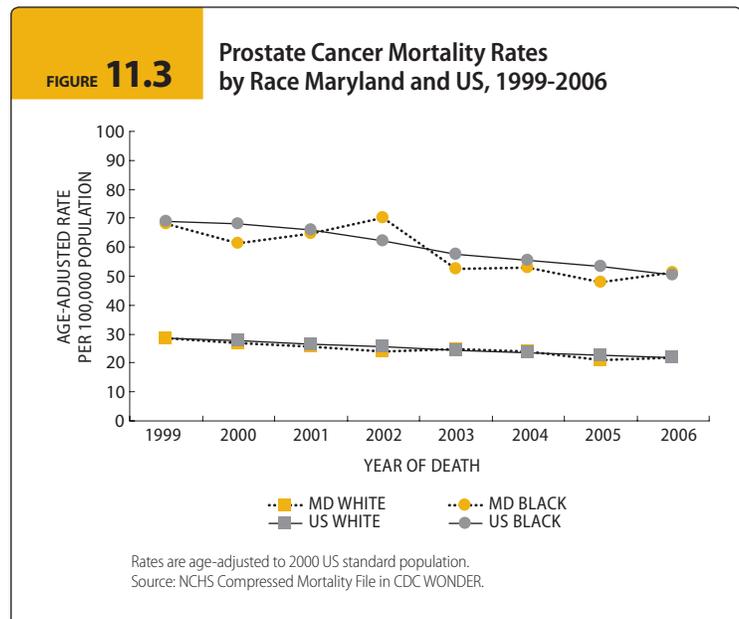
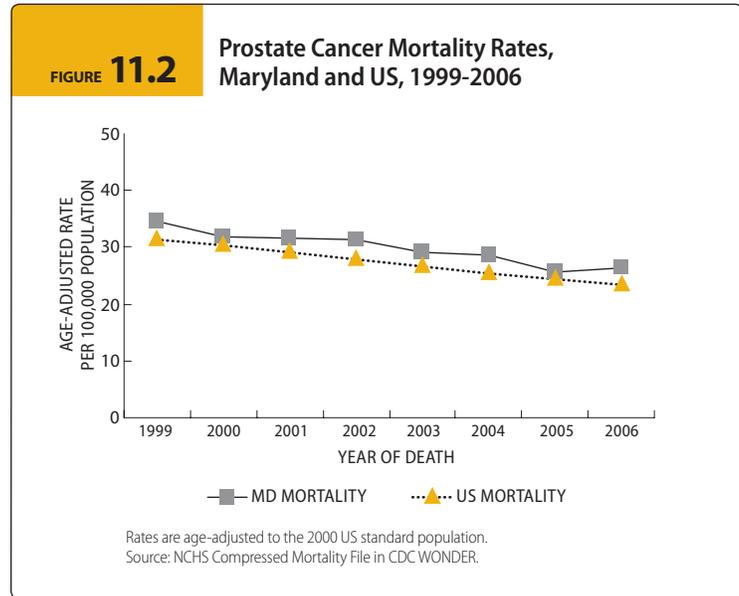
**S**INCE THE LAST CANCER PLAN prepared in 2004, results from studies investigating common variation in the sequence of DNA in men with and without prostate cancer have been published.<sup>2,3,4</sup> These findings may lead to understanding more about the genetic reasons why prostate cancer develops and who in the general population may be at greater risk.

However, unlike some other cancers, there are no well-established risk factors for prostate cancer that men can change to reduce their risk of developing it. Nevertheless, some research studies support that men who smoke and men who are obese are more likely to die of prostate cancer.<sup>5,6,7</sup>

Diet and nutrients may influence prostate cancer risk.<sup>8,9</sup> While not confirmed, men who eat a lot of meat, especially processed meat like bacon, and consume too many calories may have a higher risk of prostate cancer, whereas men who eat fish and foods containing tomato or cruciferous vegetables like broccoli may have a lower risk of prostate cancer. Taking vitamins or mineral supplements,

such as vitamin E and selenium, does not appear to be beneficial for avoiding prostate cancer, except possibly in men who have deficiency. More research needs to be done in this area. Taking calcium at levels above the recommended amount for adult men in some studies appears to increase the risk of metastatic prostate cancer.

More research needs to be done on whether common medications influence prostate cancer risk, but there are some interesting leads. Men who regularly take aspirin or other non-steroidal anti-inflammatory drugs, such as ibuprofen, may have a lower risk of prostate cancer.<sup>10</sup> Men who take a statin, a type of medication that is



commonly prescribed to lower serum cholesterol, may have a lower risk of metastatic prostate cancer.<sup>11</sup>

Smoking, obesity, and poor diet are leading causes of cardiovascular disease and other cancers in men and women. Therefore, preventing people from starting smoking and from gaining weight, intervening so that people can stop smoking and lose weight, and advocating a balanced diet are not only important strategies for good health in general, but also may be beneficial for avoiding prostate cancer.

Two drugs, finasteride and dutasteride, have been shown to reduce the risk of prostate cancer by about 25% in randomized controlled clinical trials.<sup>12,13</sup> Finasteride and dutasteride are sometimes prescribed to treat benign prostatic hyperplasia. These drugs are called “5 $\alpha$ -reductase inhibitors” because they block 5 $\alpha$ -reductase, an enzyme that helps convert testosterone to dihydrotestosterone, a more potent androgen. Based on the findings of these studies, the American Society of Clinical Oncology/American Urological Association issued a Clinical Practice Guideline recommending that healthy men who are screened regularly for prostate cancer and show no symptoms of the disease should talk to their doctors about using 5 $\alpha$ -reductase inhibitors to prevent the disease. However, these men should also understand the potential risks of using 5 $\alpha$ -reductase inhibitors including sexual side effects and the possibility of high-grade prostate cancer.<sup>14</sup>

For more information on prostate cancer risk factors and primary prevention, see the NCI Prostate Cancer Prevention Physician Data Query (PDQ) at [www.cancer.gov](http://www.cancer.gov).

**FAST FACT** Many organizations (including the American Cancer Society, the US Preventive Services Task Force, and the National Comprehensive Cancer Network) recommend that men discuss the benefits and risks of prostate cancer screening with a physician before deciding whether or not to be screened.

## Prostate Cancer Early Detection

**Two tests are used to screen for prostate cancer: a blood test called the prostate-specific antigen or PSA test, and a physical examination call the digital-rectal examination or DRE.**

**T**HE PSA TEST is done by drawing a man’s blood and measuring the level of PSA, which is a protein made by the prostate. The risk of prostate cancer rises gradually with an elevated PSA level.<sup>15</sup> However, an elevated PSA level does not necessarily mean that a man has prostate cancer. PSA levels are sometimes elevated when a man has benign prostatic hyperplasia or prostatitis. Because the PSA test is not specific for prostate cancer, some doctors calculate the change in PSA levels across at least three tests done over at least 18 months. This calculation is called the PSA velocity. Men who have a high PSA velocity are more likely to have prostate cancer. Measurement of PSA components such as free PSA improves the discrimination between cancer and benign prostatic disease. In men with prostate cancer, the percentage of free PSA (percent-free PSA) is lower in blood.

The DRE involves a physician inserting a gloved and lubricated finger into the rectum to feel the back portion of the prostate gland. Most often men are screened with both the PSA test and the DRE.

The benefits versus the problems of PSA screening are controversial. Two randomized controlled trials investigated whether PSA screening coupled with earlier treatment reduces the risk of prostate cancer death. The trial, conducted in Europe in populations without prior routine PSA screening, showed that the men who were randomized to receive PSA screening had a lower risk of dying from prostate cancer.<sup>16</sup> The trial conducted in US populations with prior routine PSA screening did not find that screening had any benefit in lowering deaths from prostate cancer.<sup>17</sup> Both trials found that in the group of men who were screened, many men were diagnosed and treated even though their prostate cancer was unlikely to have ever caused them ill health or death.<sup>18,19</sup>

At the time of the publication of the Prostate Cancer chapter, recommendations for prostate cancer screening vary by organization. However, many groups recommend against screening men who are older than 75 years or whose expected remaining lifespan is less than ten years, or recommend individualized decision-making for men over 75 years. Visit the Prostate Cancer page of [www.marylandcancerplan.org](http://www.marylandcancerplan.org) to learn more about prostate cancer screening recommendations.

The uncertainties of the benefits of screening versus the potential complications of treatment for prostate cancer have led many organizations—including the ACS, the US Preventive Services Task Force, and the National Comprehensive Cancer Network (NCCN)—to recommend that men discuss the benefits and risks of prostate cancer screening with a physician before deciding whether or not to be screened.

The American Cancer Society Web site has materials that may be helpful to men in deciding whether to be screened for prostate cancer: <http://www.cancer.org/>.

Prostate cancer screening is commonly offered to patients in physicians' offices. Sometimes screening is offered at community hospitals and in the community at health fairs and other special occasions focused on health. The Prostate Cancer Medical Advisory Committee of the Maryland State Department of Health and Mental Hygiene has developed guidelines (entitled Prostate Cancer Minimal Elements for Information, Screening, Diagnosis, Treatment and Follow-up) to provide guidance for public health programs that decide to screen for prostate cancer: <http://fha.maryland.gov/cancer/resources.cfm/>.

If a man has an abnormal screening PSA test and/or an abnormal screening DRE, he and his doctor may decide that the man should have a prostate biopsy. The biopsy involves removing samples of prostate tissue using needles inserted into the prostate through the rectum. A pathologist then reviews the prostate biopsy tissue to determine whether prostate cancer is present. If cancer is present, the pathologist will assign a Gleason score, a measure of how disorganized the cancer tissue appears relative to normal prostate tissue. Prostate cancers with a higher Gleason

**TERMS TO KNOW** *Watchful waiting, active surveillance, and expectant management* are all terms that describe an approach of prostate cancer management where a man diagnosed with prostate cancer that has not grown outside of the prostate and appears to be slow growing chooses to be monitored by his doctor, being treated only if additional biopsies indicate that the disease has worsened.

score are more likely to progress. For more detail on the Gleason score, visit the Prostate Cancer page of the Cancer Plan Web site: [www.maryland-cancerplan.org](http://www.maryland-cancerplan.org).

After a man is diagnosed with prostate cancer, his cancer stage is determined. Local stage means that the prostate cancer is confined to the prostate gland. Regional stage means that the prostate cancer has grown beyond the prostate gland to surrounding organs or tissues and/or regional lymph nodes. Distant stage means that the prostate cancer has spread to other parts of the body remote from the prostate gland, such as bone.

## Prostate Cancer Treatment

**Treatment for prostate cancer may involve surgery, radiation therapy, or hormonal therapy. Treatment options for prostate cancer depend, in part, on a man's age, overall health, and whether the cancer has grown outside of the prostate and spread elsewhere.**

**F**OR CANCERS THAT HAVE NOT GROWN OUTSIDE OF THE PROSTATE, surgery and radiation therapy are common treatment options. Surgery involves the removal of the entire prostate (radical prostatectomy). This surgery can be done either in an open fashion or laparoscopically. In the traditional open surgery for prostate cancer, the operation is performed after making an incision in the lower abdomen or perineum. In laparoscopic surgery, the operation is performed through small incisions with the aid of a camera. In most laparoscopic surgeries for prostate cancer, a surgical robot is used. Radiation therapy uses x-rays to

kill cancer cells. The radiation is delivered by an external beam or by radioactive seeds that are implanted in the prostate in or near the tumor (brachytherapy).

For some men whose prostate cancer has not grown outside of the prostate and appears to be slow growing, especially if they are older or have other serious medical problems, the risks and possible side effects of surgery and radiation therapy may outweigh the possible benefits. These men often choose to be monitored by their doctor and are treated only if additional biopsies indicate that the disease has worsened.<sup>20</sup> This approach to managing prostate cancer goes by several names including watchful waiting, active surveillance, and expectant management.

For cancers that have grown outside of the prostate, hormonal therapy is commonly used. Hormonal therapy combats prostate cancer by cutting off the supply of male hormones that encourage prostate cancer growth. Hormonal control can be achieved by drugs or by surgery to remove the testicles.

Clinical trials are being conducted to determine new ways of treating prostate cancer. The National Cancer Institute has a Web site for learning about clinical trials for prostate cancer treatment: <http://www.cancer.gov/>.

Each treatment for prostate cancer has risks, including impotence (erectile dysfunction), urinary incontinence, and bowel problems, such as diarrhea or rectal bleeding.

For more information on prostate cancer treatment options:

- National Cancer Institute:  
<http://www.cancer.gov/>.
- For physicians (requires registration):  
The National Comprehensive Cancer Network (NCCN): <http://www.nccn.org/index.asp>.

# GOALS - OBJECTIVES - STRATEGIES

## GOAL 1

**Reduce morbidity related to the detection and management of prostate cancer in Maryland men.**

### OBJECTIVE 1

By 2015, increase the proportion of men 40 years and older who report having had a discussion with their healthcare provider about prostate cancer screening to 74% (2008 Baseline: 64%).

Source: Maryland Cancer Survey.

### STRATEGIES

- 1 EDUCATE MEN AND THEIR FAMILIES AND FRIENDS** through public service announcements, Web sites, printed materials, etc. about the risks and benefits of prostate cancer screening and encourage them to discuss whether prostate cancer screening is right for them with their primary care provider or urologist.
- 2 EDUCATE PROVIDERS** with updated information about the potential benefits and problems of prostate cancer screening.
- 3 DEVELOP STRATEGIES FOR MONITORING** Objective 1, including:
  - Promote inclusion of questions about prostate cancer screening on the Maryland BRFSS.
  - Identify sources of funding for future Maryland Cancer Surveys and include questions about prostate cancer screening.
  - Encourage state-funded or other healthcare systems to monitor adherence to prostate cancer screening guidelines via electronic medical records systems.
- 4 REDUCE** the number of men being screened for prostate cancer past age 75.

### OBJECTIVE 2

By 2015, use Web sites, printed materials, and other media to educate Maryland men who have been diagnosed with prostate cancer and their families and friends about prostate cancer treatment options.

### STRATEGIES

- 1 EDUCATE MEN RECENTLY DIAGNOSED** with prostate cancer and their families and friends through Web sites, printed materials, and other media about evidence-based treatment options, including active surveillance. Include information about how and why treatment options vary by the stage and grade of the man's disease and age. Encourage them to discuss treatment options and accompanying risks and benefits with their doctor (or doctors if the men choose to have a second opinion or attend a multidisciplinary clinic).
- 2 EDUCATE MEN RECENTLY DIAGNOSED** with prostate cancer and their families and friends through Web sites, printed material, and other media about prostate cancer staging and grading (Gleason score) and how this information is used by doctors, in part, to determine treatment options for a given patient.
- 3 EXPLORE THE POSSIBILITY** of insurance companies in Maryland sending an educational pamphlet about prostate cancer treatment options to men with a pathologically confirmed diagnosis of prostate cancer.
- 4 DEVELOP A CLEARINGHOUSE** Web site to point men to information on treatment options.
- 5 SET UP AND ENCOURAGE MEN TO REGISTER** on a Web site that will provide them updated information on screening and treatment options.

## GOALS - OBJECTIVES - STRATEGIES

### OBJECTIVE 3

By 2015, increase the information available on overall well being for men recently diagnosed with prostate cancer and men who have survived prostate cancer.

#### STRATEGIES

- 1 **INFORM MEN AND THEIR FAMILIES AND FRIENDS** at the time of diagnosis about the availability of support and survivorship groups.
- 2 **EDUCATE MEN, INCLUDING MEN DIAGNOSED WITH PROSTATE CANCER**, about the major causes of death in the US and how to reduce their risks of premature death through dietary and lifestyle modification and medical care.

## GOAL 2

Continue to reduce the prostate cancer mortality rate in Maryland men.

#### TARGET (2015)

**MORTALITY** 14.9 per 100,000  
(2006 Baseline: 26.3 per 100,000)  
Source: CDC WONDER.

### OBJECTIVE 1

By 2015, increase the percentage of Maryland men receiving appropriate treatment for prostate cancer.

#### STRATEGIES

- 1 **DEVELOP METHODS TO MEASURE APPROPRIATE TREATMENT**, including by modifying cancer registry reporting criteria.
- 2 **INCREASE ACCESS TO APPROPRIATE TREATMENT** based on stage, grade, and other patient-specific characteristics, such as co-morbidities.
- 3 **IMPROVE TREATMENT ADHERENCE** for men diagnosed with prostate cancer through enhanced efforts to care for uninsured and underinsured men and increased availability of patient navigation.

- 4 **REDUCE THE PREVALENCE** of unstaged prostate cancer cases by continuing to modify cancer registry criteria for staging of early disease, by encouraging complete reporting from hospitals, doctors, and independent pathology groups, and by ensuring adequate patient staging, which is needed to make treatment decisions.

### OBJECTIVE 2

By 2015, reduce the disparity in prostate cancer mortality rates between black or African American and white men to reach the following targets:

<b>WHITE</b>	12.4 per 100,000 (2006 Baseline: 21.7 per 100,000)
<b>BLACK OR AFRICAN AMERICAN</b>	23.0 per 100,000 (2006 Baseline: 51.2 per 100,000)

Source: Maryland Vital Statistics.

#### STRATEGIES

- 1 **UTILIZE PATIENT NAVIGATORS**, community health workers and case managers to increase access to appropriate treatment (based on stage, grade, and other patient-specific characteristics).
- 2 **IMPROVE THE QUALITY** of and adherence to treatment for black or African American men diagnosed with prostate cancer through enhanced efforts to reach underserved populations and increased availability of patient navigators.

### OBJECTIVE 3

By 2015, create and maintain a Web site to educate Marylanders, including men diagnosed with and surviving prostate cancer, about ongoing research on risk factors for prostate cancer incidence and mortality, explanations for the racial disparity in these rates, screening, prognosis, treatment, and survivorship.

- 1 **DETERMINE WHICH GROUPS** are best able to develop and maintain the Web site and identify funding to do so.

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# 12 · Oral Cancer



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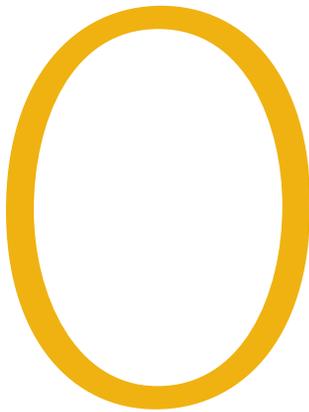
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# 12

## ORAL CANCER



Oral cancer is cancer of the mouth and surrounding tissues. It includes the lips, inside lining of the lips and cheeks (buccal mucosa), gingiva (gums), tongue, floor of the mouth below the tongue, hard palate (roof of the mouth), and the area behind the wisdom teeth called the retromolar trigone.

### **DID YOU KNOW?**

Oral cancer can form in any part of the mouth or throat. Most oral cancers begin in the tongue and in the floor of the mouth.

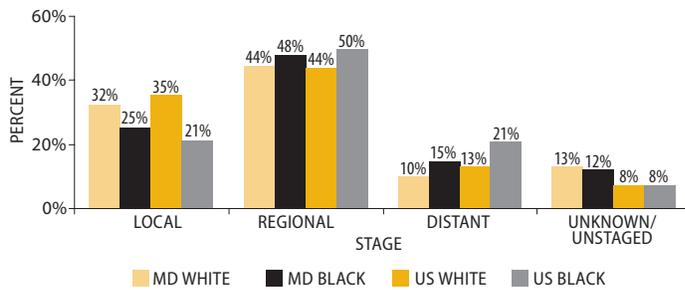
**ORAL CANCER** also includes the oropharynx (base of the tongue), soft palate (roof of the mouth behind the hard palate), tonsils, and sides and back wall of the throat. The American Cancer Society estimates that approximately 55,700 new cases of oral cancer will occur in the United States in 2009, and about 7,600 individuals will die from this disease.<sup>1</sup> In the United States, oral cancers are more common than Hodgkin lymphoma, or cancer of the brain, liver, bone, stomach, ovary, or cervix.<sup>1</sup> The signs and symptoms of oral cancer are described on the Maryland Cancer Plan Web site ([www.marylandcancerplan.org](http://www.marylandcancerplan.org)) on the Oral Cancer page.

Approximately 90% of all oral cancers are squamous cell carcinomas, and the remainder are salivary gland tumors and lymphomas. Oral squamous cell carcinomas generally develop after a long period of time from precancerous red-colored patches (erythroplakia) and, to a lesser extent, from white-colored patches (leukoplakia) in the mouth or on the lips. These cancers are primarily caused by tobacco use alone or in combination with heavy alcohol use.<sup>2</sup> If not detected early, squamous cell carcinomas can extend into nearby tissues and metastasize to regional lymph nodes in the head and neck. Treatment for oral cancer at all stages can cause disfigurement and dysfunction, but once oral cancer spreads, the course of treatment can cause severe disfigurement, pain, and dysfunction that affects speech, chewing, swallowing, and general quality of life. The most common sites for oral cancers are the tongue including the ventrolateral (side of the tongue near the back) and base of the tongue (25% of all oral cancers), tonsils

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FIGURE 12.1

Oral Cancer Stage at Diagnosis by Race in Maryland and the US, 2002-2006



Source: Maryland Cancer Registry, 2002-2006.

**FAST FACT** Anyone can get oral cancer, but the risk is higher for users of tobacco or alcohol, males, those over age 40, and those who have a history of head or neck cancer. Frequent sun exposure is also a risk for lip cancer.

(10-15%), lips (10-15%), and salivary glands (10-15%) with the remainder in the floor of the mouth, gingiva, and other sites.<sup>2</sup>

Individuals 45 years of age and over comprise more than 90% of all oral cancers.<sup>2</sup> Nationally, oral cancers account for 2% of all cancers for both genders; men account for more of these cancers than women.<sup>2,3</sup> Because of changing smoking patterns, the male-to-female ratio has decreased from 6:1 in 1950 to 2.5:1 at present.<sup>4</sup> Further, oral cancers occur slightly more frequently in blacks or African Americans than in whites with black or African American males accounting for this disparity.<sup>4</sup> Fortunately, new cases of oral cancer have been decreasing for both whites and blacks or African Americans since 2000.<sup>4</sup> While oral cancer mortality rates are decreasing for both blacks or African Americans and whites, these rates remain disproportionately high for US blacks or African Americans. This is especially true for black or African American males, who experience approximately one and a half times the mortality rate of US white males.<sup>4</sup>

The five-year oral cancer survival rate has improved somewhat over the past 30 years although not as much as for most major cancers. The overall five-year relative survival rate for 1999-2006 for oral cancer was 62.7%. Black or African American men had disproportionately lower five-year relative survival rates (40.1%) compared to white men (64.4%), white women (65.6%), and black or African American women (65.8%).<sup>4</sup> Diagnosis of oral cancer at advanced stages is likely responsible for the low survival

rate associated with oral cancers relative to other major malignancies.

Nationally, approximately 34% of oral cavity and pharynx cancer cases were diagnosed while the cancer was still confined at a localized stage (i.e., primary site) with 44% being diagnosed at a regional stage (after the cancer has spread to regional lymph nodes or directly beyond the primary site), 14% diagnosed at a distant stage (after the cancer has already metastasized), with the remaining 8% reported as unknown stage.<sup>4</sup> The corresponding five-year relative survival rates were 82.7% for localized, 54.3% for regional, and 31.8% for distant stage.<sup>4</sup>

In the United States, only 23% of blacks or African Americans with oral cancer are diagnosed at a local stage compared to 36% for whites.<sup>4</sup> A comparison of regional staging shows higher rates in blacks or African Americans (50%) than in whites (44%); for distant staging, blacks or African Americans (21%) have nearly a twofold difference compared with whites (13%).<sup>4</sup> Figure 12.1 shows a comparison of cancer stage at diagnosis by race in Maryland and nationwide; Maryland exhibits less difference by race than the US. Although clinically more visible than most other cancers, and amenable to detection through screening tools such as physical observation and palpation, most oral cancers are detected and diagnosed at regional or distant stages.

## Risk Factors and Primary Prevention

Several risk factors increase the chance of developing oral cancer, including the following.

### Tobacco and alcohol use

**THE PRIMARY RISK FACTORS** for oral cancer are past and present use of tobacco products including cigarettes, cigars, pipe and spit tobacco, and alcohol.<sup>5,6,7</sup> Tobacco and alcohol use account for 75% of all oral cancers. Compared to nonsmokers, smokers have up to an 18-fold risk of developing oral cancer. Heavy alcohol drinkers (men who drink more than four standard drinks per day or more than fourteen per week and women who drink more than three per day or more than seven per week)<sup>8</sup> who smoke more than one pack of cigarettes a day are at an even higher risk for oral cancer than those who use neither tobacco nor alcohol. It is believed that alcohol acts as a facilitator for the penetration of tobacco carcinogens into the soft tissues of the mouth. In addition, evidence suggests that marijuana use may also increase the risk for oral cancer.<sup>9</sup>

Because of confounding factors from concurrent tobacco and alcohol use and different patterns of spit tobacco use, the role of spit tobacco in oral cancer development is less clear than that of other forms of tobacco use.<sup>10,11</sup> However, various national and international agencies and advisory committees have concluded that the many forms of spit tobacco, including snuff and chewing tobacco, do play a role in oral cancer development, especially in younger age groups who more frequently use this form of tobacco.<sup>12</sup> Other types of tobacco use and behaviors specific to Southeast Asia and India but increasing in the US (such as paan, bidis, and betel or areca nut use) have been found to give rise to submucous fibrosis, a precancerous condition consisting of generalized fibrosis of the oral soft tissues.<sup>13,14,15</sup>

### Sun exposure

**UNPROTECTED EXPOSURE** to UV radiation is the primary risk factor for lip cancer.<sup>16</sup>

### Viruses

**EXPOSURE TO VIRUSES** such as human papillomavirus (HPV), herpes simplex type 1, and Epstein-Barr Virus (EBV) are risk factors.<sup>17,18</sup> Viruses are

capable of producing cancer-causing genes called oncogenes. Many oncogenes have been found in oral cancers and are thought to develop through an array of genetic mutations and alterations. Various herpes virus types have been discovered in oral cancers including Kaposi's sarcoma, a rare cancer found in AIDS patients that is often first detected in the oral cavity.<sup>19,20</sup> In addition to these viruses acting as etiologic agents in oral cancer development, fungal infections caused by strains of *Candida albicans* may cause oral cancer through the development of carcinogenic nitrosamines in the oral soft tissues.<sup>21</sup>

HPV has been isolated in oropharyngeal precancerous and squamous cell carcinoma lesions and is known to act as a co-factor in cancer development in both cervical and oral cancers.<sup>22,23</sup> Targets for HPV-associated oral cancer include the tonsils and base of the tongue; cancer at these sites appears to be more prevalent in younger, non-smoking individuals, who have a different risk profile than groups traditionally at risk for oral cancer. The risk factors for HPV infection preceding oral and cervical cancer development include having multiple sex partners, having a partner who has had numerous partners, and having a weakened immune system.<sup>24</sup>

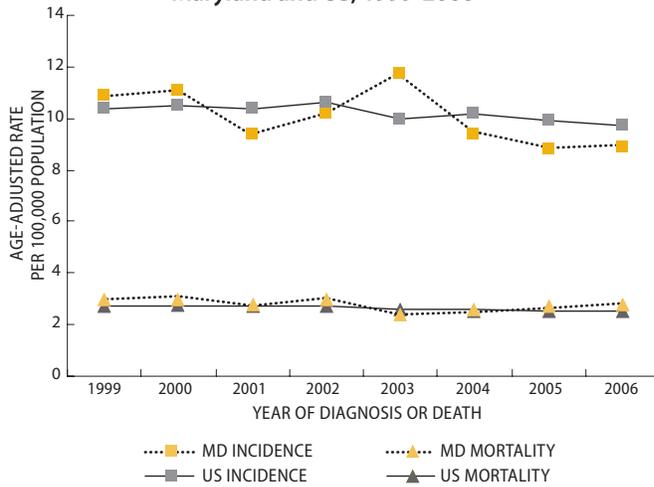
Approximately 25% of all head and neck cancers (primarily cancers of the base of the tongue and tonsil) are caused by HPV.<sup>22</sup> A recent study showed that 34% of head and neck cancers were HPV positive in white patients whereas only 4% of head and neck cancers were HPV positive in black or African American patients. This may contribute to poor treatment outcomes in the black or African American population because HPV-positive tumors are more sensitive to treatment than HPV-negative tumors.<sup>25</sup> More information on HPV and oral cancer is posted on the Maryland Cancer Plan Web site ([www.marylandcancerplan.org](http://www.marylandcancerplan.org)) on the Oral Cancer page.

### Diet

**POOR DIETARY INTAKE OF ESSENTIAL NUTRIENTS** from fruits and vegetables may also be a risk factor for oral cancer.<sup>26</sup> A diet consisting of daily intake of fruits, vegetables, and dietary fibers may protect against early oral cancers and precancerous lesions, especially among smokers. In addition, the role of antioxidants—including vitamins A, C, and E,

FIGURE 12.2

**Oral Cancer Incidence and Mortality Rates by Year of Diagnosis or Death, Maryland and US, 1999-2006**



Rates are age-adjusted to 2000 US standard population.  
Sources: Maryland Cancer Registry, 1999-2006.  
NCI SEER\*Stat (US SEER 13 rates).  
NCHS Compressed Mortality File in CDC WONDER.

dietary selenium, folate, and certain carotenoid and retinoid compounds— is being studied. If such a link is definitively established, dietary nutrients could play a major role in helping prevent oral cancer development.<sup>27,28</sup>

## Burden of Oral Cancer in Maryland

### Incidence Rates

IN 2006, 520 newly diagnosed cases of oral cavity and pharynx cancer were reported in Maryland. The annual age-adjusted incidence rate for oral cancers in Maryland is 8.9 per 100,000, which is less than the national rate of 10.2 (Figure 12.2). In 2006, 28.1% of oral cancers were diagnosed at the localized (early) stage, and more than 44% were diagnosed at a regional stage (Figure 12.5). Because oral cancer has a far better prognosis when found early at the local stage, diagnosis at a regional stage contributes to a lower survival rate.

From 1999 to 2006, Maryland males had a higher oral cancer incidence rate than females. Incidence rates for black or African American men and women continue to decline faster than for whites (Figure 12.4).

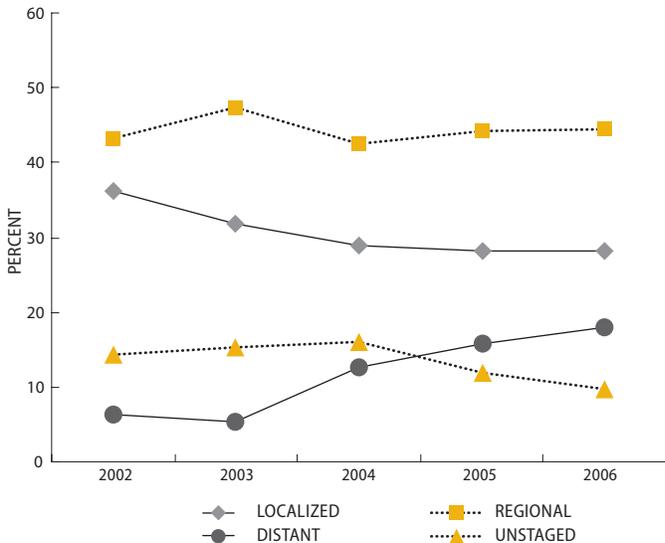
### Mortality Rates

THE ORAL CANCER MORTALITY RATE in Maryland has significantly decreased over the past ten years. According to the CDC, Maryland ranked 20th among all states between 2002-2006, compared to 8th in the time period from 1997-2001.<sup>4</sup> An overall decline in the oral cancer mortality rate for black or African American males since 1999

has contributed to this improved oral cancer mortality (Figure 12.5).

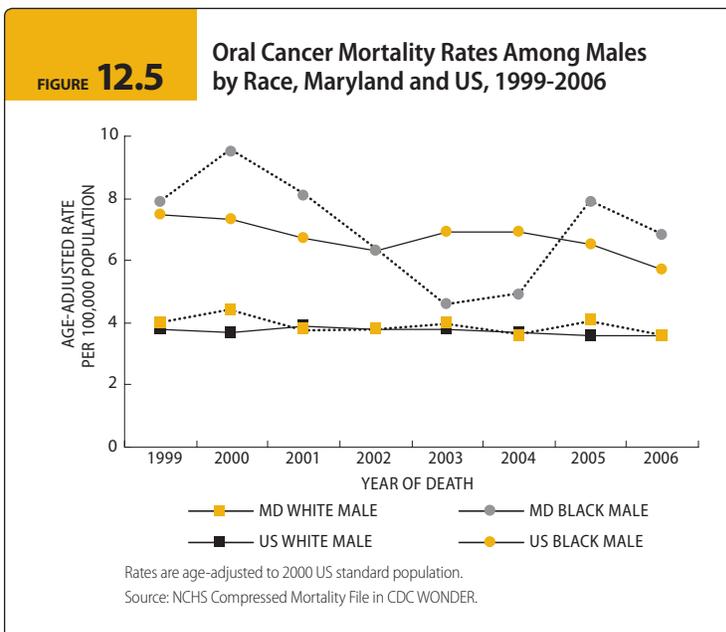
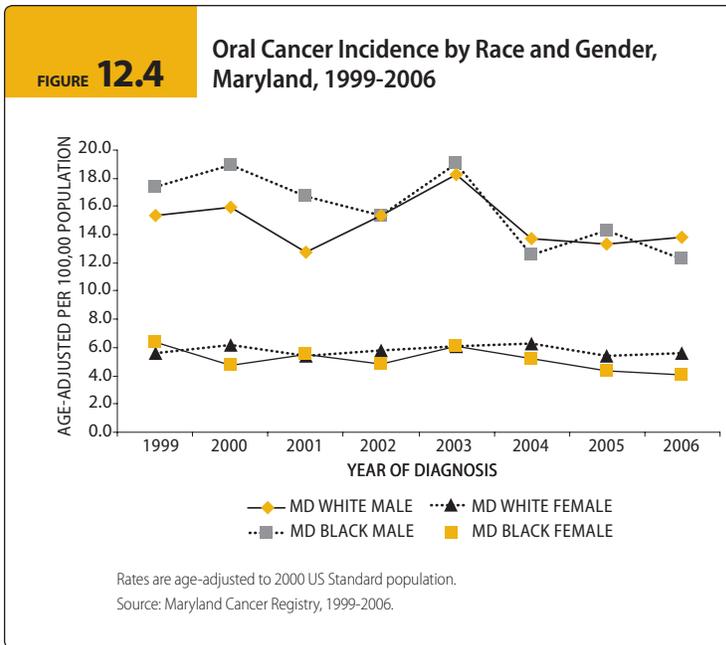
FIGURE 12.3

**Oral Cancer by Stage at Diagnosis Maryland, 2002-2006**



Source: Maryland Cancer Registry, 2002-2006.

**FAST FACT** A diet consisting of daily intake of fruits, vegetables, and dietary fibers may protect against early oral cancers and precancerous lesions, especially among smokers.



In 2006, there were 158 deaths from oral cancer in Maryland. Mortality rates for oral cancer show an overall slight downward trend (Figure 12.2). When compared by race and gender, males consistently have higher mortality rates than females. Historically, black or African American males have a higher mortality rate than white males although the gap between white and black or African American males has decreased.<sup>29</sup>

**FAST FACT** When comparing by race and gender, males consistently have higher mortality rates than females. Historically, black or African American males have a higher mortality rate than white males although the gap between white and black or African American males has decreased.

## Disparities

Maryland blacks or African Americans bear a disproportionate share of the oral cancer burden including higher incidence and mortality and later stage at diagnosis when compared to white men (Figures 12.1, 12.4, 12.5).

IN ADDITION TO DIFFERENCES in risk factors and tumor types, this disparity in oral cancer burden is likely related to the inequity in access to healthcare, specifically oral healthcare, which exists between blacks or African Americans and whites.<sup>30</sup> While access to oral healthcare in Maryland is not this chapter's focus, access clearly looms as a significant impediment to receiving routine oral cancer examinations to facilitate early diagnosis.

In addition, new research<sup>31</sup> suggests that lower levels of HPV infection in blacks or African Americans compared to whites may contribute to poorer outcomes in blacks or African Americans because HPV-positive patients with oral cancer respond better to treatment.

## Oral Cancer Examination

Incorporating routine oral cancer examinations (and other screening methods for oral cancer) into the daily practice of healthcare practitioners can increase the likelihood of earlier detection of oral

cancer. However, there is no evidence that such early detection can decrease oral cancer mortality.<sup>32</sup>

NEVERTHELESS, ROUTINE EXAMINATIONS for early detection of oral cancer should still be recommended because:

- Oral cancer is a serious yet treatable disease in its early stages.
- Treatment in the early stages of oral cancer is generally better tolerated compared with later treatment of symptomatic patients.
- Screening examinations are inexpensive and safe.<sup>33</sup>

THE ORAL CANCER EXAMINATION can be performed easily and takes no more than two minutes.<sup>34</sup> Although dentists and dental hygienists are the ideal health practitioners to perform this examination, other providers (i.e., nurse practitioners, physician assistants, and physicians) can and should provide oral cancer examinations as part of routine physical examinations. Because individuals at high risk for oral cancer are more likely to visit these providers than to visit a dentist or dental hygienist, non-dental healthcare providers may be critically important to screening efforts.

First, a careful health history must be completed, assessing risk factors such as past and present tobacco and alcohol use, diet and lifestyle, prior cancer history, sun exposure experience and behaviors, surgeries, medications, and sexual practices (to discern possible HPV exposure).<sup>35</sup> A detailed description of the oral cancer examination may be found at the Maryland Cancer Plan Web site ([www.marylandcancerplan.org](http://www.marylandcancerplan.org)) on the Oral Cancer page.

Two technologies that may aid identification and diagnosis of oral cancer are toluidine blue stain and the chemoluminescent light. These two agents are useful to identify lesions that may require biopsy, but are not ordinarily used for population-based screening.<sup>35</sup>

## Screening Recommendations of Professional Groups

Prominent professional and governmental groups have developed guidelines for oral cancer screening, but there is a lack of consensus. There is no clear direction or guidance for healthcare professionals and the public.

A SUMMARY OF THESE RECOMMENDATIONS can be found on the Maryland Cancer Plan Web site ([www.marylandcancerplan.org](http://www.marylandcancerplan.org)) on the Oral Cancer page. The appropriate clinical trials to assess the effectiveness of early detection in finding oral cancer at a local stage and/or reducing oral cancer mortality have not been performed. However, in the absence of such research-based evidence for oral cancer screening, there is anecdotal data to support the need for oral cancer screening by all healthcare professionals.

Despite a lack of consensus among groups that issue screening guidelines, the Oral Cancer Committee believes that oral cancer screening is and should be an important and necessary part of each dental and medical examination. Early detection of oral cancer and pre-oral cancer conditions at a local stage enables less invasive treatment options. Quality of life for the patient (and family) is markedly improved compared to treatment for oral cancer at a later stage. In addition, treatment costs for oral cancer may be reduced when oral cancer is detected and treated early.

## Oral Cancer Examination Rates

Progress has been made in oral cancer screening rates in Maryland.

THE 2008 MARYLAND CANCER SURVEY found that 40% of Marylanders ages 40 or over reported that they had received an oral cancer examination in the past year (compared to 33.9% in 2002). Fifty percent of adults ages 40 and over reported that they received an oral cancer examination at least once in their lifetime (compared to 42.8% in 2002). Only 23% of black or African American Marylanders ages 40 or over reported having an

**FAST FACT** According to the 2008 Maryland Cancer Survey, 40% of Marylanders ages 40 or over have received an oral cancer exam in the past year, and 50% of adults ages 40 and over have received an oral cancer exam at least once in their lifetime.

oral cancer examination in the past year. Nevertheless, these oral cancer exam rates surpass the goal of the Healthy People 2010 target of 20% (Figure 12.6).<sup>36</sup> Despite this progress, there is considerable room for improvement in the proportion of Marylanders who receive oral cancer examinations: while 73% of Marylanders ages 40 and over reported that they had a dental visit in past year, only 40% reported that they had had an oral cancer exam.

In sum, despite the significant improvement in oral cancer exam rates, a trend toward earlier diagnosis of patients with oral cancer has yet to be seen.

## Barriers to Oral Cancer Examination

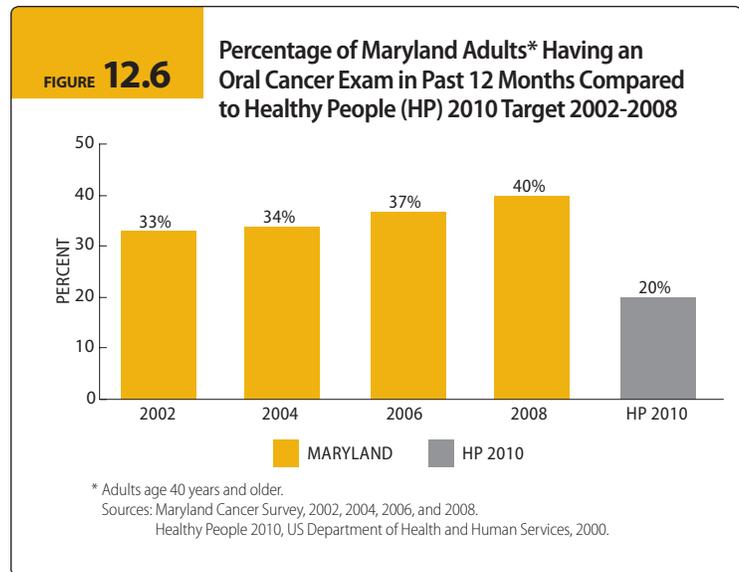
**In addition to the lack of consensus for oral cancer screening guidelines, the low examination rates described here result from a number of significant financial, educational, and behavioral barriers.**

**THESE OBSTACLES** include lack of access to dental care services as well as a lack of oral cancer knowledge that likely affects behaviors of both the public and healthcare practitioners.

### Lack of access to, and use of, oral health services for high-risk populations

#### ORAL CANCER EARLY DETECTION AND DIAGNOSIS SERVICES

**FOR THOSE AT HIGHEST RISK** for oral cancer, access to the healthcare system is limited both in the US and in Maryland. Access is critical in order to receive timely and appropriate oral cancer examinations. It is well established that those populations with the highest oral cancer mortality rates experience the poorest access to the overall healthcare



system.<sup>30</sup> Populations at high risk for oral cancer with restricted access to the healthcare system include individuals with minority status, low income, low education, no health insurance, and who are 65 years of age or older. Unfortunately for these populations, access to dental care services is even more limited.

Medicare Part A covers costly hospital-based surgical procedures for oral and pharyngeal cancer but does not cover inexpensive and routine dental procedures (including oral cancer examinations). Medicare Part B covers outpatient doctor visits but not dental visits. As in most states, Medicaid dental coverage in Maryland for adults 64 years and younger is very limited and unavailable to patients over 65. As a result of the lack of coverage for dental visits, populations at risk for oral cancer are more likely to visit a healthcare provider other than a dentist, and the frequency of visits to primary care providers is far greater than it is to dental practices.<sup>37</sup> Studies show that primary healthcare providers diagnosed more oral cancers than dentists and that the majority of these malignancies were detected at a late stage in their development.<sup>38</sup>

#### ORAL CANCER TREATMENT AND REFERRAL SERVICES

**GENERALLY, PRIVATE OR PUBLIC** medical insurance packages provide access to oral cancer treatment services. However, these services are usually unavailable for uninsured adults not yet eligible for Medicare. Further, once a lesion is detected

or suspected of being malignant through oral cancer examination, many patients experience difficulties in obtaining more extensive and definitive diagnostic services such as biopsy. Referral systems for these services are often small and random, if present at all, leading to additional continuity problems for patients who will eventually need treatment for oral cancer.

### Lack of Oral Cancer Literacy

#### INADEQUATE PUBLIC KNOWLEDGE AND PREVENTIVE BEHAVIORS

**STUDIES CONDUCTED** in the US and Maryland show that the public is not well informed about oral cancer and its prevention. Only 23% of the Maryland public could identify an early oral cancer symptom.<sup>39</sup> While most respondents correctly identified tobacco use as an oral cancer risk factor, only 13% knew that alcohol was also a major risk factor for this disease. Similar low responses were given for other oral cancer risk behaviors.

Inadequate health knowledge is compounded by the public's poor health-conscious practices, as evidenced by minimal use of dental health-care services among individuals at high risk for oral cancer when controlling for socioeconomic, demographic, and health-related characteristics. Poor use of dental healthcare services occurs among high-risk adults who are long-term smokers and low consumers of fruits and vegetables.<sup>40</sup>

Long-term adult cigarette smokers are less likely than never smokers to have visited the dentist in the previous year. Among long-term cigarette smokers, the likelihood of a yearly dental examination decreases with increasing smoking duration and number of cigarettes smoked per day. Beyond not receiving oral cancer examinations by dental practitioners, these individuals are also not receiving healthy lifestyle and diet counseling by the healthcare practitioners most likely to make connections between risk factors and oral cancer.<sup>40</sup>

In addition to helping the Maryland public gain greater knowledge and understanding about oral cancer, it is vital that the public become functionally literate in how to obtain appropriate health services.

**DID YOU KNOW?** According to a Maryland study, only 25% of the public can identify an early oral cancer symptom. Only 13% know that alcohol is a major risk factor for the disease.

#### INADEQUATE TRAINING IN ORAL CANCER PREVENTION AND SCREENING DETECTION PRACTICES

**A PILOT STUDY** conducted in Maryland found that dentists were not as knowledgeable about oral cancer prevention as they thought and that most physicians did not believe that their oral cancer knowledge was current.<sup>41</sup> The oral cancer knowledge base of these practitioner groups was found to play a significant role in their related examination behaviors. While the vast majority of dentists were providing oral cancer examinations, a high proportion of these examinations likely were not performed properly. Among physicians, those who did not believe their oral cancer knowledge to be current were less likely to provide routine oral cancer examinations.<sup>41</sup>

More representative, broad-based studies of Maryland dentists and dental hygienists corroborated the findings of the earlier pilot study. However, these studies also found that healthcare providers did not feel adequately trained to palpate neck lymph nodes as part of their oral cancer examination and that they were not examining high-risk edentulous patients.<sup>42,43</sup> Non-dental health providers such as family physicians and family nurse practitioners were also found to have low oral cancer knowledge.<sup>44,45</sup>

Further, to increase patient comprehension and encourage patients to play a more active role in their own healthcare and maintenance, healthcare providers must receive training to improve their communications skills.

### Ideal Model for Oral Cancer Control

**An Oral Cancer Prevention, Early Detection, and Treatment Model has been developed to decrease oral cancer incidence and mortality by increasing oral cancer literacy among specific groups: the public, healthcare providers, and policymakers.**

**SUCH KNOWLEDGE** includes an understanding and awareness of oral cancer risk assessment and reduction, risk factors and behaviors, signs and symptoms, and the rudiments and frequency

of adequate and timely oral cancer examinations.

Improving oral cancer literacy will promote more routine, timely, and comprehensive oral cancer examinations that are requested by an informed public and adequately provided by informed dental and non-dental healthcare practitioners. In addition, informing and engaging policymakers will impact oral cancer prevention through legal, educational, scientific, fiscal, and curricular change. The public needs to be specifically targeted for these messages through appropriate channels. Dental and non-dental provider education must be enhanced through wider availability of oral cancer continuing education courses and curricular change. These public and healthcare provider strategies should increase the number of appropriate oral cancer examinations and related referral, follow-up, and treatment modalities.

The increase in appropriate oral cancer examination, referral, follow-up, and related treatment efforts, coupled with policy change, should lead to reduced oral cancer morbidity and mortality in Maryland and a significantly smaller disparity in these rates between blacks or African Americans and whites. Further, policymakers at all levels, including legislative, governmental, professional associations, and education (K-12 and higher education), must be an integral part of a comprehensive oral cancer prevention program. A diagram of the Ideal Model is posted on the Maryland Cancer Plan Web site ([www.maryland-cancerplan.org](http://www.maryland-cancerplan.org)) on the Oral Cancer page.

## Current Efforts in Maryland

**Oral cancer prevention and early detection efforts in Maryland are largely facilitated by the Department of Health and Mental Hygiene’s (DHMH) Office of Oral Health (OOH) and Cigarette Restitution Fund Program (CRFP).**

**B**OTH THE OOH AND CRFP ORAL CANCER PROGRAMS provide grant funds to local health departments for the provision of oral cancer screening and education to the general public and healthcare providers. The focus of oral cancer prevention and early detection activities within DHMH can be attributed to several significant developments in the past 20 years.

In the early 1990s, a small partnership among diverse organizations developed in an attempt to reduce the high rates of oral cancer morbidity and mortality in Maryland and to reduce the disparity in oral cancer rates between whites and blacks or African Americans.<sup>38</sup> This partnership encompassed educational, networking, and advocacy activities throughout the state in order to enhance awareness, knowledge, and understanding of oral cancer. These activities led to two important outcomes that advanced oral cancer awareness in Maryland: 1) inclusion of two oral cancer prevention objectives in the Maryland Health Improvement Plan and 2) inclusion of oral cancer as one of seven targeted cancers in the Cigarette Restitution Fund (CRF) program.

Another major outcome of this partnership was the funding of a DHMH oral-cancer-specific program by the Maryland General Assembly in 2000. This program resulted in the current statewide oral cancer prevention initiative led by OOH. This legislation requires OOH to prevent and detect oral cancer in the state, with a specific emphasis on targeting the needs of high-risk, underserved populations. The major components of this initiative include:

- Oral cancer education for the public.
- Education and training for dental and non-dental healthcare providers.
- Screening and referral, if needed.
- Conducting an evaluation of the program.

**SINCE 2002**, when funds were made available for the initiative, 15,254 people have been screened for oral cancer, 1,889 people have been referred to smoking cessation services, and 3,671 healthcare providers have received oral cancer prevention and early detection education through OOH grants to local health departments throughout Maryland.

Additional OOH efforts resulting from the initiative include the development and distribution of a toolkit to assist local jurisdictions in promoting and facilitating oral cancer prevention activities, the creation of educational materials for low-literacy populations, and the annual observance of Oral Cancer Awareness Week in Maryland.

During this same time period, the Maryland General Assembly created the Cigarette Restitution Fund Program (2000), providing funds for

cancer prevention, education, screening, and treatment for the seven targeted cancers. Some local jurisdictions have opted to provide oral cancer screening and/or education to residents. To date, 5,535 people have been screened for oral cancer, and 6,596 health professionals have received oral cancer prevention and early detection education through CRFP grants. Garrett County continues to use CRFP funding to provide oral cancer activities, and the Baltimore City program initiated an oral-cancer-screening program in fiscal year 2011. The CRFP develops and maintains the Oral Cancer Minimal Elements for Screening, Diagnosis, Treatment, Follow-Up, and Care Coordination to provide guidance for public health programs that screen for oral cancer. In addition, CRFP cancer research funds provided to Johns Hopkins University and the University of Maryland have been used to conduct oral cancer research.

As a result of these cumulative efforts, thousands of Maryland residents have been screened for oral cancer and considerably more have received oral cancer prevention messages and information. Others have been referred to smoking cessation programs. Finally, more than 10,000 healthcare practitioners have received education and training regarding oral cancer prevention and examinations. Plans to evaluate the success of these programs are scheduled for the future and include upcoming surveys of both the public and healthcare providers.

## Scientific Advances in Oral Cancer

**With improved understanding of oral cancer biology and the availability of state-of-the-art molecular technologies, a number of molecular markers have been tested for their potential use as biomarkers to enhance prediction of oral cancer risk or early oral cancer diagnosis for patients with oral lesions. In a large study, investigators found certain biomarkers can predict oral cancer risk years before clinical diagnosis of oral cancer in patients with oral precancerous lesions.<sup>46</sup>**

**S**ALIVA HAS BEEN EXPLORED as a diagnostic medium for oral cancer detection with promising results.<sup>47</sup> Many of the salivary biomarkers will need to be validated in large clinical trials before they can be recommended for routine clinical use.

Because of logistical concerns and lack of funding, evidence-based clinical trials for oral cancer prevention modalities that demonstrate a definitive impact on morbidity and mortality rates have yet to be conducted. In the absence of such research, oral cancer prevention guidelines and protocols will continue to lack consensus and fail to guide the public, healthcare practitioners, policymakers, and healthcare delivery systems.

More evidence-based information is needed to evaluate and compare the practice patterns of primary care and dental providers, and to assess the effectiveness of existing oral cancer prevention programs. Currently, funding to expand ongoing oral cancer research and the development of more sensitive and specific oral cancer screening tools is limited. Additional resources are needed for this and for research that aids our understanding of the etiologic pathways from potential viral, environmental, behavioral, and familial sources.

# GOALS - OBJECTIVES - STRATEGIES

## GOAL 1

### Reduce oral cancer incidence and mortality.

#### TARGETS (2015)

**INCIDENCE** 6.5 per 100,000  
(2006 Baseline: 8.9 per 100,000)  
Source: Maryland Cancer Registry.

**MORTALITY** 2.1 per 100,000  
(2006 Baseline: 2.8 per 100,000)  
Source: CDC WONDER.

#### OBJECTIVE 1

By 2015, increase the proportion of adults 40 years and older who have had an oral cancer exam in the past year to 48% (2008 Baseline: 40%).

Source: Maryland Cancer Survey.

#### STRATEGIES

- 1 INCREASE ORAL CANCER SCREENINGS** among adults by providing access to both primary care providers and oral health providers for low-income and underserved adult populations in Maryland by supporting community health centers, mobile screening services, seeking new funding sources (public and/or private), and advocating for policy changes and funding at the local, state, and federal levels.
- 2 ESTABLISH A SUBCOMMITTEE** for the purpose of investigating policies aimed at incorporating oral cancer exams into routine medical and dental exams and assessing the availability and consistency of oral cancer continuing education.
- 3 DEVELOP A STATEWIDE EDUCATIONAL CAMPAIGN** designed to increase the demand for oral cancer screening by encouraging individuals to ask healthcare providers for an annual oral cancer exam as part of routine health exams.

#### OBJECTIVE 2

By 2015, increase the proportion of oral cancer detected at a local stage to greater than 28% (2006 Baseline: 28%).

Source: Maryland Cancer Registry

- 1 INCREASE THE PROPORTION** of primary care providers who perform oral cancer screening by working with professional organizations to teach and encourage physicians, dentists, nurse practitioners,

nurse-midwives, and physicians' assistants to conduct oral cancer screening as part of a routine physical exam.

- 2 DEVELOP AN ORAL CANCER EDUCATION/EARLY DETECTION PROGRAM** to target healthcare providers at Federally Qualified Health Centers, local health departments, other community health centers, and Veterans' Administration hospitals to ensure oral cancer screening is conducted during routine visits.

- 3 PROVIDE HEALTHCARE PROVIDERS** with referral mechanisms for oral cancer by identifying local and state referral resources.

#### OBJECTIVE 3

By 2015, increase oral cancer literacy in the public and among healthcare providers to meet the following targets:

- **Increase the proportion of adults 40 years and older who have heard of an exam for oral cancer to 35% (2003 Baseline: 27%)**

Source: Survey of Maryland Adults' Knowledge of Oral Cancer.

- **Increase the percentage of all healthcare providers who report adequate training for conducting oral cancer exams.**  
(Survey currently underway to assess healthcare provider oral cancer literacy.)

#### STRATEGIES

- 1 INCREASE THE ORAL CANCER KNOWLEDGE** of the public about oral cancer risk factors (such as tobacco use, alcohol use, and HPV infection) by developing targeted and culturally relevant oral cancer messages in plain language about high-risk activities.
- 2 INCREASE THE NUMBER OF HEALTHCARE PROVIDERS** who are educated about oral cancer prevention (including tobacco, alcohol, and HPV risk-reduction strategies) and early detection through the education of health professionals including current practitioners and students in dentistry, medicine, nursing, and allied health fields.
- 3 CREATE A JOINT COMMITTEE** of professional associations to encourage the development of a collaborative relationship among medicine, nursing, and dentistry in providing effective oral health education, including oral cancer prevention education and patient care.
- 4 ENCOURAGE AND SUPPORT** professional organizations to include oral cancer prevention and early detection as a topic at educational seminars and meetings.

## GOALS - OBJECTIVES - STRATEGIES

- 5 **PROMOTE THE INCLUSION** of oral health and oral cancer education materials in the health education curricula for grades K-12 in Maryland by working with local boards of education and other parent and teacher groups.

### OBJECTIVE 4

**By 2015, decrease the prevalence of oral cancer risk factors among adults 18 years and older in Maryland.**

*See specific objectives and strategies in the following chapters: Nutrition, Physical Activity, and Healthy Weight; Tobacco Use Prevention/Cessation and Lung Cancer; and Cervical Cancer (HPV).*

#### STRATEGIES

- 1 **ENCOURAGE, INCREASE, AND REVIEW** research to determine effects of current and emerging risk factors.

## GOAL 2

**Reduce disparities in the incidence and mortality of oral cancer**

### OBJECTIVE 1

**By 2015, increase the proportion of black or African American adults with oral cancer detected at a local stage to greater than 25% (2006 baseline: 25%).**

Source: Maryland Cancer Registry.

#### STRATEGIES

- 1 **INCREASE THE NUMBER OF PRIMARY CARE** medical and dental providers in minority communities who perform routine oral cancer exams by determining and reducing barriers that prevent oral cancer screening.
- 2 **DEVELOP AND IMPLEMENT** an oral cancer education program to target healthcare providers at Federally Qualified Health Centers, local health departments, other community health centers, and Veterans' Administration hospitals to reduce the number of late stage of oral cancer diagnoses.
- 3 **DEVELOP, TEST, AND IMPLEMENT** an oral cancer education program to target black or African American adults about prevention and early detection of oral cancers.

### OBJECTIVE 2

**By 2015, increase the percentage of black or African American adults who have been screened in the past year for oral cancer to 25.8% (2008 Baseline: 23%).**

Source: Maryland Cancer Survey.

#### STRATEGIES

- 1 **ADVOCATE AT THE STATE LEVEL** for increased funding for oral cancer in order to increase grant opportunities for community oral cancer programs targeted at underserved and minority communities.
- 2 **UTILIZE MOBILE DENTAL AND/OR MEDICAL SERVICES** to conduct oral cancer exams in minority and underserved communities.
- 3 **DEVELOP APPROPRIATE MATERIALS** and a distribution network in order to increase community-based and culturally relevant oral cancer programs and messages that target minority and underserved communities.

### OBJECTIVE 3

**By 2015, increase the number of healthcare providers who provide oral cancer exams and risk reduction counseling to minority and underserved populations.**

#### STRATEGIES

- 1 **INCREASE THE HEALTH LITERACY** and cultural awareness of healthcare providers to improve their communication techniques with patients regarding oral cancer by providing continuing education.
- 2 **DEVELOP A METHOD** to measure the number of healthcare providers in underserved communities who conduct oral cancer exams and include this measure on future oral cancer surveys of healthcare providers.
- 3 **ENCOURAGE HEALTHCARE PROVIDERS** to engage in oral cancer volunteerism by providing continuing education credits or other potential incentives for participating in community oral cancer screenings.

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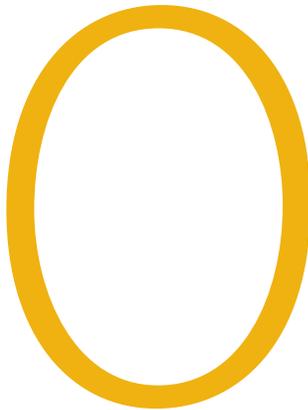
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# 13

## CERVICAL CANCER



Of all cancers that affect women, cervical cancer is one of the most preventable. Yet, worldwide, cervical cancer remains the second most common cancer among women. In 2008, there were nearly 530,000 new cervical cancer cases and 275,000 deaths attributed to cervical cancer around the globe.<sup>1</sup>

### **DID YOU KNOW?**

Since the development of the Pap test in the early 1940s the number of women dying from cervical cancer in the US has decreased dramatically. The HPV vaccine also shows promise to aid declines in cervical cancer death.

**THE AMERICAN CANCER SOCIETY** projects that about 12,000 cases of cervical cancer will be diagnosed nationally in 2010.<sup>2</sup> In that same year in Maryland, it is estimated that approximately 200 women will be told that they have invasive cervical cancer and 80 women will die because of this disease.<sup>3</sup>

To a greater extent than with many cancers, effective tools for the control of cervical cancer have been identified. Since the development of the Pap test (Pap smear) in the early 1940s, the number of women dying from cervical cancer in the United States has decreased dramatically. Each year, more than 55 million Pap tests are performed in the United States. Of the 79.6% of women in the United States who report having a Pap test within the past three years, approximately 6% will have an abnormal result that requires additional testing.<sup>4</sup> However, the majority of new cervical cancer cases (60% to 80%) are among women who have not had a Pap test in the past five years, demonstrating the success of the Pap test as an early screening tool.<sup>5</sup>

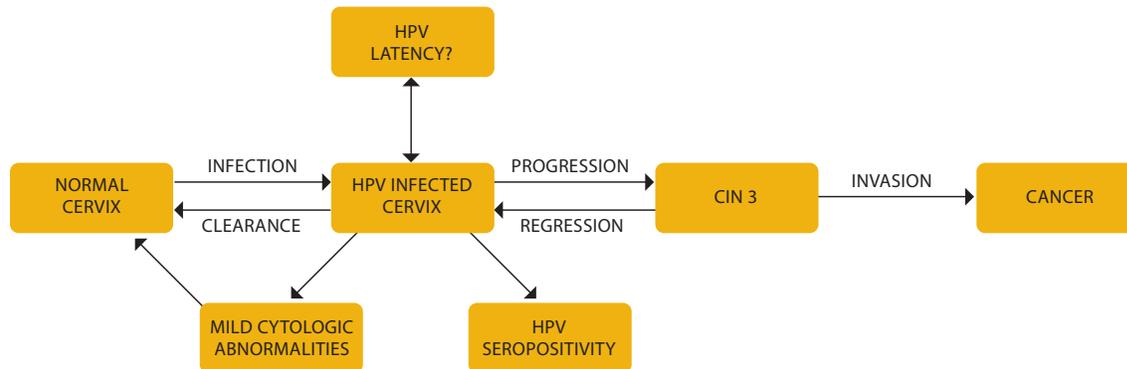
The HPV (human papillomavirus) vaccine also shows promise to aid declines in cervical cancer death.

### **Natural History of Cervical Cancer**

**T**HE LOWER PART OF THE UTERUS is known as the cervix, and it connects the uterus with the birth canal. Cervical cancer originates when cells on the surface of the cervix begin to grow uncontrollably, usually initiated by persistent infection with the human papillomavirus. Initially the

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**FIGURE 13.1** Natural History of Cervical Cancer



Source: Mark Schiffman, MD, MPH, National Cancer Institute.

uncontrolled growth is not cancerous and may be referred to as cervical dysplasia or SIL (squamous intraepithelial lesions). If left untreated, the dysplasia may worsen and become carcinoma in situ. This is the earliest stage of cancer, when the tumor has not yet spread or invaded surrounding tissues. At this stage, dysplasia and carcinoma in situ can often be removed by a colposcopy-directed biopsy, or LEEP (loop electrosurgical excision).<sup>6</sup> Invasive cancer develops when abnormal cells begin to invade normal cells.

Figure 13.1 describes the natural history of cervical cancer. Changes in the cells of the cervix can range from atypical squamous cells of undetermined significance (ASC-US) to low-grade squamous intraepithelial lesions (LSIL) to high-grade squamous intraepithelial lesions (HSIL) to invasive cancer. The precancerous conditions LSIL and HSIL are also referred to as cervical intraepithelial neoplasia (CIN) 1, 2, and 3. These lesions can persist, regress, or progress to an invasive malignancy. High-grade SIL (CIN 2-3) is more likely to persist or progress and less often regresses spontaneously, while low-grade SIL (CIN 1) often regresses without treatment. The average time for progression of CIN 3 to invasive cancer has been estimated to be 10 to 15 years.<sup>7</sup> There is a small subset of rapidly progressive cervical cancers that are diagnosed within three years of a confirmed negative Pap test. These tumors occur in younger women. One-third of these cancers are adenocarcinomas of endocervical origin, which

may not be adequately screened by conventional Pap test methods.<sup>8</sup>

## Risk Factors

### Biologic Processes and Causal Risk Factors

#### HPV INFECTION

Cervical infection with HPV is the primary risk for cervical cancer. There are more than 80 types of HPV. About 30 types can infect the cervix and about half of these have been linked to cervical cancer. Infection with this type of HPV is necessary but not sufficient for the development of invasive cervical cancer.<sup>9</sup>

Infection with HPV is extremely common; most women will become infected with HPV at some point in their lives. Most infections are cleared, although emerging research is exploring the issue of HPV latency in the cervix.

#### OTHER RISKS AND CO-FACTORS

**ALTHOUGH HPV INFECTION** is the primary risk factor for cervical cancer, other risks have been identified. There are also co-factors that increase the risk for cervical cancer among women infected with HPV. These risks and co-factors are described below:<sup>10</sup>

- **Sexual history:** Because HPV infections are spread through sexual contact, women who become sexually active at a young age and have many sexual partners have a greater risk of being infected with HPV and developing cervical cancer.

- Tobacco exposure (co-factor): Smoking and exposure to environmental smoke is associated with increased risk among HPV-infected women although the mechanism is not definitively identified.
- Human Immunodeficiency Virus (HIV) infection (co-factor): Women who are HIV positive have a higher risk for cervical cancer because HIV weakens the immune system and reduces the body's ability to destroy cancer cells.<sup>11</sup>
- Giving birth to many children: Women who have had seven or more full-term pregnancies may have an increased risk for cervical cancer.
- Long-term use of oral contraceptives: Women who have used oral contraceptives ("the pill") for five years or more may have an increased risk for cervical cancer.

## Epidemiologic Patterns of Association

### AGE

**RATES OF INVASIVE CERVICAL CANCER** increase with age. The median age of diagnosis for invasive cervical cancer at all stages is 47. However, the burden of cervical cancer is greatest in older women.<sup>12</sup>

### PAP TEST HISTORY

Women who have never had a Pap test or who have not had one for several years have a higher than average risk of developing cervical cancer.<sup>13</sup>

## Burden of Cervical Cancer in Maryland

**INVASIVE CERVICAL CANCER** represents about 2% of all newly diagnosed cancers among Maryland women. In 2006, 199 Maryland women were diagnosed with invasive cervical cancer. The Maryland overall age-adjusted incidence rate for invasive cervical cancer was 6.7 per 100,000, and the national rate was 8.0 per 100,000 (Table 15.1).

Cervical cancer incidence rates in Maryland and in the US are higher for black or African

**Cervical Cancer Incidence Data by Race, Maryland and the US, 2004-2006**

TABLE 13.1

	TOTAL	WHITES	BLACKS	OTHER
<b>2004</b>				
MD New Cases (count)	226	133	83	s
MD Incidence Rate	7.5	6.7	10.1	**
US SEER Rate	8.2	8.0	11.0	7.2
<b>2005</b>				
MD New Cases (count)	254	155	76	15
MD Incidence Rate	8.5	7.8	9.1	**
US SEER Rate	8.1	8.0	9.2	7.8
<b>2006</b>				
MD New Cases (count)	199	112	57	17
MD Incidence Rate	6.7	5.8	7.1	9.8
US SEER Rate	8.0	7.9	9.4	7.1

Rates are per 100,000 and are age-adjusted to 2000 US standard population. Total includes cases reported as unknown race.

s = Counts are suppressed in CRF Cancer Report tables to prevent disclosure of data in other cell(s).

\*\* MD incidence rates based on case counts of 1-15 are suppressed per DHMH/MCR Data Use Policy.

Sources: Maryland Cancer Registry, 2004-2006. NCI SEER\*Stat (US SEER 17 rates).

American women than for white women, although the gap has narrowed in recent years (Figure 13.2). National data show that white women are diagnosed at the local stage more frequently than black or African American women.<sup>14</sup> Currently the Maryland Cancer Registry does not calculate survival rates, but national data show that the overall five-year survival rate for invasive cervical cancer is about 73% for white women and 61% for black or African American women. Black or African American women have lower five-year survival rates than white women at each stage (Table 13.2).<sup>15</sup>

In 2006, 69 Maryland women died from invasive cervical cancer, which is a mortality rate of 2.2 per 100,000. Mortality rates for both white and black or African American women are lower than the respective national rates (Table 13.3). However, mortality rates for black or African American women are statistically significantly higher than rates for white women in both Maryland and the United States (Figure 13.3).

Figure 13.4 shows cervical cancer mortality by geographic area compared to the US rate. Baltimore City is the only jurisdiction or region that has a significantly higher cervical cancer mortality rate than the United States.

### Burden among Other Ethnic and Cultural Groups

Historically reliable data have only been available on cancer rates for whites and blacks or African Americans. The numbers of cancer cases and deaths among other minority groups have been small, making rates unreliable for comparisons. Due to recent improvements in national and state standards, there are now some limited Maryland cervical cancer incidence statistics available for Hispanic or Latina and Asian or Pacific Islander populations.

According to the Census 2008 American Community Survey, about 248,000 Maryland residents are foreign born and entered Maryland in year 2000 or later. This includes an estimated 65% increase in the number of Hispanics or Latinas in Maryland between 2000 and 2008, and an estimated 35% increase in the number of Asians or Pacific Islanders.<sup>16,17</sup>

As shown in Table 13.4, the incidence rates among Hispanics or Latinas in both Maryland and the US are significantly greater than white and or black or African American rates. The Maryland and national Asian or Pacific Islander incidence rates are significantly lower than both the Maryland and national black or African American and Hispanic or Latina rates. There were not enough cervical cancer deaths to provide Maryland statistics on mortality among Hispanic or Latina or Asian or Pacific Islander women.

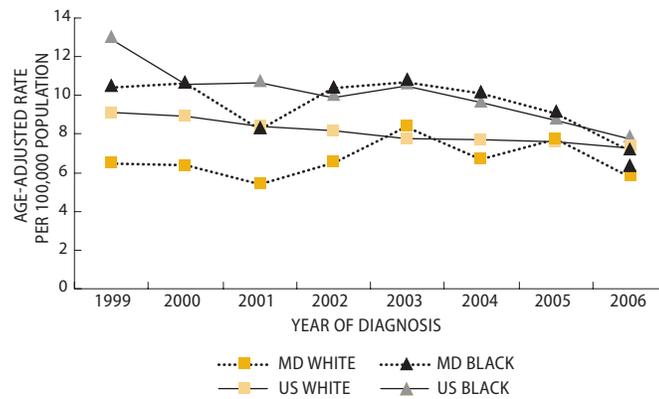
### Disparities

**R**ACIAL DISPARITIES in cervical cancer incidence, mortality, and survival are described throughout the Burden of Cervical Cancer in Maryland section of the chapter and include:

- Black or African American women have a statistically significantly higher incidence rate and mortality rate for invasive cervical cancer than white women.
- For each stage, black or African American women have lower five-year survival rates than

FIGURE 13.2

Cervical Cancer Incidence Rates by Race Maryland and US, 1999-2006



Rates are age-adjusted to 2000 US standard population.  
Sources: Maryland Cancer Registry, 1999-2006.  
NCI SEER\*Stat (US SEER 13 rates).

TABLE 13.2

Cervical Cancer Five-Year Survival Rates by Stage and Race in the US, 1999-2006

	ALL RACES	WHITE	BLACK
All Stages	70.2%	71.7%	60.7%
Local Stage	91.2%	92.4%	83.5%
Distant Stage	17.0%	17.9%	11.6%

Source: National Cancer Institute, SEER 17 Rates, 1999-2006.

- white women.
- Hispanic or Latina women have statistically significantly higher cervical cancer incidence rates than both black or African American and white women.

### Primary Prevention

**A**VOIDING RISK FOR HPV INFECTION is one important strategy for primary prevention of cervical cancer. Barrier methods of contraception, and possibly spermicides,<sup>18</sup> may prevent the spread of HPV between partners.

In addition, there are currently two different HPV vaccines offered to young women prior to initial exposure to HPV. The quadrivalent vaccine Gardasil, approved by the FDA in 2006, protects against four HPV types. Gardasil was also recently approved to be administered to boys and men ages 9 to 26 to prevent genital warts. In October

2009, the bivalent HPV vaccine Cervarix was approved for use in US women. Both HPV vaccines protect against HPV types 16 and 18, thought to cause the majority of invasive cervical cancers in US women. Unresolved issues include cost, long-term efficacy, and logistics of storage and delivery of the three-vaccine series. However, uptake has been rapid, with state-level policy initiatives throughout the country ranging from education to mandates for insurance coverage and/or mandatory vaccination for school attendance. Goals for next-generation vaccines include reduction of issues related to cost and delivery and wider effectiveness in regard to HPV types.

As more evidence is established to identify and explain the role of co-factors related to women’s risk for persistent HPV infection and cervical abnormalities, efforts to educate and enable women to reduce risk for cervical cancer will benefit from attention to these co-factors. For example, reduction of exposure to both active and passive tobacco use, primary prevention as well as treatment of HIV may be effective strategies to reduce the risk for invasive cervical cancer.

**TABLE 13.3** Cervical Cancer Mortality Data by Race, Maryland and US, 2004-2006

	TOTAL	WHITES	BLACKS	OTHER
<b>2004</b>				
MD Deaths (count)	77	46	s	<6
MD Mortality Rate	2.5	2.2	3.9	**
US Mortality Rate	2.4	2.2	4.5	2.2
<b>2005</b>				
MD Deaths (count)	62	34	s	<6
MD Mortality Rate	2.0	1.5	3.2	**
US Mortality Rate	2.4	2.2	4.4	1.9
<b>2006</b>				
MD Deaths (count)	69	38	s	<6
MD Mortality Rate	2.2	1.7	3.6	**
US Mortality Rate	2.4	2.2	4.3	2.1

\* Rates are per 100,000 and are age-adjusted to 2000 US standard population.  
 \*\* MD mortality rates based on death counts of 0-15 are suppressed per DHMH/CCSC Mortality Data Suppression Policy.  
 s = Counts are suppressed in CRF Cancer Report tables to prevent disclosure of data in other cell(s).  
 <6 = MD death counts of 0-5 are suppressed per DHMH/CCSC Mortality Data Suppression Policy.  
 Source: NCHS Compressed Mortality File in CDC WONDER.

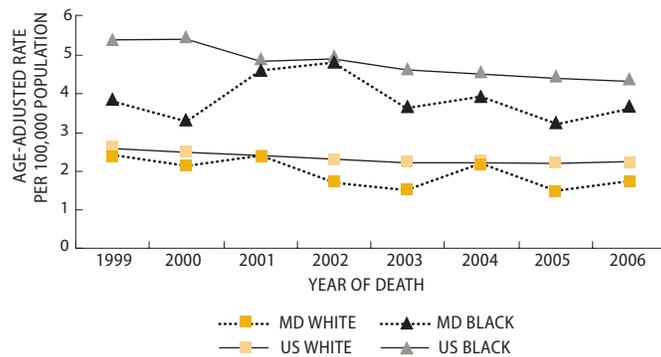
## Secondary Prevention of Invasive Cervical Cancer Through Early Detection

### Screening Guidelines

Detection of cervical abnormalities using the Pap test will remain an important tool for reducing the burden of cervical cancer. However, with the evolution of better tools for primary prevention, including vaccination, as well as more sophisticated tools for identifying HPV type and likelihood of progression to invasive cancer, recommendations and best practices for screening across the life course will evolve. New developments can take advantage of knowledge that HPV is the primary cause of cervical cancer. Utilization of both Pap and HPV testing at appropriate intervals across the life course can conserve resources and allow for safer, less frequent screening.

**FIGURE 13.3**

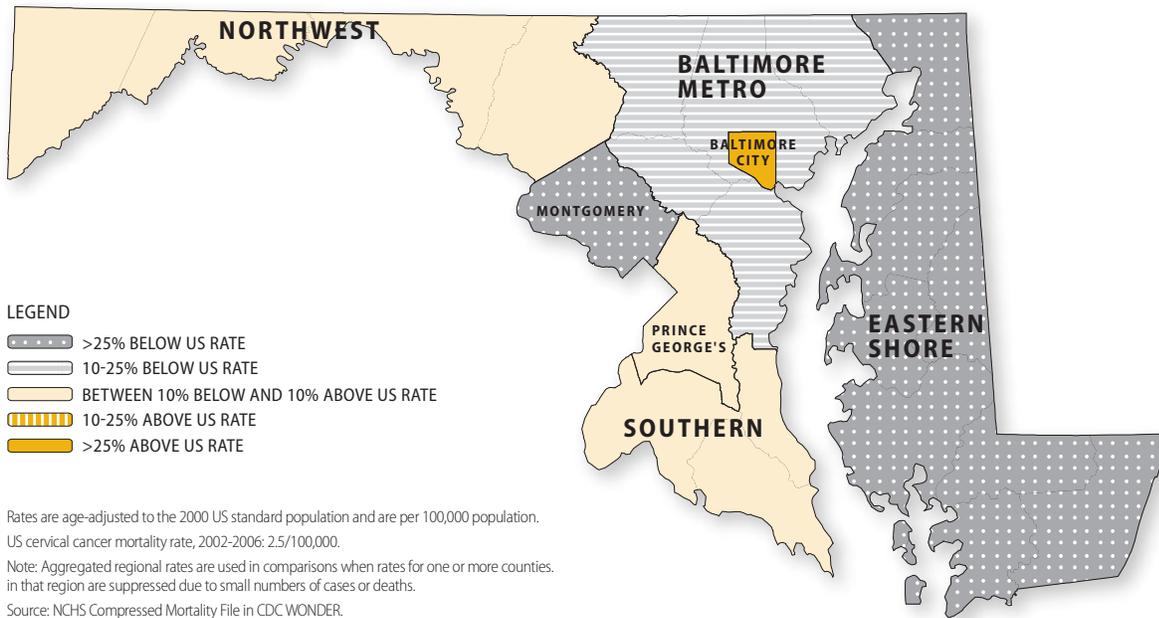
**Cervical Cancer Mortality Rates by Race Maryland and US, 1999-2006**



Rates are age-adjusted to 2000 US standard population.  
 Source: NCHS Compressed Mortality File in CDC WONDER.

FIGURE 13.4

Maryland Cervical Cancer Mortality Rates by Geographical Area: Comparison to US Rate, 2002-2006



**CURRENT RECOMMENDATIONS FOR SCREENING USING THE PAP TEST**

The recommendations for the initiation of cervical cancer screenings and the interval in between cervical cancer screenings can differ slightly among national organizations. Several organizations recommend waiting approximately three years following initiation of sexual activity, but no later than age 21, to receive Pap testing because transient HPV infections and insignificant cervical cell changes are common among young women and it typically takes years for a significant abnormality or cancer to develop.<sup>19</sup> A table displaying guidelines from several reputable sources can be found on the Cervical Cancer page of the Maryland Cancer Plan Web site: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

**CURRENT RECOMMENDATIONS FOR SUPPLEMENTING PAP TEST WITH HPV TEST**

Tests exist to detect the presence of active human papilloma virus in the cervix as well as to test for the presence of antibodies in the blood (seropositivity), indicating prior infection. Testing

the cervix for the presence of active HPV infection is not recommended as a routine screening tool for women under age 30 due to the likely transient nature of infections. For women ages 30 and older, several national organizations (including the American Cancer Society, National Cancer Institute, and the American Society for Colposcopy and Cervical Pathology) recommend high-risk HPV DNA testing as an adjunct to the Pap test because the risk of new infection is much lower after age 30. Research suggests the HPV test may identify women who have had a normal Pap test and a negative HPV test who may safely lengthen their screening interval to three years.<sup>20</sup> Further-

TABLE 13.4

**Cervical Cancer Incidence Rates among Racial and Ethnic Groups, Maryland and US, 2002-2006**

	TOTAL	WHITES	BLACKS	HISPANIC	ASIAN/PACIFIC ISLANDER
MD New Cases (# annual average)	239	142	77	16	8
MD Incidence Rate	8	7.2	9.6	14.4	5.4
US SEER Rate	8.3	7.9	11.1	12.8	7.5

Rates are age-adjusted to the 2000 US standard population and are per 100,000 population.  
 Source: National Cancer Institute, State Cancer Profiles, [www.statecancerprofiles.cancer.gov](http://www.statecancerprofiles.cancer.gov).

more, it may more accurately identify women who are HPV positive and have had a normal Pap test, who would benefit from repeat screening and closer management.

Scientific research on the effectiveness of HPV testing as primary screening for cervical cancer is ongoing, and it should be noted that the US Preventive Services Task Force found poor evidence to determine the benefits and harms of HPV screening as an adjunct or alternative to regular Pap test screening.<sup>21</sup>

The flow chart in Figure 13.5 demonstrates the FDA-approved use of HPV DNA testing for women ages 30 and older.

Use of HPV testing is also recommended by the American Society for Colposcopy and Cervical Pathology (ASCCP) and the National Comprehensive Cancer Network (NCCN) for the clinical management of women with abnormal Pap test results of “atypical squamous cells of undetermined significance” (ASC-US). HPV testing following an ASC-US Pap test result allows focus of work-up and treatment on women most likely to progress to advanced disease. HPV testing could also be used post-treatment where a positive test may indicate residual disease.<sup>22,23,24,25,26</sup>

The flow chart in Figure 13.6 describes the ASCCP recommendations for ASC-US management.

## Screening Rates

At this time, the Behavioral Risk Factor Surveillance System (BRFSS) collects data on Pap testing rates but not on HPV testing rates. Data from the BRFSS show that the proportion of Maryland women 18 years and older who reported having a Pap test in the previous three years decreased from about 90% in 2000 to about 84% in 2008. Maryland’s Pap test screening rates still remain slightly higher than those for the United States. Pap test screening rates are similar among white and Black or African American women in Maryland. However, while Pap test rates among women between the ages of 25 and 64 years have remained relatively high and stable, Pap test rates have declined among women ages 65 and older and women ages 18 to 24 years (Figure 13.7).

Some of the decline among women ages 65 and older may be a result of the January 2005 recommendation by the US Preventive Services Task Force (USPSTF) that women ages 65 or older did not need routine Pap tests if they have had normal screens in the past and are not otherwise at higher risk for cervical cancer.

The same USPSTF recommendation advised that women should begin Pap testing at age 21 or within three years of initiation of sexual activity, whichever came first. This may also account for some of the reduction in the younger age group.

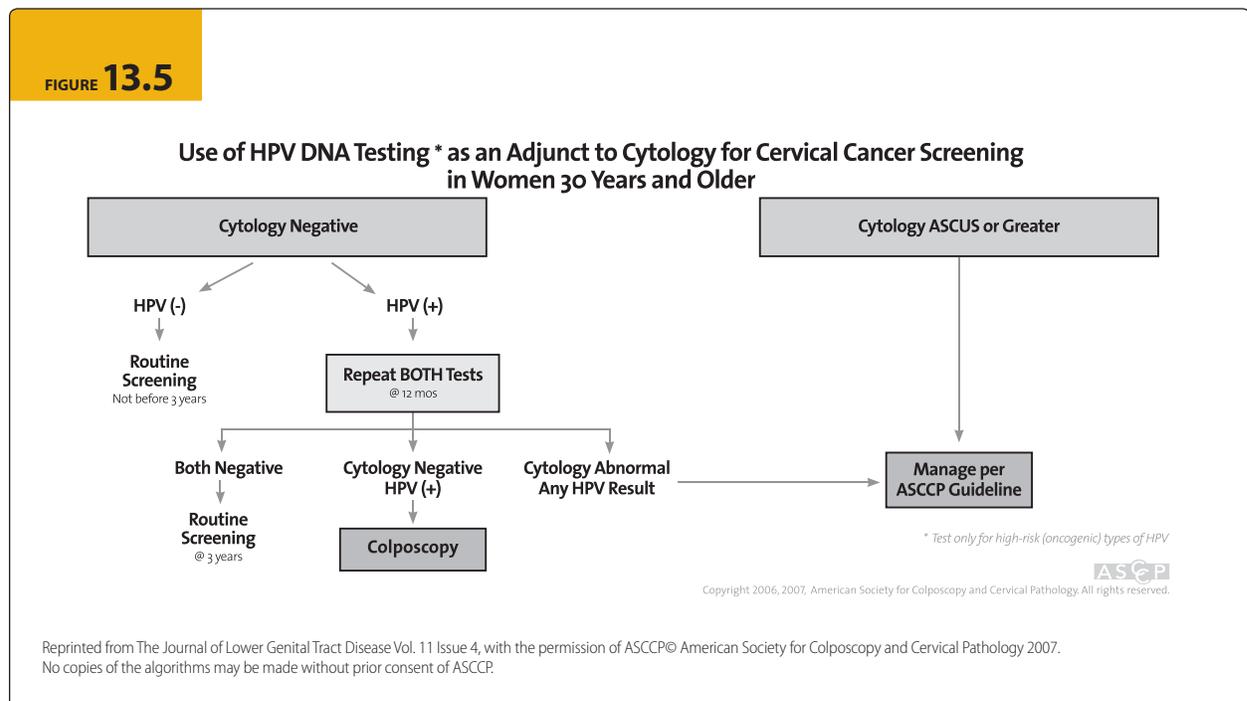
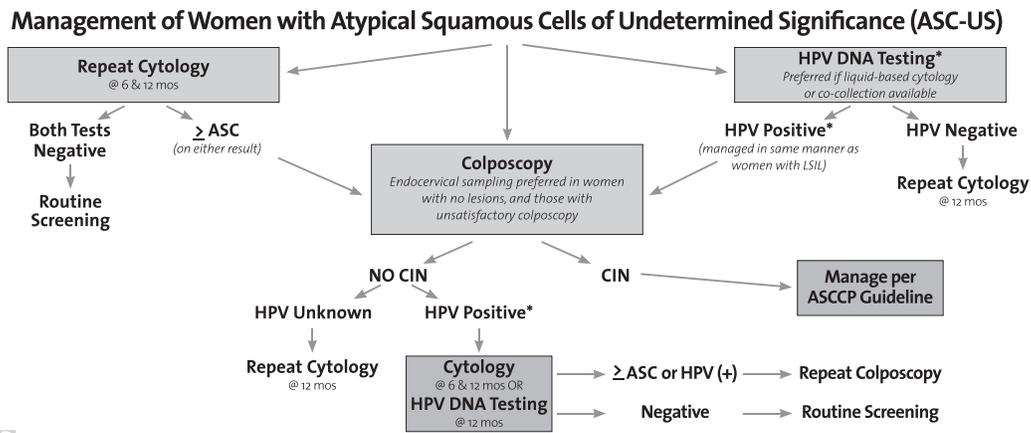


FIGURE 13.6



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\* Test only for high-risk (oncogenic) types of HPV

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The percentage of women ages 18 to 24 who reported never having a Pap test increased from about 13% in 2000 to more than 33% in 2008. If younger women are only delaying routine Pap testing until their mid-to-late 20s, there may be little impact on the cervical cancer incidence rates because of the low incidence rate in that age group and the slow progression of the disease. However, if this is the start of a trend of no routine Pap testing, rates of cervical cancer may increase for this cohort within 20 to 30 years.

### Screening Behavior: Facilitators and Barriers

Multiple, complex factors may affect cervical cancer screening behavior in women, including socioeconomic status, age, beliefs, and experiences, among other factors. Factors that influence screening behavior can be categorized as facilitators and barriers. Studies on this topic illuminate the following facilitators and barriers to obtaining cancer screening.

#### FACILITATORS

The presence of one or more facilitators increases the likelihood that a woman will get regular Pap tests.

- Fewer competing priorities (such as being a younger age).
- Urban or suburban residence.
- A history of utilization of preventive health

services, particularly receiving regular mammograms, having a regular source of healthcare, or having contact with an OB/GYN.<sup>27</sup>

- Positive past experiences and relationships with healthcare providers.<sup>28</sup>
- Medical recommendation for a Pap test.
- Personal health concerns or a history of cancer.
- Advice or encouragement from a spouse, family member, or friend.
- Easy access to health insurance and/or affordable screenings.
- Availability of transportation to medical appointments.<sup>29</sup>

#### BARRIERS

The presence of one or more barriers increases the likelihood that a woman will not receive regular Pap tests.

- Lack of transportation.
- Social and geographic isolation.
- Competing priorities (advanced age, health issues, limited time, economic and/or social resources).
- Insufficient availability of healthcare and/or insurance.
- Perception of good health and/or insufficient knowledge about Pap testing.
- Fear of past and future negative experiences.
- Modesty/discomfort.

- History of self-care traditions.<sup>30</sup>
- Language and cultural barriers.<sup>31</sup>
- Fear or apathy regarding cancer diagnoses.<sup>32</sup>

### Screening in the Hospital Setting

In 1977, the Maryland legislature passed Senate Bill 59, which requires hospitals to offer a Pap test to all female inpatients. In many hospitals, this is implemented not through testing during the inpatient visit itself, but by referring interested women to outpatient sources post-discharge. However, in cases where hospitals have provided resources to offer testing during the inpatient stay, such as establishing a dedicated Pap-testing nurse who visits all appropriate new admissions, there is some evidence that this can successfully screen women at high risk for cervical abnormality.<sup>33</sup>

### Physician Practices and Barriers

Physicians play an important role in recommending and providing cancer screening. A recently published national survey examined physician practices regarding Pap testing. The survey found that more than 75% of OB/GYNs ordered or performed more than 40 Pap tests per month, compared with 5.2% of internists and 12.7% of general or family practice physicians. OB/GYNs were also more likely than internists or general or family practice physicians to use patient reminders for Pap testing. Less than half of Pap-test providers reported using physician reminders such as chart reminders and computer prompts. The survey also found that physician recommendations for Pap-test screening were generally found to be inconsistent with major guidelines.<sup>34</sup> Deviance from guideline-based screening has also been demonstrated in several other studies.<sup>35,36,37</sup>

The recent introduction of the HPV vaccine for primary cervical cancer prevention has led to the continued examination of cervical-cancer-screening strategies, including the cost-effectiveness of such strategies.<sup>38,39,40</sup> As newer HPV-testing technologies enter the US market, appropriate screening with both HPV and Pap testing will depend on

the evolving natural history of cervical HPV infections in HPV-vaccinated women as well as non-vaccinated females and males.<sup>41</sup> There is a need for continued education of clinical providers in the state of the science to ensure adherence to changing guidelines and screening methodologies and to maintain cost-effectiveness of primary and secondary cervical cancer prevention.<sup>42</sup>

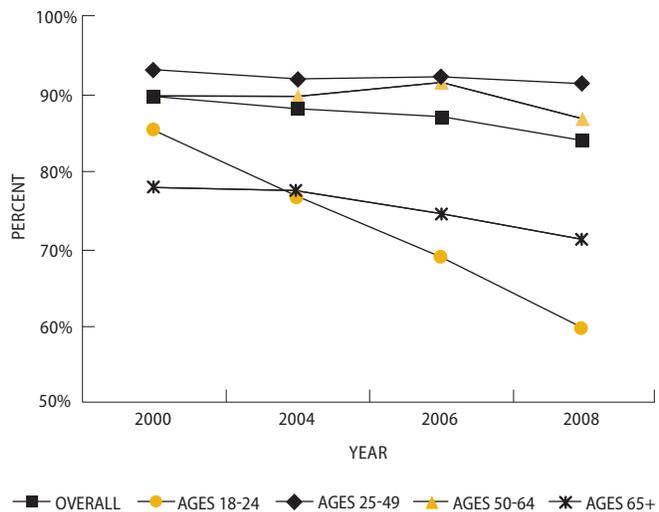
## Diagnosis and Treatment of Cervical Cancer

**W**HEN ABNORMAL CELLS are diagnosed early and treated appropriately, most cases of cervical cancer can be prevented.

Diagnostic procedures include colposcopy, endocervical curettage, and loop electrosurgical excision procedure (LEEP). When cervical cancer is diagnosed, pathologists and oncologists work together to determine the extent, or stage, of the cancer. Staging the cancer allows providers to best recommend treatment options. Treatment for cervical cancer can include surgery, chemotherapy, radiation, or a combination of these therapies. More information regarding cervical cancer diagnosis and treatment can be found in the National Cancer Institute publication, “What You Need to Know About Cervical Cancer”

FIGURE 13.7

Percentage of Maryland Women Reporting a Pap Test within Previous Three Years by Age, 2000-2008



Source: Maryland BRFSS, 2000-2008.

at <http://www.cancer.gov/cancertopics/wyntk/cervix.pdf>.

## The Survivorship Experience

**A** S MORE WOMEN ARE DIAGNOSED with cervical cancer at earlier stages and also benefit from improved treatment and follow-up, the number of women living as cervical cancer survivors has increased. Many important issues arise in the treatment and post-treatment periods for survivors.

Because cervical cancer is a disease of the reproductive organs, quality of life for cervical cancer survivors includes not just quality of overall health and well-being, but also important considerations specific to sexuality and reproductive health across the life course. For women who are diagnosed with cervical cancer prior to menopause, there are additional important considerations related to treatment effects on fertility and childbearing.

Access to high-quality healthcare can ensure early detection and appropriate treatment. Beyond extending the survivorship period, this also minimizes the burden of morbidity related to treatment and improves reproductive health throughout survivorship.

Because cervical cancer is a relatively rare disease, especially among women of reproductive age, the importance of both clinical and nonclinical resources for cervical cancer survivors is substantial. Contact with other cervical cancer survivors through support groups and organizations can allow women with cervical cancer important clinical and psychosocial support. More information on survivor resources can be found at [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

## Ideal Model for Cervical Cancer Control

**T**HERE ARE SIX STEPS in the ideal cervical cancer control process. A table with detailed information on this ideal model can be found on the Cervical Cancer page of the Maryland Cancer Plan ([www.marylandcancerplan.org](http://www.marylandcancerplan.org)) and is summarized here.

**STEP 1** Primary prevention is done at the population level, including HPV vaccination and

reduction of co-factor exposures.

- STEP 2** Patients have knowledge of and access to screening, diagnosis, treatment, and survivorship resources.
- STEP 3** Primary-care providers provide or refer for long-term preventative care including appropriate Pap and HPV testing/follow-up for all patients and are aware of resources for women who are uninsured or underinsured.
- STEP 4** Pap tests are sent to labs in compliance with the Clinical Laboratory Improvement Act (CLIA) and read by cytotechnologists or cytopathologists who report results using the Bethesda System and who have passed the Cytology Proficiency Testing Program of the state of Maryland.
- STEP 5** If a diagnosis is required, various diagnostic procedures are carried out by a trained colposcopist.
- STEP 6** Treatment is performed by a gynecologist, gynecologic oncologist, or other trained specialist to remove precancerous or cancerous lesions of the cervix.

Barriers to implementing some steps of the ideal cervical cancer control process have been identified throughout the chapter. The following barriers were identified by the Cervical Cancer Committee as specific to Maryland residents, and many are addressed in the Goals, Objectives, and Strategies to follow.

- Achieving herd immunity for the HPV vaccine may be difficult due to potential provider concerns with reimbursement, the cost of the vaccine to patients, and costs associated with stocking the vaccination.
- The Maryland Breast and Cervical Cancer Program has only enough funds to screen 15% to 20% of uninsured women ages 40 to 64 in the state for cervical cancer.
- Accessibility to screening services may be limited because of hours of operation, availability of public transportation, or lack of knowledge among patients and providers about the availability of existing services, especially for the socioeconomically disadvantaged.
- A lack of written information in patients' native languages or reading level and limited availability of language and translation services

may prevent women from seeking screening and treatment.

- There is a need to educate physicians (particularly primary care providers) regarding screening, follow-up guidelines, and new technologies.
- Residents in rural Maryland counties may encounter longer wait times for diagnostic or treatment services due to a limited number of specialists practicing in their local area.
- Many women who lack insurance and the financial means to pay for their care may go without diagnostic tests and treatment.

## Current/Ongoing Efforts in Maryland

**T**HE MARYLAND DEPARTMENT OF HEALTH AND MENTAL HYGIENE (DHMH) Breast and Cervical Cancer Program (BCCP) is a statewide program that provides breast and cervical cancer screening services to uninsured or underinsured low-income (less than 250% of the federal poverty level) women 40 to 64 years of age. Across the state, the DHMH awards funds to each jurisdiction to coordinate the provision of breast and cervical cancer outreach, patient and public education, screening, referral, follow-up, and case management services for its residents. The DHMH formed a Cervical Cancer Medical Advisory Committee, which develops clinical guidelines: “Minimal Clinical Elements for Cervical Cancer Detection and Diagnosis.” This document provides guidance for public health programs that screen for cervical cancer.

The Maryland BCCP provides approximately 6,000 Pap tests annually. Thirty percent of the women screened in the BCCP indicated that they were never or rarely screened (not in the past five years) for cervical cancer.

In addition to the BCCP, funding from the Cigarette Restitution Fund has been awarded to the University of Maryland Medical System/ University Care to provide breast and cervical cancer screening for low-income uninsured or underinsured women who live in Baltimore City. Several other Maryland jurisdictions also offer cervical cancer education and screening services under this program. These local programs provide approximately 700 Pap tests and educate about 23,000 people on cervical cancer annually.

**THERE ARE SEVERAL OTHER PROGRAMS IN MARYLAND** that provide testing, diagnostic, treatment, and support services for women including, but not limited to, the following.

- The Maryland Family Planning Program offers a variety of services including Pap tests according to current evidenced-based guidelines, access to colposcopy services, and education and counseling on reproductive health topics. The program serves more than 75,000 clients each year, is open to women and men of reproductive age, and provides services under a sliding fee scale.
- The Maryland Breast and Cervical Cancer Diagnosis and Treatment Program is state-funded and reimburses participating medical providers for breast and cervical cancer diagnostic and/or treatment services for Maryland residents who have received an abnormal breast or cervical test result or are diagnosed with either breast or cervical cancer, meet income guidelines (250% of the poverty level), and are either uninsured or underinsured for these services. This program is not restricted by age.
- The Women’s Breast and Cervical Cancer Health Program provides Medicaid coverage to eligible women screened under the BCCP who have been diagnosed with either breast or cervical cancer. Women in this program are eligible for full Medical Assistance while they are undergoing treatment for breast or cervical cancer.
- The American Cancer Society (ACS) provides educational and support services for cervical cancer patients, including several support groups. Assistance with transportation for cancer treatments can be obtained in some areas of the state through the Road to Recovery program. The ACS publishes numerous educational brochures and can send speakers to community meetings.

## GOALS - OBJECTIVES - STRATEGIES

### GOAL 1

**Decrease the incidence of invasive cervical cancer in Maryland by reducing risk and improving early detection.**

INCIDENCE TARGET (2015)

Less than 6.7 per 100,000  
(2006 baseline: 6.7 per 100,000)

Source: Maryland Cancer Registry.

#### OBJECTIVE 1

By 2015, increase the proportion of guideline-eligible populations who are informed and have access to HPV vaccinations.

#### STRATEGIES

- 1 **EXPAND EXISTING SURVEILLANCE** and monitoring systems to collect information on the education of and access to HPV vaccinations in order to establish a baseline and monitor progress.
- 2 **INCREASE THE DISSEMINATION** of state-of-the-art HPV vaccination guidelines to health professionals and other stakeholders.
- 3 **REDUCE BARRIERS** to access, affordability, and administration of HPV vaccinations as identified in the "Maryland Human Papilloma Virus Vaccines Subcommittee Report" (available at [www.marylandcancerplan.org](http://www.marylandcancerplan.org)).
- 4 **IMPLEMENT PARTNERSHIPS** between private, nonprofit, and governmental healthcare groups to increase Maryland residents' knowledge about the HPV vaccine, particularly those in at-risk populations, as outlined in the "Maryland Human Papilloma Virus Vaccines Subcommittee Report."

#### OBJECTIVE 2

By 2015, collaborate with state, local, and community partners to reduce the risks related to co-factors of cervical cancer (including HIV and the use of tobacco products).

#### STRATEGIES

- 1 **INCREASE SAFE REPRODUCTIVE HEALTH PRACTICES** through public education and increased access to male and female condoms.
- 2 **IMPLEMENT INNOVATIVE SYSTEMS** and health-based approaches to prevent and control HIV and the use of tobacco products. *See Chapter 5, Tobacco-Use Prevention/Cessation and Lung Cancer, for specific objectives and strategies on decreasing the use of tobacco products.*

#### OBJECTIVE 3

By 2015, utilize state-of-the-art recommendations to:

- **Increase the proportion of women ages 21 to 70 receiving a Pap test in the last three years to greater than 88% (2008 baseline: 88%).**  
Source: Maryland BRFSS.
- **Increase the number of women who have had appropriate HPV testing.**

#### STRATEGIES

- 1 **EXPAND EXISTING SURVEILLANCE** and monitoring systems to collect information on HPV testing in order to establish a baseline and monitor progress.
- 2 **INCREASE THE DISSEMINATION** of state-of-the-art screening recommendations to healthcare providers.
- 3 **INCREASE OUTREACH EFFORTS** by public health organizations and healthcare providers to women who have never or rarely been screened.
- 4 **INCREASE PAP TESTING** of hospital inpatients by amending Senate Bill 59, Section 19-348 language to require hospitals to "provide" Pap tests to all inpatients. Examine hospitals that succeed at providing Pap tests to inpatients and share lessons learned with other hospitals.

# GOALS - OBJECTIVES - STRATEGIES

## GOAL 2

**Decrease the mortality and morbidity of cervical cancer in Maryland.**

**MORTALITY TARGET (2015)**

1.4 per 100,000  
(2006 baseline: 2.2 per 100,000)

Source: CDC WONDER.

### OBJECTIVE 1

By 2015, utilize state-of-the-art guidelines—such as the American Society for Colposcopy and Cervical Pathology (ASCCP)—to educate Maryland providers about the appropriate use of diagnostic procedures and the potential negative outcomes of overuse and underuse of diagnostic methods.

#### STRATEGIES

- 1 DISSEMINATE STATE-OF-THE-ART GUIDELINES** to healthcare providers through Web-based methods and provider meetings and conferences.
- 2 ENCOURAGE QUALITY ASSURANCE MONITORING** of cervical cancer diagnostic procedure management by providers.

### OBJECTIVE 2

By 2015, increase access to cervical diagnostic and treatment services including:

- An increase in the percentage of women who are diagnosed within 90 days of abnormal screening, and
- An increase in the percentage of women whose treatment is initiated within 90 days of diagnosis.

#### STRATEGIES

- 1 UTILIZE EXISTING FRAMEWORKS** and clinical data to develop a tracking system that will establish the baseline rates and measure progress for Objective 2.
- 2 CONTINUE TO EDUCATE THE GENERAL PUBLIC** on the availability of screening, diagnostic, and treatment programs throughout Maryland.
- 3 ENCOURAGE MORE GYNECOLOGIC SPECIALISTS** or gynecologic oncologists to practice (permanently or traveling) in rural and underserved areas in Maryland.
- 4 PROVIDE EDUCATION ACTIVITIES** on the importance of obtaining diagnostic and treatment services in a timely manner.

### OBJECTIVE 3

By 2015, ensure that Maryland cervical cancer survivors have a survivorship cancer plan in order to minimize morbidity and quality-of-life burden from their disease and treatment.

#### STRATEGIES

- 1 ASSESS THE NUMBER OF CERVICAL CANCER SURVIVORS** in Maryland who receive survivorship care plans in order to establish a baseline and measure progress.
- 2 ENSURE THAT SURVIVORSHIP CARE PLANS** include survivorship resources (such as informational resources and support groups).
- 3 INCREASE AWARENESS** among primary care practitioners and gynecologic oncologists of survivorship issues, needs for medical care, and survivorship resources.
- 4 MONITOR THE UNMET NEEDS** for survivors through data collection from both providers and survivors.

### OBJECTIVE 4

By 2015, conduct Maryland-specific surveillance research on barriers to cervical cancer detection and treatment by establishing a statewide follow-back study mechanism to allow for monitoring of failures through follow-back and to evaluate and modify intervention strategies.

#### STRATEGIES

- 1 MODEL A PROGRAM** after the Fetal Infant Mortality Review Program to establish and maintain mechanisms to:
  - Collect information on factors that influence or hinder health-seeking behaviors and influence screening, diagnosis, and treatment of cervical cancer.
  - Monitor the proportion of cervical cancer cases and deaths attributable to failures of detection and treatment.
  - Identify strategies and implement activities to minimize failures of detection and treatment.
- 2 CONSIDER THE INCLUSION OF CIN 3** in the tumor registry reporting to the Maryland Cancer Registry to aid in the surveillance research.

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# 14 · Pain Management



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# 14

## PAIN MANAGEMENT

**P**ain affects more people in the United States than diabetes, heart disease, and cancer combined.<sup>1</sup> It is the most frequent reason patients seek physician care in the United States. When including healthcare expenses, lost income, and lost productivity, the annual cost of chronic pain in the US is estimated at \$100 billion.<sup>2</sup> A major category of pain and contributor to pain costs is cancer-related pain.

**ALTHOUGH THE INCIDENCE OF CANCER PAIN** has been difficult to measure,<sup>3</sup> some studies have shown that cancer pain is reported by about 50% of patients at all stages, and more than 70% of patients with advanced neoplasms.<sup>4</sup> Pain is also an issue for children with cancer, and in more than 70% of cases the pain will be severe at some stage.<sup>5</sup> Cancer pain can be managed effectively in up to 90% of Americans who have cancer or a history of cancer. Unfortunately, pain associated with cancer is frequently undertreated.<sup>6</sup>

Cancer is the second leading cause of death in Maryland, accounting for 24% of all deaths. More than 24,000 Marylanders were diagnosed with cancer in 2006.<sup>7</sup> The fact that a large number of these patients will experience unrelieved pain constitutes a public health crisis. Additionally, as the population ages and people over the age of 65 become our fastest-growing demographic group, cancer pain issues will become even more prevalent.<sup>8</sup>

In a recent report card on the palliative care programs in the United States published by the Center to Advance Palliative Care and the National Palliative Care Research Center, Maryland earned a grade of “B” in regard

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to the percentage of hospitals (50+ beds) with a palliative care program that enable physicians to treat pain for patients with terminal illnesses such as cancer.<sup>9</sup> According to the 2008 report card, 67% of Maryland hospitals have palliative care programs (Table 14.1). This is an increase in comparison to the findings in the 2002 Last Acts report, “Means to a Better End: A Report on Dying in America Today,” which found that only 25.8% provided palliative care programs. The Last Acts report also noted that 59.7% of Maryland hospitals offered pain management programs, 19.4% provided hospice programs, and referrals to hospice and length of stay in hospice were low.<sup>10</sup>

This chapter addresses the status of cancer pain assessment and management in Maryland, with a focus on both patient and clinician issues, and offers recommendations for addressing barriers within each group.

## Patient Issues

**P**ATIENTS WITH CANCER PAIN frequently report feeling out of control and vulnerable. As a result, they are often unable to advocate for themselves in the challenging healthcare arena. Empowering patients to form a partnership with their treating healthcare providers is an important step in making progress toward better cancer pain management in Maryland. To achieve this empowerment, patient education, access to pain management resources, and legislation and advocacy should be addressed.

### Patient Education

**EDUCATING PATIENTS ABOUT CANCER PAIN** is an important piece of pain management. The following fundamental issues make up the syllabus for pain management and should be included in educational efforts directed to patients.

- Importance of pain control.
- Value and process of pain assessment.
- Types and purposes of various pain treatments.
- Effective methods of communication with medical professionals about pain.

TABLE 14.1

Percentage of Hospitals Reporting a Palliative Care Program

	REPORT CARD GRADE (based on midsize & large hospitals)	MIDSIZE & LARGE (50+ beds)	LARGE (300+ beds)	MIDSIZE (50-299 beds)	SMALL (< 50 beds)
<b>MARYLAND</b>	B	67%	80%	63%	0%
<b>REGION (SOUTH)</b>	C	41%	65%	32%	13%
<b>UNITED STATES</b>	C	53%	75%	45%	20%

Sources: Center to Advance Palliative Care and National Palliative Care Research Center, 2008.  
 “America’s Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals.”

### Pain Care Bill of Rights

**As a person with pain, you have the right to:**

- Have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, social workers, and other healthcare professionals.
- Have your pain thoroughly assessed and promptly treated.
- Participate actively in decisions about how to manage your pain.
- Be informed and know your options. Talk with your healthcare provider about your pain: possible cause(s), treatment options, and the benefits, risks, and costs of each choice.
- Have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- Be referred to a pain specialist if your pain persists.
- Get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

*Although not always required by law, these are the rights you should expect for your pain care.*

Source: American Pain Foundation (<http://www.painfoundation.org>).

- Patients’ Pain Bill of Rights as put forth by the American Pain Foundation. (See text box above, “Pain Care Bill of Rights”).
- Assurance that everyone has a right to pain control without regard to age, race, gender, culture, and/or history of substance abuse.

Providing education to patients is a key step in empowering them to help seek treatment and manage cancer pain. Educational efforts could include summits or conferences, educational videos to be shown in physician-office or

treatment-center waiting rooms, and media outreach such as public service announcements. Adequate funding is needed to support these efforts.

### Access to Pain Management Resources

**IN ADDITION** to the need for patient education, accessing pain management resources continues to be a major problem. Pain management resources can include education, medication, support, comprehensive care, and specialists to treat pain. As a result of this lack of access to resources, there are many untreated cancer patients suffering in pain unnecessarily.

For example, one New York study found that only 25% of pharmacies in nonwhite neighborhoods had a sufficient supply of opioids required to treat severe pain, compared with 72% in predominately white neighborhoods.<sup>11</sup> This is a serious concern for those practitioners attempting to treat cancer patients adequately for pain who can be limited by the patients' access to receiving the prescribed medications. The availability of opioids in Maryland pharmacies is not currently known, but based on anecdotal reports it is perceived by the cancer pain community to be inadequate. For this reason, further research studies on opioid availability in Maryland should be conducted, especially in urban settings. Such studies can be used to inform future attempts at increasing access to this pain management resource.

Another barrier to accessing pain management resources is a lack of comprehensive insurance coverage for pain management.<sup>12</sup> Formularies developed by insurance companies and Medicaid, along with the use of "caps" on prescription drugs, can also limit access to pain management resources.<sup>13</sup> Such barriers can seriously affect cancer patients seeking pain relief. According to a survey conducted by the Maryland State Medical Society (MedChi), Maryland physicians have voiced concern about these and other barriers including cost-containing measures such as prior authorization, pre-certification, step therapy, and therapeutic switching. The survey reported that nearly 95% of Maryland physicians believe that insurance carrier requirements that dictate how and what physicians can prescribe have a negative impact on their ability to treat

patients.<sup>14</sup> To address some of these barriers, MedChi has petitioned the Maryland Insurance Administration for a formal review.<sup>15</sup>

### Legislation and Advocacy

**A 2008 PROGRESS REPORT CARD** published by the University of Wisconsin Paul P. Carbone Comprehensive Cancer Center rates the quality of state policies affecting pain treatment. Maryland was given a "B" on the report card, scoring lower than 16 states.<sup>16</sup> One strategy to improve Maryland's national standing related to pain is to focus on correcting the conflicting terminology used in Maryland controlled substance statutes and regulations related to pain (i.e., physical dependence, addiction, tolerance). A consensus document from the American Academy of Pain Medicine, the American Pain Society, and the American Society of Addiction Medicine points out that inconsistent use of this terminology often results in misunderstandings among regulators, healthcare providers, patients, and the general public regarding the use of medications for the treatment of pain.<sup>17</sup> Correcting these commonly misused terms would contribute to improving

#### Definitions Related to the Use of Opioids for the Treatment of Pain

**PHYSICAL DEPENDENCE** Physical dependence is a state of adaptation that is manifested by a drug-class-specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist.

**ADDICTION** Addiction is a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.

**TOLERANCE** Tolerance is a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time.

*Discussion: Most specialists in pain medicine and addiction medicine agree that patients treated with prolonged opioid therapy usually do develop physical dependence and sometimes develop tolerance, but do not usually develop addictive disorders.*

Source: American Pain Society. Definitions Related to the Use of Opioids for the Treatment of Pain; 2001. Accessed August 26, 2010 from <http://www.ampainsoc.org/advocacy/opioids2.htm>.

Maryland's national standing on pain treatment policies. The American Pain Society has provided definitions of these terms, shown in the text box "Definitions Related to the Use of Opioids for the Treatment of Pain" on page 5.

Increased patient and healthcare provider participation in legislative events will be necessary to educate lawmakers on the importance of adequately treating pain. Together, patients and providers should work to move pain issues to the forefront of Maryland's legislative agenda. One way to do this would be to empower patients to advocate for themselves in the legislative arena. Teaching patients to effectively engage in advocacy will bring an important voice to the process of changing the face of pain in Maryland.

Lastly, to enhance the impact of pain advocacy, it is recommended that all committees, associations, and legislative activities related to pain include patient representation. Pain is a very multidimensional experience and even the most knowledgeable clinicians cannot fully understand the experience of living with cancer pain. This influence is vital to ensure that advocacy activities are targeted toward improving patients' quality of life.

## Clinician Issues

**T**HE APPROACH TO PAIN MANAGEMENT by clinicians can be influenced by many barriers, including the understanding of pain and pain management, the quality of pain assessments, and attitudes and legal issues regarding pain medications. Such barriers can be overcome by an emphasis on clinician education and training, an effort to involve pain specialists in the interdisciplinary management of pain, and the use of policy tools to move pain control forward. These factors must be addressed in order to optimize pain control and minimize the impact on quality of life for cancer patients.

### Understanding Pain

One of the first steps in achieving effective pain control is an understanding that pain is not only a symptom but also a disease process in itself. There are many systemic effects and

consequences of unrelieved pain (Table 14.2). Pain is a disease state of the nervous system and deserves the same management attention given to any other disease states.<sup>18</sup>

The issue of prognosis and pain is often interrelated, particularly in the patient's mind. In some cases cancer pain may be an almost an existential threat to the patient, bringing up questions such as: *Does this pain mean that my cancer is worse? That my cancer has recurred? That I am going to die? That I am going to die sooner than expected?* Patients may handle their pain very poorly because it is an unfamiliar or new pain with undetermined and/or undiscussed prognostic

**FAST FACT** Pain is not only a symptom. It is also a disease process in itself.

TABLE 14.2

### Consequences of Unrelieved Pain

**CARDIOVASCULAR** Increased heart rate, peripheral vascular resistance, arterial blood pressure, and myocardial contractility resulting in increased cardiac work, myocardial ischemia and infarction.

**PULMONARY** Respiratory and abdominal muscle spasm (splinting), diaphragmatic dysfunction, decreased vital capacity, impaired ventilation and ability to cough, atelectasis, increased ventilation/perfusion mismatch, hypoventilation, hypoxemia, hypercarbia, increased postoperative pulmonary infection.

**GASTROINTESTINAL** Increased gastrointestinal secretions and smooth muscle sphincter tone, reduced intestinal motility, ileus, nausea, and vomiting.

**RENAL** Oliguria, increased urinary sphincter tone, urinary retention.

**COAGULATION** Increased platelet aggregation, venostasis, increased deep vein thrombosis, thromboembolism.

**IMMUNOLOGIC** Impaired immune function, increased infection, tumor spread or recurrence.

**MUSCULAR** Muscle weakness, limitation of movement, muscle atrophy, fatigue.

**PSYCHOLOGICAL** Anxiety, fear, anger, depression, reduced patient satisfaction.

**OVERALL RECOVERY** Delayed recovery, increased need for hospitalization, delayed return to normal daily living, increased healthcare resource.

Source: Office of the Army Surgeon General. Pain Management Task Force Report: "Providing a Standardized DoD and VHA Vision and Approach to Pain Management to Optimize the Care for Warriors and their Families"; 2010.

significance. Adopting a strictly biomedical model of pain fails to address the full meaning of the pain in a cancer patient. The topic of prognostic implications should be addressed with patients at the earliest possible point. In some cases, support to the patient in the form of psychological counseling should be offered.

Effective pain management is possible for patients with cancer or a history of cancer and will improve the patient’s quality of life throughout all stages of the disease. However, it is important for clinicians to have an understanding of the pain and remain flexible in its management. As patients differ in diagnosis, stage of disease, and responses to pain and treatments, this management must be individualized.<sup>19</sup>

### Comprehensive Pain Assessments

**C**OMPREHENSIVE PAIN ASSESSMENT is critical to provide healthcare providers with information for cancer pain management. Providers cite the lack of systematic assessment as one of the biggest obstacles to providing effective pain management.<sup>20</sup> Routine screening using pain measurement tools can help healthcare providers determine when a patient is experiencing pain and thus respond to changes in pain. However, simple pain screenings do not assess how pain affects that patient’s life, the quality of the pain, when it occurs, or how much or what kind of medication(s) or other therapies will help reduce a particular patient’s pain.

Delivery of quality cancer care includes providing pain and symptom management, alongside disease-directed treatment, which requires frequent and comprehensive pain assessment. As improvements continue in cancer management that extend life expectancy for patients, it will be increasingly important to also control cancer-related pain during the active treatment course to reduce the likelihood that cancer survivors will have to endure chronic pain later on. However, mounting evidence indicates that inadequate assessment and treatment of cancer pain continues to be a significant public health problem that requires immediate and concerted action.<sup>21,22,23,24</sup>

**FAST FACT** Effective pain management is possible for patients with cancer or a history of cancer and will improve quality of life throughout all stages of the disease.

### Pain Medication: Attitudes and Legal Issues

**MEDICATIONS ARE AN IMPORTANT TOOL** in pain management. However, one of the major barriers to managing pain are the words associated with pain management medications: “narcotics,” “addiction,” “painkillers.” These words can be strong, scary, and stigmatizing, thus discouraging patients from taking the medicines they need.<sup>25</sup> In addition, patients, families, and healthcare professionals often have misconceptions and confusion about addiction, physical dependence, and tolerance, which contribute to patient and family fears about using pain medications and to practitioners’ reluctance to prescribe them.<sup>26,27,28,29,30,31</sup> As noted in the Patient Issues section, the misuse of terminology in Maryland policies also contributes to this problem.

Pain management is affected by legal and legislative barriers developed in response to concerns about drug abuse. Laws concerning controlled substances vary. In states with pain coalitions, efforts are being made to revise legislation to remove barriers to the use of opioids, such as removing dosage restrictions. However, 16 states’ controlled-substance or professional-practice laws, including Maryland’s, would still incorrectly define any patient who is physically dependent on an opioid medication as an “addict.”<sup>32</sup> An up-to-date interpretation differentiates clearly between dependence and addiction. A balanced approach to the dispensation of pain medication is needed so the effort to prevent drug abuse does not impede access to controlled substances to pain sufferers.<sup>33,34</sup>

### Overcoming Barriers

#### CLINICIAN EDUCATION AND TRAINING

**EDUCATION AND TRAINING** for future and current healthcare providers is necessary for improving pain management for cancer patients. Knowledge gaps, inadequate assessment skills, and negative attitudes toward opioids are all barriers to effective cancer pain management that can be addressed through education and training.

The low priority traditionally given to pain treatment in professional training<sup>35,36,37,38,39</sup> and educational texts<sup>40</sup> has contributed to the barriers of pain management. Senior medical students were found, in one study, to be reluctant to prescribe opioid therapy for pain.<sup>41</sup> Another study found them to be deficient in their understanding of multiple available options for relieving suffering in cancer patients.<sup>42</sup> In addition, a recent study found pain management to be lacking among pharmacy school curricula.<sup>43</sup>

The Office of the Army Surgeon General recently released a “Pain Management Task Force Report” that includes the education of clinicians about pain treatment as a best practice for adopting an integrative and interdisciplinary approach to managing pain.<sup>44</sup> Maryland educational institutions provide opportunities for education in pain and symptom management as part of some curricula, residency programs, and fellowship programs for physicians, nurses, and pharmacists. However, this has been a recent addition and most clinicians practicing in Maryland did not complete their training in the state in recent years. Therefore, many clinicians in Maryland may not have been exposed to adequate pain management training during their basic or advanced training. Postgraduate training for practicing healthcare providers may address this gap and increase the use of effective methods of pain assessment and treatment.<sup>45,46</sup> Pain management education for Maryland’s healthcare professionals could be further facilitated by completion of additional training in this area through required continuing education programs.

#### **INTEGRATING PAIN SPECIALISTS TO INTERDISCIPLINARY PAIN MANAGEMENT**

**CANCER PAIN IS TYPICALLY MANAGED** by an interdisciplinary approach including a broad team of health professionals. In a “Pain Management Task Force Report” released by the Office of the Army Surgeon General, one best practice identified was that healthcare organizations and professionals must be accountable to their patients for the attentive treatment of pain.<sup>47</sup> One way to achieve this is with the integration of pain specialists into the interdisciplinary pain management team.

However, the number of pain specialists may be inadequate to meet these needs. According to

a recent report jointly produced by the Center to Advance Palliative Care and National Palliative Care Research Center, there is a lack of palliative medicine physicians certified by the American Board of Hospice and Palliative Medicine (ABHPM), as well as advanced practice nurses (APN) and registered nurses (RN) certified by the National Board for Certification of Hospice and Palliative Nurses (NBCHPN). For example in 2007, 2,651 United States physicians held board certification in the practice of palliative medicine (1 physician per 560 Medicare deaths). In comparison, there are 16,800 cardiologists in the US (or 1 per 71 heart attack victims). In 2007 in Maryland, there were only 56 physicians with board certification in the practice of palliative medicine (1 physician per 487 Medicare deaths).<sup>48</sup>

To achieve the optimal interdisciplinary approach to pain management utilizing pain specialists, this deficiency will have to be addressed by increasing the number of clinicians with the ability to provide specialized consultations on pain.

#### **POLICY TOOLS**

**ONE OF THE BEST PRACTICES** identified in the “Pain Management Task Force Report” released by the Office of the Army Surgeon General includes the need for policies on reimbursement for health professionals, medications, and other palliative treatments (e.g., counseling, cognitive treatment for symptoms, and other supportive care), as well as controlled substance regulations designed so that they do not create barriers to symptom treatment. The task force report also calls for the establishment of:

- Pain management requirements to standardize patient care services.
- Interdisciplinary pain management services to oversee optimum pain care.
- An effective pain management advisory board.
- A state-level pain management education plan that addresses the full spectrum of stakeholders and issues.<sup>49</sup>

In addition, the National Pain Care Policy Act of 2009 highlights the continued need to increase awareness of pain assessment and management and its barriers, expand pain research, and improve the education and training of health

professionals on a national scale.<sup>50</sup> Language to this effect is also included in the recently passed federal healthcare reform legislation, the Affordable Care Act.<sup>51</sup>

By utilizing identified best practices and recommendations as well as national and state policy models, many of the barriers to effective pain management could be addressed with a statewide Maryland Pain and Palliative Care Act. A statewide act could improve pain management by establishing a statewide advisory council on palliative care and pain management, creating and enhancing undergraduate and graduate training programs, establishing Centers for Excellence, and certifying one or more resource centers to assist physicians in the treatment of patients in pain.

## Summary of Recommendations

**T**HE PERVASIVENESS OF PAIN as a problem to the many cancer pain patients and survivors in Maryland is not in question: the issue is what should be done to alleviate their pain. Both clinicians and the patients themselves have responsibilities in this realm. It is hoped that the outcome of this chapter will facilitate the lessening of chronic, acute, and breakthrough pain and afford caregivers with more tools to accomplish this outcome.

Specifically, pain patients as well as their families and other caregivers must be empowered to manage and advocate for their own needs regarding pain and the quality of their lives. Pain education, including the importance of pain control, the variety of pain treatments, a Patients' Pain Care Bill of Rights, and effective means of communication with providers must be offered. It is also essential that barriers to accessing quality

pain management resources, specifically medications, be removed.

It is also necessary to develop clinicians' skills to optimize their ability to manage patients' pain, either personally or through referrals, so that the quality of life of oncology patients, survivors, and their families is elevated. Clinicians should be encouraged to use the services of accredited pain management practitioners and facilities, which will require addressing the deficit of pain specialists that currently exists. To facilitate these actions, a plan to insure that all oncology patients' pain is professionally assessed and treated within the first 24 to 48 hours after diagnosis or admission to a hospital should be developed by a group of pain and palliative care specialists.

Legislative issues cut across both the patient and clinician domains. Enacting a Pain and Palliative Care Act in Maryland would provide a useful policy tool to help move pain control forward, including the creation of training programs for students and clinicians, the establishment of a statewide advisory council as well as a Center for Palliative Care Excellence, and the provision of palliative care resources at all hospitals with oncology centers. In addition, if Maryland enacts any legislation related to Prescription Drug Monitoring Programs, electronic medical records, or electronic prescribing, it should not hinder a patient's access to adequate pain control. These same considerations must be paramount every time the Medicaid formulary is reevaluated.

Successful implementation of these recommendations will help to improve pain management for cancer patients and their families in ways that all of society can appreciate.

## GOALS - OBJECTIVES - STRATEGIES

### GOAL 1

**Empower cancer patients to take an active role in partnering with healthcare providers in managing pain and minimizing impact on quality of life.**

#### OBJECTIVE 1

By 2015, increase the proportion of Maryland cancer patients exposed to pain education.

#### STRATEGIES

- 1 **PROVIDE ADEQUATE FUNDING** to support events to educate cancer patients about important pain topics.
- 2 **ORGANIZE A PATIENT EDUCATION SUMMIT** in partnership with interested organizations on topics such as:
  - Importance of pain control.
  - Value and process of pain assessment.
  - Types and purposes of various pain treatments.
  - Effective methods of communication with medical professionals about pain.
  - Patients' Pain Bill of Rights as put forth by the American Pain Foundation.
- 3 **PRODUCE AN EDUCATIONAL VIDEO** to be shown in cancer office waiting rooms and other venues where patients can learn about cancer pain principles. Include in this video all of the rest of the strategies with an emphasis on the assurance that all patients have a right to quality pain control without regard to age, race, gender, culture, and/or history of substance abuse.
- 4 **DEVELOP AND IMPLEMENT A SURVEY** of accredited cancer centers in Maryland to measure the proportion of cancer patients exposed to pain education.

#### OBJECTIVE 2

By 2015, decrease barriers to accessing quality pain management resources (specifically pain medications) for all Marylanders regardless of age, race, culture, and history of substance abuse as outlined in the strategies below.

#### STRATEGIES

- 1 **COLLABORATE WITH PHARMACIES** to ensure that pain medication is adequately stocked in all communities and explore legislation that would require pharmacies to stock pain medication.
- 2 **CONDUCT A STUDY** to measure availability of opioids in Maryland pharmacies, especially in urban settings. Set targets and measure changes over time.
- 3 **TEACH PATIENTS** how to navigate third-party challenges to decrease insurance barriers.
- 4 **CONDUCT AN INVESTIGATION** of insurance practices regarding adequate and fair coverage for patients in pain and create a report card that would allow patients to make informed decisions when selecting a health plan.

#### OBJECTIVE 3

By 2015, assure that legislation in areas such as **Prescription Drug Monitoring Plans, electronic medical records, electronic prescribing, and Medicaid formulary does not hinder a patient's access to adequate pain control.**

#### STRATEGIES

- 1 **INCREASE INVOLVEMENT** in legislative events to move pain issues to the forefront of Maryland's agenda.
- 2 **SPONSOR AN EVENT** for patient empowerment to teach patients how to engage in the legislative aspect of pain advocacy.
- 3 **CORRECT THE TERMINOLOGY** in the state report card to improve the pain report care grade (i.e., definition of addiction, dependency, etc.).
- 4 **INCLUDE PATIENT REPRESENTATION** in committee meetings, associations, and legislative activities related to pain.

# GOALS - OBJECTIVES - STRATEGIES

## GOAL 2

**Educate and involve clinicians to optimize cancer pain control and take an active role in partnering with other healthcare providers and patients in managing pain and minimizing impact on quality of life.**

### OBJECTIVE 1

By 2015, increase clinician education and awareness by providing seminars, grand rounds, and/or other opportunities for pain management education at 50% of accredited cancer centers in Maryland.

#### STRATEGIES

- 1 PROVIDE SUPPORT** through academic institutions and training programs to develop education tools that emphasize the importance of quality of life and optimum symptom management and pain control.
- 2 PROVIDE A MECHANISM** for the education to be available at cancer centers.
- 3 DEVELOP A TRACKING MECHANISM** to measure the utilization of this program by cancer centers.

### OBJECTIVE 2

By 2015, increase the proportion of Maryland physicians utilizing pain consult from practitioners in the area of pain and palliative care.

#### STRATEGIES

- 1 UTILIZE EXISTING STRUCTURES** to implement and make programs available to clinicians with the focus on pain control by partnering with state agencies such as the Maryland Board of Physicians to require CME in pain for renewal of medical licenses.
- 2 DEVELOP METHODS** to measure the proportion of physicians utilizing pain consult from pain and palliative care practitioners in order to establish a baseline and monitor progress.

### OBJECTIVE 3

By 2015, enact a statewide Maryland Pain and Palliative Care Act modeled after the New York Palliative Care Education and Training Act of 2007, which improves palliative care and pain management by:

- Establishing a statewide advisory council on palliative care and pain management.
- Creating undergraduate and graduate training programs.
- Establishing Centers for Palliative Care Excellence.
- Certifying one or more palliative care resource centers to assist physicians in the treatment of patients in pain.

#### STRATEGIES

- 1 INVOLVE ADVOCATES** such as the Maryland Department of Health and Mental Hygiene, MedChi, and physician specialty groups in developing a legislative strategy to pursue this objective.

### OBJECTIVE 4

By 2015, develop a plan that ensures that patients' pain is assessed and promptly treated in 80% of cancer patients.

#### STRATEGIES

- 1 CONVENE A GROUP** of pain and palliative care specialists to develop the plan.

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# 15 · Palliative and Hospice Care



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## PALLIATIVE AND HOSPICE CARE

**P**alliative care addresses the physical, emotional, social, and spiritual needs of patients and families. It offers vigorous treatment of pain and other symptoms; relief from worry, anxiety, and depression; close communication about care; well-coordinated care during illness transitions; support for family caregivers; and a sense of safety in the healthcare system.<sup>1</sup>

**THE FOCUS OF PALLIATIVE CARE** is promoting quality of life by preventing, treating, and relieving pain and suffering and other debilitating effects of illness experienced by patients and families.

### Palliative and Hospice Care: A New Paradigm of Care

**P**ALLIATIVE CARE is a new paradigm of care that is moving into the mainstream of healthcare. It is both a philosophy of care and an organized, highly structured system for delivering care for any patient and family experiencing serious, progressive, chronic, or life-threatening illness at any point during the illness experience.<sup>2</sup>

To achieve maximum benefit, palliative care ideally begins at the time of diagnosis with a life-threatening illness and continues throughout the course of illness until the death of the patient and into the bereavement period of families.<sup>3</sup> Offered by an interdisciplinary team of health professionals, palliative care responds to both the episodic and long-term nature of multifaceted illness. Given that it is not dependent on prognosis, palliative

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care can be delivered at the same time as curative or life-prolonging treatments are being offered or as the main focus of care when solely comfort and supportive interventions are desired.<sup>4</sup>

Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and families, optimizing function, helping with decision-making, and providing opportunities for personal growth.<sup>5</sup> It is important to recognize that palliative care is focused on matching treatments with the patient's and family's values and preferences.<sup>6</sup> Palliative care involves the integration of the best evidence possible regarding treatments, with the clinical judgment of health professionals, while taking into account the wishes and preferences of patients and their families.

In contrast to palliative care, which begins at the time of diagnosis with any life-threatening illness and continues throughout the illness experience, hospice care provides care to patients who have a prognosis of six months or fewer to live. The focus of hospice care is the care of patients and families during the last months and days of life. Both palliative care and hospice care are based on the same key elements: the care of all patients with life-threatening illness of all ages, patient- and family-centered care, and comprehensive care (physical, emotional, social, and spiritual) offered by an interdisciplinary team of health professionals.

There are several clinical models of palliative care including programs offered in hospitals through palliative care consultation services or on inpatient palliative care units, as well as in nursing homes, assisted living facilities, community home-based programs, or outpatient clinics. Hospice care is also offered in a variety of settings including hospice units in hospitals, hospice care in nursing homes, residential hospices, and home hospice. Today, many hospices are providing palliative care so that patients who have greater than six months prognosis may also receive the holistic support needed to promote their quality of life. Therefore, the difference between palliative care and hospice care is the timing: palliative care may be offered at any point in time while hospice care is offered at the end of life.<sup>7</sup>

## The Need for Palliative and Hospice Care

**P**ALLIATIVE CARE HAS BEEN INCREASINGLY IN DEMAND due to the aging of the population and an increase in life expectancy of patients with cancer, HIV/AIDS, and end-stage organ diseases. Public awareness, the education of health professionals, Joint Commission Accreditation, and the desire for Magnet status (an award given by the American Nurses Credentialing Center to hospitals that satisfy a set of criteria designed to measure the strength and quality of their nursing) by hospitals has served as the impetus for an increase in palliative care consultations and hospice referrals. Media attention has informed patients and families that they have a right to expect relief of pain and other symptoms; support for psychological, psychiatric, spiritual, or social distress; active involvement in decision-making regarding treatment options; and consideration of their wishes and preferences. The importance and value of palliative care is highlighted by the following data:

- The US population ages 85 and over is expected to grow from 5.3 million in 2006 to nearly 21 million by 2050.<sup>8</sup>
- The sickest 10% of the US population accounts for 64% of healthcare expenditures.<sup>9</sup>
- Palliative care consultation reduces the cost per patient by almost \$1,700 for live discharges and almost \$5,000 for patients who die in the hospital. This is an annual cost savings of more than \$1.3 million per year for a 400-bed hospital.<sup>10</sup>
- In 2006, 67% of Maryland hospitals with more than 50 beds reported the presence of a palliative care program.<sup>11</sup>

**PALLIATIVE CARE** is emerging at a time when Marylanders most need it to complement current cancer care. Cancer is the second leading cause of death in the state of Maryland, with one of every four deaths attributed to cancer. It is estimated that in 2009, Maryland had more than 26,000 new cancer patients diagnosed (excluding basal and squamous cell skin cancers), and more than 10,000 deaths.<sup>12</sup> More individuals and families are living with cancer as a “chronic disease,” which increases the need for expert survivorship care. The aging population and improvements in cancer

treatment mean that the number of survivors will grow, and more than half of those diagnosed will live for more than five years with illness and ongoing treatment.<sup>13</sup>

Palliative care is poised to become a universally available approach to meet the needs of the sickest and most vulnerable populations and is an important factor in improving healthcare in the US.<sup>14</sup> This is based on data that palliative care outcomes include:<sup>15</sup>

- Improvement of quality while lowering cost of hospital care.
- Improvement of quality of life for patients and families.
- Handling of time-intensive family/patient/team meetings.
- Coordination of care.
- Support of patients and families.
- Specialty-level assistance to the attending physician.
- Support for attending physicians and discharge planning staff.
- Improvement in patient/family satisfaction.
- Improvement in nurse and physician satisfaction.

**BECAUSE PALLIATIVE CARE** has seen an increase in demand and become an expected part of the treatment regimen for many, it is imperative that teams of interdisciplinary professionals are educated to address the palliative care needs of patients and families. In addition, there is an increased need to offer outpatient palliative care services for individuals who prefer to remain at home or in other settings.<sup>16</sup>

With this comes the realization that each resident of Maryland must be aware of the importance of advanced care planning as well as palliative and hospice care options. The bioethical principle of patient autonomy states that a competent individual has the right to decide for or against any medical treatment.<sup>17</sup> Individuals have the right to be informed to make decisions regarding their healthcare at all points in the cancer care trajectory. To be an informed consumer of healthcare, individuals must have a clear understanding of all treatment options, including palliative care in conjunction with curative therapy, as well as palliative and hospice care as the focus at end of life.

## Key Stakeholders in Palliative and Hospice Care

For the purposes of this chapter, the following key stakeholders have been identified as important for creating a comprehensive palliative care system.

### Patients, Families, and Communities

- **PATIENTS:** Individuals with a diagnosis of cancer at any phase of the illness experience.
- **FAMILY:** Any individual who provides direct or indirect support of a patient experiencing cancer.
- **COMMUNITY:** A group of interacting people living in a common location and who share common values or interests.

### Healthcare Professionals and Associated Staff

- **HEALTHCARE PROFESSIONALS:** All members of the palliative care and hospice interdisciplinary team including physicians, nurses, social workers, psychologists, chaplains, pharmacists, physical or occupational therapists, as well as patients' oncologist or primary care physician.
- **ASSOCIATED STAFF:** All individuals involved in the caring process who offer direct or indirect support in the care of oncology patients and their families across all healthcare settings.

### Institutions

**ALL HEALTHCARE DELIVERY SYSTEMS** that provide palliative or hospice care, such as medical centers, hospitals, rehabilitation hospitals, sub-acute and long-term care facilities, assisted-living facilities, hospices (inpatient, home, or residential), or related office/outpatient clinics.

### Healthcare Policymakers, Legislators, and Payers

**MARYLAND STATE AND CONGRESSIONAL LEGISLATORS**, the Maryland executive branch of government, two key federal agencies, the Centers for Medicare and Medicaid (CMS) and the Centers for Disease Control and Prevention (CDC), insurers, philanthropists, as well as the business community, including employers and caregiver advocacy organizations.

## A Blueprint for Success

**T**HE GOAL OF IMPLEMENTATION of a blueprint for success for palliative and hospice care across the state of Maryland will necessitate the achievement by each of the stakeholder groups of what is termed the “4 A’s”: Awareness, Acknowledgement, Access, and Action.

- **AWARENESS** implies knowledge and appreciation gained through one’s perceptions or by means of information about palliative and hospice care.
- **ACKNOWLEDGMENT** is the recognition and acceptance of the value of palliative and hospice care.
- **ACCESS** is the right, privilege, or ability to make use of resources and information related to palliative and hospice care.
- **ACTION** is the development, implementation, and evaluation of initiatives to promote palliative and hospice care—which will lead to inclusion of palliative and hospice care into the standards of care and setting of future goals.

It is important that each of the identified stakeholder groups develops an awareness of palliative care, acknowledges its value, promotes access to quality palliative and hospice care, and takes action to implement a standard of practice in palliative and hospice care. Based on a review of the literature and collaborative efforts of the Maryland experts in the field of palliative care, strategies have been identified for each of the stakeholder groups in relation to the 4 A’s. These strategies serve as the cornerstones of the blueprint for success for palliative and hospice care for patients and families experiencing cancer in the state of Maryland.

### Patients, Families, and Communities

**T**HE CARE OF THE SERIOUSLY ILL AND DYING has always involved the relationship of patients, their families, and communities. However, in the past century, the care of seriously ill and dying individuals has shifted away from the family and community into hospitals due to the rapid development of life-prolonging technologies. These technologies include drugs, new procedures and medical devices, and improved imaging techniques. While the goal for some patients may be to prolong life at any cost, others may want their pain and other symptoms controlled to

**FAST FACT** The ultimate goal of palliative and hospice care is to improve overall quality of care for patients with serious illness and their families. Patients and families must be able to access these services in their communities.

have a better quality of life in their final months and days. Palliative and hospice care programs are models for high-quality care with valuable services to the sickest, most vulnerable individuals and their families.

In 2008, the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC) released a report card on palliative care. The report shows that the percentage of hospitals with 50 or more beds reporting a palliative care program almost doubled from 2000 to 2006.<sup>18</sup> Despite this growth, many seriously ill individuals may not be aware of or may lack access to palliative care before they are eligible for hospice care.

Educating the community through public awareness campaigns on The Joint Commission’s (TJC) standards for institutions that seek a voluntary Palliative Care Accreditation and marketing the institutions/agencies that offer palliative and hospice services will increase public knowledge. It is also important that healthcare facilities have missions, visions, and philosophies of care that emphasize the importance of patient-centered care and teamwork.

The ultimate goal of palliative and hospice care is to improve the overall quality of care for patients with serious illness and their families. However, patients and families must be able to access these services in their community. Timely referrals to these services are affected by geographic availability, physicians’ reluctance to refer to hospice services, financial barriers such as lack of reimbursement, insufficient provider training, and patients and families being unaware of or unwilling to discuss palliative and hospice care options.<sup>19</sup>

Currently, patients and their families remain undereducated about advanced care planning, palliative, and hospice care.<sup>20</sup> This is attributed to the general cultural attitude in which death is rejected as an option and conversations about

**FAST FACT** The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care recommends that palliative and hospice care be provided by an interdisciplinary team of skilled palliative care professionals.

death and dying are uncomfortable for patients and their families. Work should be done to raise expectations about the education patients receive. Increased knowledge of palliative and hospice care may result in patient conversations with healthcare providers they might not have had otherwise.<sup>21</sup> This awareness will empower the patient and family to take an active role in conversations about goals of treatment and expected outcomes, and to have a clearer understanding of options should treatment fail to cure or control the cancer. An integral part of these conversations should be the completion of advanced directive documents with the subsequent sharing of the documents with family as well as healthcare providers.

Evidence shows that cultural change is unlikely to happen without public demand for that change.<sup>22</sup> Armed with the knowledge and experience of palliative care, individuals, families, and community can come together and take action to increase the availability and provision of such care. These open conversations will lead to supporting the creation of a healthcare environment where physical symptoms and emotional and spiritual needs are acknowledged and addressed in a holistic manner throughout the cancer trajectory. Increased awareness, improved communication, and the expectation to be involved in each decision regarding one's healthcare will ensure a better quality of life regardless of the quantity of that life.

### Healthcare Professionals and Associated Staff

**W**ITH THE RECOGNITION OF PALLIATIVE CARE as a subspecialty in both medicine and nursing, the challenge is to educate enough health professionals in palliative care to staff the rapid national increase in palliative care programs. Through programs such as the End of Life Nursing Education Consortium (ELNEC) and Education for Physicians in End of Life Care (EPEC), nurses, physicians, social workers, and other practitioners are being trained in pallia-

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tive care. Undergraduate programs in nursing, graduate programs in nursing and social work, and medical school programs are incorporating palliative care content into their curricula. Master's and post-master's certificate programs in nursing and social work are being offered in palliative care along with the development and implementation of interprofessional fellowship programs involving disciplines with interest in palliative care (medicine, nursing, psychology, social work, pharmacy, chaplaincy, occupational, and recreational therapy).

Collaboration across disciplines is a key concept in palliative and hospice care. The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care recommends that palliative and hospice care be provided by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).<sup>23</sup>

Recognizing the opportunity that interdisciplinary care provides, it will become important to provide interdisciplinary education to support the integration of palliative care and optimize interdisciplinary work to the benefit of all involved. Interdisciplinary education engages all health disciplines in learning together and more importantly in learning how to work together.<sup>24</sup> Developing a broader understanding of different viewpoints/roles and learning tolerance, cooperation, and functional communication are fostered by interdisciplinary study.<sup>25</sup> Clinical competencies address the ethical and cultural contexts of disciplines and lead to the provision of quality care.<sup>26</sup>

The American Association of Colleges of Nursing (AACN) and the Pew Health Professions have both endorsed an interdisciplinary approach to education.<sup>27,28</sup> Through education, health professionals from all disciplines will develop the competencies to increase their communication skills related to palliative care in conversations with patients and families, contribute to excellence in clinical practice by sharing their knowledge and expertise with other health professionals through publications and presentations, and promote the specialty through participation in media and marketing campaigns. By actively

participating in palliative care educational initiatives, practitioners will promote their ongoing professional development in palliative care and serve as mentors to those who are entering the profession. These practitioners must ascertain patient's values, explore potential options for goals of care, identify available resources, and assist with advanced care planning.

Through acknowledging the value, healthcare professionals will promote access to palliative care and increase their referral rates to both palliative care and hospice. The expectation is that healthcare professionals will incorporate the National Quality Forum Preferred Practices of Palliative Care as a standard of care within institutions. Research is needed to measure interdisciplinary education and care outcomes alike as part of healthcare quality improvement and system reform.<sup>29</sup>

### Institutions

**P**ALLIATIVE CARE INITIATIVES require not only clinical champions and administrative champions at the local level, but executive leaders at the corporate or systems level.<sup>30</sup> Administrators must be aware of the national initiatives related to palliative care and acknowledge its value to quality patient care.<sup>31</sup> This awareness may then lead to the incorporation of palliative care goals and tactics into the institution's strategic plan. Administrators must also budget substantial resources for educational outreach to insure appropriate utilization of palliative care and to convey the message of its value in relation to cost savings, cost avoidance, quality care, and patient and family satisfaction. Utilizing philanthropic and other contributions can also add to a revenue base for hiring a skilled and credentialed team of interdisciplinary professionals.

The State of Maryland Office of the Attorney General's "Workgroup Report on Hospice Care, Palliative Care and End of Life Counseling" emphasizes that healthcare facilities should be encouraged to develop systems to utilize health professionals currently trained in palliative and hospice care. Of extreme importance is the hiring of interprofessional palliative care practitioners to staff such services and promote the coordination of care across healthcare settings.<sup>32</sup> Facilities should be encouraged to expand educational

opportunities for all healthcare professionals at various levels and to monitor the frequency and quality of care provided by practitioners.<sup>33</sup>

Institutionally, the work is to connect people to each other, to the data, to the business case, mission, and quality case for palliative care.<sup>34</sup> The National Quality Forum Consensus Recommendations for operational features of palliative care programs include the importance of

- **ALIGNING THE MISSION** of the palliative care program with the mission of the institution.
- **OFFERING VALUED SERVICES** by inpatient consultation and outpatient practice.
- **INSURING THE AVAILABILITY** of both routine and emergency services.
- **MEASURING** patient/family and institutional outcomes.
- **INCORPORATING** quality improvement.
- **FUNDING** the marketing of palliative services.

Institutions with case management and patient navigator programs are providing some of the much-needed care coordination for cancer patients. The need for patient navigation is described in a report by the President's Cancer Panel, which recommends such programs to help communities coordinate, promote, and support community-based programs.<sup>35</sup> Patient navigation programs are found within some hospital systems to help patients navigate their cancer care while under treatment.<sup>36</sup> There are also case management programs within insurance companies that are working to provide holistic care coordination, education, navigation, and facilitation of the needs of a patient and family as the patient goes along the trajectory of the cancer experience.<sup>37</sup>

### Healthcare Legislators, Policymakers, and Payers

**S**TATE AND LOCAL GOVERNMENTS can facilitate changes in health policy, quality standards, and reimbursement incentives to provide for ongoing education and training in palliative care and to develop a Bill of Rights related to palliative and hospice care.

The State of Maryland Office of the Attorney General's "Workgroup Report on Hospice Care, Palliative Care and End of Life Counseling" identified three categories of barriers Marylanders face in getting access to quality palliative and hospice care. Barriers included lack of information about

the tradeoffs of such care, cost, and administrative hurdles.<sup>38</sup> The identified barriers and set of policy actions recommended to reduce them were not only tailored to boost access to palliative care for Marylanders, but consistent with findings about barriers and remedial policy actions nationwide.<sup>39</sup>

Additionally, state governments can effect change by promoting the development of a Center for Excellence in Palliative Care. Center resources and support would be available to remote or sole community provider hospitals, as well as 24 hour urgent care centers and clinics where continuity of care is challenged and end-of-life care planning may not occur. Legislatures can advocate for initiatives addressing quality improvement studies that track requests for palliative care consults, patient and family outcomes, healthcare professional outcomes, and financial and economic outcomes.

Achieving the goal of access to high-quality palliative care for all Marylanders and all Americans who need it regardless of geography, diagnosis, prognosis, state of illness, care setting, family situation, or social class will require government and regulatory policy to bring palliative care innovation to scale.<sup>40</sup> Policy solutions will range from the funding of career development awards in palliative medicine and nursing to lifting the cap on graduate medical education dollars for medical fellowships, increasing the National Institutes of Health funding for palliative care research, and addressing the more complex issues of payment reform and reimbursement for palliative care services.<sup>41</sup>

A specific advocacy and legislative agenda would include the integration of palliative care and hospice care. The legislative agenda should address relevant healthcare reform initiatives such as the comparative effectiveness of palliative care and hospice with traditional hospital care, bundled payments, and funding of demonstration projects that test the integration of comprehensive palliative care in the care of patients with complex medical needs.<sup>42</sup> Healthcare policymakers should be encouraged to implement programs that will improve the quality of care while slowing the growth of total healthcare spending in the nation: it is this platform that defines palliative care and its goals.<sup>43</sup>

Meier and Beresford (2008) sound the call to the palliative care community to get involved in issues at the state level, to build and identify a state’s organizational infrastructure for palliative care, and to respond quickly to public policy issues—given that palliative care practitioners “have an important stake in understanding the legislative and regulatory processes and influencing how these issues get addressed” (p.1070).<sup>44</sup>

The interface of energies and visions among healthcare professionals, institutions, healthcare policymakers, legislators, and payers is critical to create much-needed reform as well as the crafting of policies that will promote the well being of patients, families, and communities facing serious, life-threatening illness. It is this interface that provides not only an informed perspective but can achieve a “meeting of the minds” to insure high-quality care and continuous care.

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## GOALS - OBJECTIVES - STRATEGIES

A more detailed version of the Goals/Objectives/Strategies can be found on the Palliative and Hospice Care page of the Maryland Cancer Plan Web site: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

### GOAL

**Implement a blueprint for success for palliative and hospice care for patients and families experiencing cancer in the state of Maryland.**

#### OBJECTIVE 1 AWARENESS

By 2015, develop an awareness campaign to educate Maryland citizens about palliative and hospice care within 50% of Maryland jurisdictions.

##### STRATEGIES (BY STAKEHOLDER GROUP)

- 1 **PATIENTS/FAMILIES/COMMUNITIES:** seek information on palliative and hospice care and advanced care planning from their healthcare providers, public library, national and local cancer agencies, and local health department.
- 2 **HEALTHCARE PROFESSIONALS AND ASSOCIATED STAFF:** increase communication related to palliative care issues in patient conversations, healthcare publications, and media/marketing.
- 3 **INSTITUTIONS:** initiate palliative care activities with the goal of obtaining buy-in from various constituencies.
- 4 **HEALTHCARE LEGISLATORS/POLICYMAKERS/PAYERS:** conduct an internal education effort on strategies to reduce barriers that Maryland residents face in regard to quality palliative and hospice care. The education effort should include widespread distribution, discussion, and the development of an action plan based on:
  - The 2009 “Workgroup Report on Hospice Care, Palliative Care and End of Life Counseling,” released by the Maryland Attorney General’s Counsel for Health Decisions Policy workgroup, and
  - “Reports of the Maryland State Advisory Council on Quality of Care at the End Life.”

#### OBJECTIVE 2 ACKNOWLEDGING THE VALUE

By 2015, increase the participation in and support of palliative and hospice care initiatives by stakeholders as outlined in the strategies.

##### STRATEGIES (BY STAKEHOLDER GROUP)

- 1 **PATIENTS/FAMILIES/COMMUNITIES:** participate in campaigns that support/promote palliative and hospice care and advanced care planning.
- 2 **HEALTHCARE PROFESSIONALS AND ASSOCIATED STAFF:** actively participate in palliative education and palliative care initiatives as demonstrated by attendance at national conferences, increase in certification and credentialing rates, and referral to palliative care services and hospice care.
- 3 **INSTITUTIONS:** develop a strategic plan that incorporates goals and related tactics to institutionalize palliative care as it relates to ongoing professional education, implementing and maintaining supportive services for patient/families, supporting research and evidence-based practice, and driving healthcare policy and legislative initiatives that promote palliative care.
- 4 **HEALTHCARE LEGISLATORS/POLICYMAKERS/PAYERS:** conduct outreach efforts via email, town halls, and focus groups to educate constituents about the knowledge, financial, and administrative barriers Maryland cancer patients and their families face in regard to palliative and hospice care and get their input on options to reduce them.

# GOALS - OBJECTIVES - STRATEGIES

## OBJECTIVE 3 ACCESS

By 2015, increase access to palliative and hospice care services in Maryland.

### STRATEGIES (BY STAKEHOLDER GROUP)

- 1 **PATIENTS/FAMILIES/COMMUNITIES:** request access to palliative and hospice services.
- 2 **HEALTHCARE PROFESSIONALS AND ASSOCIATED STAFF:** develop and implement educational programs (formal and informal) related to palliative and hospice care.
- 3 **INSTITUTIONS:**
  - Develop a mechanism to track the percentage of palliative care consultations for hospital patients admitted with cancer, and
  - Ensure clinical support through hiring a skilled and credentialed/certified team of interdisciplinary palliative care professionals and associated support staff in order to implement a palliative care consult service or other delivery models (such as an inpatient unit, outpatient clinic, homecare program, and/or establishing partnerships with community hospices).
- 4 **HEALTHCARE LEGISLATORS/POLICYMAKERS/PAYERS:** explore legislative options for expanding access to and payment for palliative and hospice care, building on best practices.

## OBJECTIVE 4 ACTION

By 2015, stakeholders will take ownership of the Blueprint for Success and act on 70% of the strategies recommended for each stakeholder group.

### STRATEGIES (BY STAKEHOLDER GROUP)

- 1 **PATIENTS/FAMILIES/COMMUNITIES:** advocate for effective and compassionate palliative care across healthcare settings to insure that the goals of care are achieved.
- 2 **HEALTHCARE PROFESSIONALS AND ASSOCIATED STAFF:** incorporate the National Quality Forum Preferred Practices of Palliative Care as a standard of care within the institution.
- 3 **INSTITUTIONS:** initiate quality improvement studies to evaluate the provision of quality palliative care by tracking:
  - Requests for palliative care consults.
  - Patient/family and community outcomes.
  - Healthcare professional outcomes.
  - Economic outcomes.
- 4 **HEALTHCARE LEGISLATORS/POLICYMAKERS/PAYERS:** support pilot programs that test:
  - The feasibility and impact of training lay workers to serve as palliative and hospice care counseling coaches and navigators.
  - Reimbursement models for providing end-of-life care counseling.
  - The impact of innovative clinical-financial models of palliative and hospice care for cancer patients and their families designed to reduce knowledge, financial, and administrative barriers to their use.

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# APPENDIX

## DATA TERMS, SOURCES, AND CONSIDERATIONS

### Data Terms

#### Age-Adjustment

Age is the most important risk factor for the incidence of most cancers. Cancer rates derived from populations that differ in underlying age structure are not comparable. Therefore, age-adjustment is a statistical technique that allows for the comparison of rates among populations having different age distributions by weighting the age-specific rates in each population to one standard population.

#### Incidence Rate

An incidence rate is the number of new cases of a given cancer or other event per 100,000 population during a defined time period, usually one year. Cancer incidence rates in this plan are reported for one year, such as for 2006, or as the average annual incidence rate for several aggregated years, usually 2002 through 2006.

#### Mortality Rate

A mortality rate is the number of deaths per 100,000 population during a defined time period, usually one year. Cancer mortality data in this plan are reported for one year, such as for 2006, or as the average annual rate for several aggregated years, usually 2002 through 2006.

#### Rate

A rate is an estimate of the burden of a given disease on a defined population in a specified period of time. A crude rate is calculated by dividing the number of cases or deaths by the population at risk during a given time period. Cancer incidence and mortality rates are usually

presented per 100,000 population during a defined time period. All rates in this plan are either age-specific or age-adjusted using the method described above.

#### Stage at Diagnosis

The stage at diagnosis describes the extent to which a cancer has spread from the organ of origin at the time of diagnosis. The stage information used in this plan is based on the SEER Summary Stage Guidelines:

- **IN SITU:** The cancerous cells have not invaded the tissue basement membranes. In situ cancers are not considered malignant (with the exception of bladder cancers) and are not included in incidence rate calculations.
- **LOCALIZED:** The tumor is confined to the organ of origin.
- **REGIONAL:** The tumor has spread to adjacent organs or tissue. Regional lymph nodes may also be involved.
- **DISTANT:** The tumor has spread beyond the adjacent organs or tissues. Distant lymph nodes, organs, and/or tissues may also be involved.
- **UNSTAGED:** The stage of disease at diagnosis was unable to be classified or was not reported to the Maryland Cancer Registry.

#### Survival Rate

A survival rate refers to the percentage of people in a study or treatment group who are alive for a given period of time after diagnosis. This plan generally presents five-year survival rates.

## Sources of Maryland Data

**T**HE MARYLAND-SPECIFIC DATA used in this plan were supplied by the Maryland Department of Health and Mental Hygiene (DHMH), including the Maryland Cancer Registry; National Center for Health Statistics (data in CDC WONDER); the Office of Health Policy and Planning; the Center for Health Promotion, Education, and Tobacco-Use Prevention; and the Center for Cancer Surveillance and Control.

### Maryland Cancer Registry

Cancer incidence and stage data were provided by the Maryland Cancer Registry (MCR), Center for Cancer Surveillance and Control, Department of Health and Mental Hygiene (201 W. Preston Street, Room 400, Baltimore, MD 21201, [www.fha.state.md.us/cancer/registry/](http://www.fha.state.md.us/cancer/registry/), 410-767-4055). We acknowledge the state of Maryland, the Maryland Cigarette Restitution Fund, and the National Program of Cancer Registries of the Centers for Disease Control and Prevention for the funds that support the collection and availability of the cancer data and analysis.

The MCR is a computerized data system that registers all new cases of reportable cancers (excluding non-genital squamous cell or basal cell carcinoma) diagnosed or treated in Maryland. The Maryland cancer reporting law and regulations mandate the collection of cancer information from facilities that are licensed in Maryland, including hospitals, radiation therapy centers, diagnostic laboratories, freestanding ambulatory care facilities, surgical centers, and physicians whose non-hospitalized cancer patients are not otherwise reported. The MCR also participates in data exchange agreements with neighboring states including Delaware, Pennsylvania, Virginia, West Virginia, and the District of Columbia. Information on Maryland residents diagnosed or treated for cancer in these states is included in this plan.

### Maryland Behavioral Risk Factor Surveillance System

The Maryland Behavioral Risk Factor Surveillance System (BRFSS) is an annual telephone survey conducted on a random sample of Maryland adult residents. This survey, managed by the DHMH Family Health Administration, Office of Health Policy and Planning, provided cancer risk behavior

(e.g., tobacco use, sun exposure, diet, physical activity) and cancer screening information used in this document. Maryland data can be accessed online at <http://www.marylandbrfss.org>. Both Maryland and state-aggregated national data on health risk behavior can also be obtained from the CDC BRFSS Web site at <http://www.cdc.gov/brfss>.

### Maryland Youth Tobacco Survey and Maryland Adult Tobacco Survey

The Maryland Youth Tobacco Survey (MYTS) and the Maryland Adult Tobacco Survey (MATS), managed by the DHMH Family Health Administration, Center for Health Promotion, Education, and Tobacco Use Prevention, are administered to gather information regarding tobacco-use behaviors, attitudes, knowledge, and beliefs among Marylanders. The MYTS focuses on underage Maryland middle and high school youth, while the MATS focuses on Maryland adults age 18 years and older. Survey results are used to monitor progress toward reducing smoking and tobacco use in Maryland, and in apportioning Local Tobacco Use Prevention and Cessation grants among Maryland's 24 major political subdivisions. The MYTS and MATS have been conducted in 2000, 2002, 2006, and 2008. Data have been re-analyzed and revised by the Maryland Tobacco Use Prevention and Cessation Program, as necessary, to address definitional changes (e.g., changes in variables, survey questions) between surveys and to enhance comparability of survey data from different years. Published reports are available on the DHMH Web site at: <http://www.crf.state.md.us/html/stats.cfm> and [http://crf.maryland.gov/tobacco\\_behaviors.cfm](http://crf.maryland.gov/tobacco_behaviors.cfm).

### Maryland Cancer Survey

The Maryland Cancer Survey (MCS) is a biennial telephone survey managed by the DHMH Center for Cancer Surveillance and Control. The purpose of the MCS is to determine cancer screening rates and to measure cancer risk behaviors among persons age 40 years and older living in Maryland, for selected cancers targeted by DHMH. MCS survey data are included for 2002, 2004, 2006, and 2008. MCS data are tabulated and reported as not including missing values; all percentages are based on the number of respondents who answered the question. Some charts in this

document include both MCS and Maryland BRFSS data, as a basis for comparison with Healthy People 2010 targets. Caution should be used when comparing results from the MCS and BRFSS.

Although they are similar, these surveys have certain design and methodological differences, including targeted age groups, scope and timing of the surveys, and weighting. The MCS reports, including detailed information on the survey methods, are available on the Web at [http://fha.maryland.gov/cancer/surv\\_data-reports.cfm](http://fha.maryland.gov/cancer/surv_data-reports.cfm).

### **National Center for Health Statistics**

Maryland mortality rates presented in this plan were obtained from the National Center for Health Statistics (NCHS) Compressed Mortality Files in the CDC Wide-ranging Online Data for Epidemiologic Research (WONDER) system, a national Web-based data source.

## **Sources of National Data**

National statistics cited in this plan were obtained from the Centers for Disease Control and Prevention (CDC), the Office of Disease Prevention and Health Promotion (part of the US Department of Health and Human Services), the National Center for Health Statistics (NCHS), and the National Cancer Institute (NCI).

### **Surveillance, Epidemiology, and End Results Program**

The Surveillance, Epidemiology, and End Results (SEER) Program, managed by the National Cancer Institute, is an authoritative source of information on cancer incidence, stage, and survival in the US. The SEER Program, which began in 1973, collects, analyzes, and publishes cancer incidence and survival data from population-based cancer registries participating in the program. The SEER Program was expanded in 1992 (creating the SEER 13 registry database) and again in 2001 to increase representation of minority and rural low-income populations including Hispanics/Latinos, American Indian/Alaska Native populations, and rural blacks/African Americans. Since 2000, SEER incidence data have been collected from 15 SEER registries and four expansion registries throughout the US (SEER 17 registry database) and are estimated to represent approximately 26% of the US population. The SEER database

represents cancer incidence in the US population with regard to race, ethnicity, age, gender, poverty, and education, and by collecting data on epidemiologically significant population subgroups.

SEER 17 incidence data are used in this document for comparisons with the most recent Maryland data (2002-2006) because they provide the broadest population coverage that is currently available. For longer-term comparisons that include Maryland data prior to 2000, SEER 13 registry data are used. All SEER 13 and 17 rates were obtained from SEER\*Stat (version 6.5.1), a statistical software tool for the analysis of SEER and other cancer-related databases. Further information about SEER can also be found on the Web site at [www.seer.cancer.gov](http://www.seer.cancer.gov).

### **National Center for Health Statistics**

US mortality rates presented in this plan were obtained from the National Center for Health Statistics (NCHS) Compressed Mortality Files in the CDC Wide-ranging Online Data for Epidemiologic Research (WONDER) system, a national Web-based data source.

### **Healthy People 2010**

Healthy People (HP) 2010 is a collaboration of local and national governmental agencies and private organizations that have developed prevention-oriented national objectives to improve the health of Americans. The HP initiative is under the Office of Disease Prevention and Health Promotion at the US Department of Health and Human Services (DHHS). There are 28 focus areas and 467 specific objectives in HP 2010. For cancer prevention, the overarching HP 2010 goal is to “reduce the number of new cases as well as the illness, disability, and death caused by cancer.” To achieve this goal, measurable objectives related to cancer screening and cancer risk behaviors were established, each with a specific quantitative target. In 2006, a Midcourse Review of HP 2010 was completed by DHHS to assess progress toward the original HP 2010 objectives and to revise those objectives for which new data had become available. The HP 2010 targets in this document have been updated to reflect changes resulting from the HP 2010 Midcourse review. Further information about HP 2010 can be found at <http://www.healthypeople.gov> and [MARYLAND COMPREHENSIVE CANCER CONTROL PLAN](http://www.</a></p>
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healthypeople.gov/data/midcourse.

In this document, quantitative HP 2010 targets, where available, are compared to Maryland data related to cancer risk behaviors (e.g., smoking, sun exposure) and adherence to cancer screening recommendations. Specifically, HP 2010 targets are compared to data from the Maryland BRFSS and the MCS.

### **CDC Behavioral Risk Factor Surveillance System**

The national counterpart to Maryland's BRFSS system is operated by the CDC's National Center for Chronic Disease Prevention and Health Promotion. National statistics on behavioral health risks, as well as select individual state data may be accessed at <http://www.cdc.gov/brfss>.

### **National Cancer Institute Physician Data Query**

The national cancer institute physician data query (PDQ) provides information for health professionals and the public on various aspects of cancer control such as prevention, screening, treatment, genetics, and clinical trials. The information is reviewed by a scientific editorial board and is updated as new research becomes available. Each statement listed in the PDQ is based on current knowledge as defined by the most recent literature using established levels of evidence. More information about NCI's PDQ can be accessed at <http://www.nci.nih.gov/cancerinfo/pdq/cancerdatabase>.

### **Smoking-Attributable Mortality, Morbidity, and Economic Costs**

The CDC manages the Smoking-Attributable Mortality, Morbidity, and Economic Costs (SAMMEC) application to estimate the disease impact of smoking for the nation, states, and large populations. The SAMMEC application is primarily used to measure the deaths and years of life lost due to smoking, but it can also calculate smoking-attributable mortality (SAM), years of potential life lost (YPLL), direct medical expenditures, and productivity costs. More information and SAMMEC data can be accessed at <http://apps.nccd.cdc.gov/sammec/intro.asp>.

## **Data Considerations**

### **Data Confidentiality**

The DHMH regards all data received, processed, and reported to and by the Maryland Cancer Registry as confidential. Data are secured from unauthorized access and disclosure.

The MCR manages and releases cancer information in accordance with the laws and regulations established by the state of Maryland as set forth in the Code of Maryland Regulations, COMAR 10.14.01 (Cancer Registry) and Health-General Article, § 18-203 and § 18-204, Annotated Code of Maryland. To ensure patient confidentiality and to comply with the MCR Data Use Policy, cells with counts of 1-5 cases are suppressed and presented as "<6." Complementary suppression of case counts in additional cell(s) is used, denoted by "s," to prevent back-calculation of numbers in those cells with primary suppression. Incidence rates based on 15 or fewer (non-zero) cases are presented with asterisks (\*\*), because the rates are unstable and do not provide reliable information.

Mortality data in this report, obtained from NCHS Compressed Mortality Files in CDC WONDER, comply with data use restrictions stipulated by both CDC and NCHS.

### **Gender**

Gender is now reported to the Maryland Cancer Registry as (a) male, (b) female, (c) hermaphrodite, (d) transsexual, and (e) unknown. The totals shown in the count for number of cancer cases may not equal the sum of males and females because of cases in these other gender categories.

### **Rate Analysis and the Year 2000 US Population Standard**

Age-adjustment, also called age-standardization, is one of the tools used as a control for the different and changing age distributions of the population in states, counties, etc., and to enable meaningful comparisons of vital rates over time. Federal agencies have adopted the year 2000 US standard population as the new standard for age-adjusting incidence and mortality rates, beginning in data year 1999. Incidence and mortality rates in this plan were calculated and age-adjusted using the 2000 US population as the standard population. Additional information on age-adjustment can be

found at <http://www.cdc.gov/nchs/data/statnt/statnt20.pdf>.

### Statistical Significance

Statistical significance, as cited in this plan, was determined by identifying non-overlapping 95% confidence intervals for the age-adjusted incidence, mortality or other rates.

### Racial and Ethnic Minority Populations

The 1997 update of Directive 15 of the Federal Office of Management and Budget defined a minimum list of categories for racial and ethnic data collection. In that system of categorization, persons are classified as of Hispanic or Latino ethnicity or not (without regard to race), and then classified into one or more of the following racial categories (without regard to Hispanic ethnicity): black or African American, Asian, Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native, or white. In Maryland, the Native Hawaiian or Other Pacific Islander category comprises only 0.1% of the population, and is combined with Asian in a category of Asian and Pacific Islander for reporting purposes (which was the categorization before 1997).

In this document, “black or African American” is used where space permits, and “black” is used to represent that group in tables and figures where space limitations exist. Similarly, space considerations lead to interchangeable use of “Hispanic or Latino” with “Hispanic,” “Asian or Pacific Islander” with “Asian,” and “American Indian and Alaska Native” with “American Indian.”

Some data sources report race without regard to Hispanic or Latino ethnicity, and report Hispanic or Latino ethnicity without regard to race. Other data sources report results in categories of non-Hispanic race and Hispanic. Thus, in this document where “white” or “black” appear not specified as non-Hispanic, those data include both Hispanics or Latinos and persons not Hispanic or Latino. Where a race appears preceded by “non-Hispanic” or “NH,” those data refer only to the persons of that race who are not Hispanic or Latino.

The MCR began requiring submission of more detailed data on race and ethnicity beginning in August 1998. Previously, race reported as American Indian/Alaska Native or Asian/Pacific

Islander was counted in the category called “other” race. For many of the chapters of this plan, race and ethnicity reporting is limited to blacks and whites, though in some cases an “other” category is presented. However, for Chapter 3 on cancer disparities, an effort was made to provide as much race/ethnicity detail as possible for the Maryland population.

Hispanic ethnicity data are derived by the MCR using the NAACCR Hispanic Identification Algorithm. This algorithm uses a combination of NAACCR variables to classify people as Hispanic. Those with “Hispanic” ethnicity include people reported to the MCR as Spanish/Hispanic origin plus those with “derived” Hispanic origin. The derivation is an algorithm based on the person’s surname (last or maiden name) and their place of birth, race, and gender.

### Healthy People 2010 Objectives, Maryland BRFSS, and MCS

As measures for cancer-related behaviors (e.g., screening tests) and the recommendations for their use change, the Behavioral Risk Factor Surveillance System (BRFSS) and Maryland Cancer Survey (MCS) questions that measure screening and other health behaviors are also updated to reflect these modifications. In addition, the Healthy People 2010 objectives were updated in 2006 to reflect current health-related behavior and screening.

Healthy People 2010 objectives are generally age-adjusted to the year 2000 US standard population, while data from the Maryland BRFSS and MCS are weighted to the age of the Maryland population in that year, but are not age-adjusted to the year 2000 US standard population.

### Data Years

Significant efforts were made toward consistency of data years reported throughout this plan. Age-adjusted incidence and mortality statistics are reported through 2006, the most recent data year available at the time of writing.

Behavioral risk factor data from the BRFSS, the MCS, and the MYTS/MATS are reported for the most recent year available at the time of writing, or for several different years in order to establish a trend over time. The most recent data year available for behavioral risk factor data

varies from topic to topic, based on which survey questions were asked in various years.

### Target Setting for Goals and SMART Objectives

Some of the Goals and many of the Objectives in the Plan give specific data targets to be met by a particular year (typically 2015). The method below was used to develop the targets. In a few cases, this method was not used; rather, targets were set to mirror those previously set by another plan or program. When this is the case, it is described in a footnote in the Plan.

#### METHODS

Targets under the goal of decreasing incidence or mortality or increasing risk-reduction strategies: the DHMH Center for Cancer Surveillance and Control staff projected 2015 rates using the Microsoft Excel linear “forecast” function. By this method, known Maryland data values were used to predict a future value for the year 2015 by using linear regression. The projected value was then graphed by adding a linear trendline (in Excel) to the known data points, then extending the line forward to the year 2015.

Incidence and mortality projections were based on Maryland age-adjusted rates for the eight-year period from 1999-2006. Behavioral and risk factor projections are based on data from the Behavioral Risk Factor Surveillance System (BRFSS), the Maryland Cancer Survey, and other sources. These projections use the most recent years of data available for the period from 1999-2008. Data from these surveys are more limited, however, because surveys were either not conducted every year (e.g., MCS) or because the question(s) of interest were not asked every survey year. In all cases, a minimum of 3 data points was used for quantitative projections with Excel.

#### NOTE:

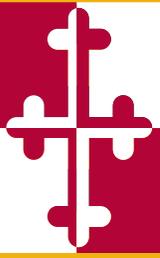
- This linear method of projecting based on actual data does not take into account demographic, screening, or funding factors that may influence the trend through 2015.
- When staff determined that a 2015 projection using this method showed that the projection was not in the direction desired to control cancer, we described the targets as being “greater than” or “less than” the 2006 baseline (depending on whether we sought an increase or decrease over baseline measurement, respectively).

Targets under the goal of decreasing race and/or gender disparities were projected using the linear forecast function described above for each race and/or gender group.

#### NOTE:

- For Colorectal Cancer incidence targets by race: The above method resulted in projected targets that represented an increase in disparity between two groups; therefore, we modified the target-setting method so that the disparity in 2015 would be no greater than that in the baseline year. We calculated the absolute difference between the age-adjusted rates of the two groups in 2006 and added this rate difference to the projected rate in 2015 of the group with the lower projected rate.
- For Oral Cancer: We excluded target projections by race or by gender-race group because the age-adjusted rates were highly variable due to small populations or low incidence or mortality rates.
- For Liver Cancer mortality targets by race and Breast Cancer incidence targets by race: The above method resulted in projected targets that represented a reversal of the baseline disparity. For the target for liver cancer for Asian/Pacific Islanders and whites, we used the baseline rate in 2006 of the white population. For breast cancer the 2015 projections were very close; therefore, we used for both racial groups the lower rate of the two projections in 2015.

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