

# Oregon Comprehensive Cancer Plan



## **OUR CALL TO ACTION**

A statewide blueprint for cancer  
prevention and control in Oregon  
2005–2010

**Oregon Partnership for Cancer Control**  
**June 2005**

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**Oregon Partnership for Cancer Control**  
**June 2005**

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This cancer plan was printed with funds from a planning grant from the Centers for Disease Control and Prevention (CDC), Cooperative Agreement #U55/CCU021984

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May 2005

To All Oregonians:

This year, 18,000 Oregonians will hear those three dreaded words: "You have cancer." They will join thousands of individuals in the state who are already living with the disease. Sadly, by the end of this year, family members, friends and co-workers will mourn the cancer-related deaths of 7,000 Oregonians.

Repeatedly, people ask, "Why can't we do something about cancer?" In 2004, the Oregon Partnership for Cancer Control was formed to address this deadly disease. Specifically, the Partnership developed Oregon's first statewide cancer control plan, providing a blueprint for action that targets the unique challenges of cancer prevention, treatment and survivorship.

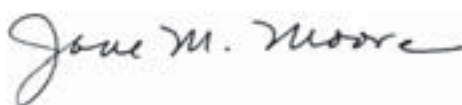
This cancer plan, created with the assistance of more than 50 organizations, builds on Oregon's many existing services and programs. The plan is merely the beginning of Oregon's statewide, coordinated effort to reduce the burden that cancer places on individuals, families and communities.

Together, we'll work to:

- Prevent cancer from occurring, whenever possible.
- Find cancer in its earliest stage when it does occur.
- Treat cancer with the most appropriate therapy available.
- Ensure the best quality of life for each individual with cancer.
- Promote policies and supportive environments that help Oregonians make healthy choices easy choices.

Thank you for using the Oregon Comprehensive Cancer Plan. The Oregon Partnership for Cancer Control invites you to join us in our ongoing efforts to reduce the impact of cancer in our state.

Regards,



Jane M. Moore  
Co-Chair



Dave Rogers  
Co-Chair

# Acknowledgements

During 2004, more than 85 meetings were convened in Oregon to create the goals, objectives and strategies in this plan. The Partnership's Coordinating Committee and Workgroup co-chairs extend a heartfelt thank you to the following individuals and organizations for their contributions to this statewide cancer plan:

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**Special thanks** to Word Jones, Inc. (**LeeAnn Kriegh**, **Jim Moore** and **Geena Park**) and the Cancer Plan Review Committee: **Donald Austin, MD, MPH**; **Emily Puukka, MS**; **Dave Rogers**; and **Roshanthi Weerasinghe, MPH**

*We couldn't have done it without you!*



# Executive Summary

*Because of the magnitude of cancer's burden and our limited resources, we need a coordinated statewide effort that provides every Oregonian with access to the full range of cancer services.*

Cancer is a complex and deadly disease that has no single cause or simple cure. As a state, we currently address cancer through a variety of approaches that include cancer prevention, treatment, survivorship and end-of-life services.

This five-year plan is Oregon's first comprehensive cancer control plan. It is designed to consolidate and further the state's ongoing efforts to address cancer and its consequences.

**The Oregon Partnership for Cancer Control** (the Partnership) was formed in 2004 to develop and implement this cancer plan for Oregon. The plan was created through collaboration between individuals from more than 50 public and private organizations, with input and assistance from many cancer survivors. The plan provides a blueprint for action, guiding cancer prevention and control activities at the state, organizational and community levels.

## Oregon's rank as compared to other states:

- 5<sup>th</sup> in lung cancer incidence among women.
- 3<sup>rd</sup> in breast cancer incidence.
- 2<sup>nd</sup> in mortality rate for invasive melanoma.

Source: Cancer in Oregon, 2002.

## WHY DO WE NEED A COMPREHENSIVE PLAN IN OREGON?

- **Currently, we don't have a coordinated approach to cancer prevention and control.** Only by working together can we optimize the state's limited resources and ensure that individuals receive the services they need.
- **We must increase our cancer prevention efforts.** Three-quarters of cancers are attributed to completely preventable lifestyle behaviors, such as smoking and poor nutrition.<sup>1</sup>

## The daily impact of cancer:

Each day, an average of 51 Oregonians are diagnosed with cancer, and 20 Oregonians die as a result of the disease.

Source: Cancer in Oregon, 2002.





*“We do not walk through the cancer experience alone. We walk hand in hand with our partner, our traditional and extended families and the sphere of people we encounter as friends and associates. Life is an amazing gift to cancer survivors ... and for those who support them.”*

—LOLLY CHAMPION (RIGHT), BREAST CANCER SURVIVOR,  
AND JOHN CHAMPION, BEND

- **Cancer care is extremely costly.** The estimated economic burden of cancer in Oregon was \$2 billion in 2002. That’s \$603 for every man, women and child in the state.<sup>2</sup>
- **Cancer care is complex.** We must advocate for continuity of care and management, much like other chronic diseases—especially because more than 85 percent of all cancer patients now live five or more years beyond diagnosis.<sup>3</sup>

**This statewide comprehensive cancer control approach will allow us to:**

- Identify ongoing activities that already contribute to the plan’s goals and objectives.
- Identify resources and gaps in cancer-related services at the state, regional and local levels.
- Reduce duplication of services.
- Promote collaborations among diverse organizations to implement cancer control activities.
- Ensure individually and culturally appropriate cancer services for all Oregonians.
- Develop effective resource and referral mechanisms for cancer services.

**This plan includes good news about Oregon’s progress in the fight against cancer:**

- Across the state, more cancers are being found in early stages, thanks to improved technology and increases in cancer screening rates.
- The death rate from cancer in Oregon is decreasing about 1 percent each year.<sup>4</sup>
- Oregon has 21 Commission on Cancer programs and an active network of cancer-related health care, community and volunteer- based organizations.

<sup>1</sup> Cancer Facts and Figures 2005.

<sup>2</sup> Cancer in Oregon: A Call to Action, March 2004.

<sup>3</sup> Cancer Facts and Figures 2005.

<sup>4</sup> Cancer in Oregon, 2002.

**This plan also identifies actions Oregonians need to take:**

- **We must reduce deaths from cancer.** Oregon's cancer mortality (death) rate is 25 percent above the National Healthy People 2010 objective.<sup>5</sup>
- **We must reduce cancer disparities.** Some Oregonians do not receive adequate cancer screening services, and their cancers are therefore being diagnosed at later, often more life-threatening stages. Disparities also relate to age, race and ethnicity, which are increasingly important considerations because Oregon's population is rapidly aging and becoming more diverse.
- **We must ensure equal access to quality cancer services.** The percent of uninsured Oregonians increased from 14 percent in 2002 to 17 percent in 2004.<sup>6</sup>
- **We must ensure appropriate and timely services and referrals for all Oregonians with cancer.** Half of the Oregonians using hospice services are cancer patients, and the average length of service is only 15 days.<sup>7</sup>

### **Baseline Measures and Targets for Change**

This plan includes the most current Baseline Measures and Targets for Change. These measures will help us track Oregon's progress in improving cancer-related services.

**Baseline Measures** include cancer incidence, mortality and screening rates, as well as health behaviors, such as the percentage of youths and adults who smoke. Baseline Measures provide the starting point for measuring Oregon's progress over time.

**Targets for Change** are 5-year goals for Oregon, based on the national health objectives set forth in Healthy People 2010.

### **PUTTING THE PLAN INTO ACTION**

This cancer plan serves as a blueprint of action for individuals and organizations throughout Oregon over the next five years. The plan is divided into five sections, which address 16 individual topics. For each cancer-related topic, we describe Oregon's key issues, current efforts and remaining challenges. These are followed by goals, objectives and strategies that were identified by the Partnership's workgroups.

By using the plan, grass-roots organizations, local coalitions, community-based organizations, health care providers, businesses, legislators and other Oregonians can become part of a state-wide effort to battle cancer in a unified manner.

# GOAL:

*An overarching goal of this cancer plan is promotion of universal access to health care and continuity of cancer care services for all Oregonians.*

## This cancer plan's five sections are:

Section I. Prevention and Early Detection.

Section II. Cancer Treatment and Quality of Life.

Section III. Cancer Disparities.

Section IV. Public Policy and Legislation.

Section V. Data Management and Surveillance.

## SUMMARY OF GOALS TO BE ACHIEVED BY 2010

### SECTION I.

#### Prevention and Early Detection

##### Prevention Goals

- **Tobacco and Related Cancers:** Decrease the incidence and impact of tobacco-related cancers among all Oregonians.
- **Physical Activity and Nutrition:** Increase Oregon's community support and promotion of healthy eating, daily physical activity and healthy weight as a means of cancer prevention and risk reduction.
- **Environmental Risk Factors:** Reduce the risk among all Oregonians of cancers related to environmental carcinogens.
- **Genetics:** Increase awareness and knowledge among all Oregonians about genetic factors that influence individual cancer risk.

#### Early Detection Goals

- **Breast Cancer Screening:** Reduce deaths from breast cancer among Oregon women.
- **Cervical Cancer Screening:** Prevent all cases of invasive cervical cancer among Oregon women, and reduce deaths from cervical cancer.
- **Colorectal Cancer Screening:** Reduce deaths from colorectal cancer among all Oregonians.
- **Prostate Cancer:** Reduce deaths from prostate cancer among all Oregon men. Increase informed and shared decision-making between men and their health care providers regarding the risks and benefits of prostate cancer screening and treatment.
- **Skin Protection and Melanoma Prevention:** Reduce skin cancers and deaths from melanoma among all Oregonians.

<sup>5</sup> Cancer in Oregon, 2002.

<sup>6</sup> Office for Oregon Health Policy and Research, January 2005.

<sup>7</sup> Oregon Hospice Association, 2002.

## SECTION II.

### Cancer Treatment and Quality of Life

- **Access to Quality Cancer Treatment:** Ensure that all Oregonians have access to quality cancer treatment and information services that are culturally and individually appropriate by age, financial situation and geographic location.
- **Symptom Management:** Ensure that all Oregonians with cancer receive information and treatment for effective management of the side effects and symptoms of their cancer treatment. The information and treatment should be culturally and individually appropriate by age, financial situation and geographic location.
- **Survivorship:** Improve cancer survivors' quality of life through services that address the physical, emotional, social and vocational challenges of survivorship.
- **Palliative Care and End-of-Life Issues:** Ensure that all Oregonians have access to and utilize high-quality palliative and hospice care that is culturally and individually appropriate by age, financial situation and geographic location.

## SECTION III.

### Cancer Disparities

The goal is to eliminate cancer disparities in Oregon through incremental reductions, with a focus on public, patient and provider education, research, data and public policy.

## SECTION IV.

### Public Policy and Legislation

The goal is to achieve the public policy objectives of this comprehensive cancer plan, as related to cancer prevention, early detection, treatment and cancer surveillance. This involves a three-tiered approach that includes a policy committee, a legislative cancer caucus and grass-roots advocacy.

## **SECTION V.**

### **Data Management and Surveillance**

The goal is to fully implement cancer surveillance—the collection, analysis, dissemination and utilization of cancer information—for Oregon’s Comprehensive Cancer Plan. A Cancer Surveillance Advisory Workgroup will be established to ensure design of an appropriate evaluation for each objective in this plan and to identify a source of data on which to base each evaluation.

### **PLEASE JOIN US!**

Please join the Partnership as we work together to reduce the burden of cancer in Oregon through a shared vision, mutual goals and collective action. We look forward to reporting each year on our statewide progress toward meeting the goals and objectives detailed in this cancer plan.

# The Face of Cancer in Oregon

While statistics cannot convey the emotional toll that cancer takes on Oregonians, the data and trends reported below may help us better understand cancer's enormous impact on our state and its citizens.

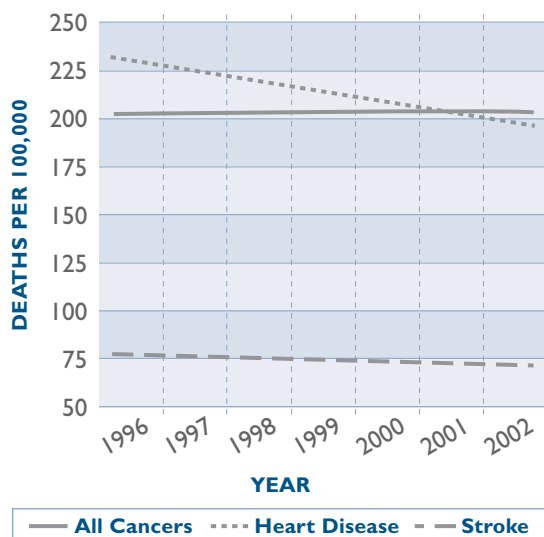
Each day in 2002, an average of 51 Oregonians were diagnosed with cancer, and another 20 Oregonians died of cancer. As shown in Figure 1, below, cancer surpassed heart disease in 2000 to become the leading cause of death among Oregonians, causing one of every four deaths in the state.<sup>1</sup>

Estimates indicate that nearly half (46 percent) of males and four out of 10 females (38 percent) will develop cancer at some point in their lifetime.<sup>2</sup>

*"More than 60 percent of all cancer deaths could be prevented if Americans stopped smoking, exercised more, ate healthier food and got the recommended cancer screenings."*

—THE AMERICAN CANCER SOCIETY,  
REPORTED ON MARCH 31, 2005.

Figure 1  
**Leading Causes of Death  
Historical Trends, Oregon 1996–2002**



Source: Cancer in Oregon, 2002.

The primary causes or contributors to cancer are lifestyle factors, inherited risk and tobacco, as described below:

- Approximately one-third of all cancer deaths in 2005 will be related to lifestyle-related factors such as poor nutrition, physical inactivity, obesity and being overweight.
- Inherited risk (passed from parents to children) causes between 5 and 30 percent of all cancers.<sup>3</sup>
- In 2002, tobacco contributed to 23 percent of all deaths in Oregon.<sup>4</sup>



## THE COSTS OF CANCER IN OREGON

The estimated economic costs of cancer are tremendous. Oregon Health Services estimates that in the year 2000, cancer-related hospitalizations alone cost \$210 million. If we consider indirect expenses such as loss of productivity from disability and death, the economic burden of cancer in 2000 was more than \$2 billion dollars. That's \$603 for every man, woman and child in Oregon.<sup>5</sup>

## CANCER IN OREGON: WHAT THE DATA TELL US

The Oregon State Cancer Registry (OSCaR) collects data from hospital registries and physicians throughout the state. The registry analyzes new cancer cases (incidence), deaths (mortality) and stage of diagnosis (in situ, localized, regional and distant) data. The registry's "Cancer in Oregon" annual reports provide state, regional and county data, as well as five-year trends and comparisons between Oregon and national cancer rates ([www.healthoregon.org/cancer](http://www.healthoregon.org/cancer)).

## Most Commonly Diagnosed Cancers in Oregon

Cancer Site	No. of People
1. Breast	3,293
2. Prostate	2,519
3. Lung	2,446
4. Colorectal	1,799
5. Melanoma	1,613

Source: Cancer in Oregon, 2002.

## MOST COMMON CANCERS

While more than 100 different types of cancer exist, over half of the cancers diagnosed among Oregonians each year are one of four types: breast, prostate, lung or colorectal.

<sup>1</sup> Cancer in Oregon, 2002.

<sup>2</sup> SEER Cancer Statistics Review, 1975–2001.

<sup>3</sup> National Cancer Institute, PDQ, Genetics, 2004.

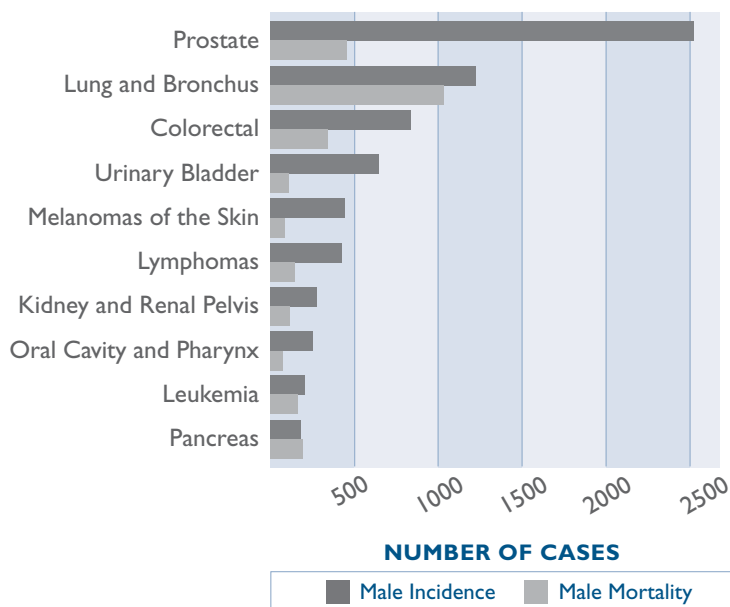
<sup>4</sup> Oregon Death Certificate Statistical File, 2002.

<sup>5</sup> Cancer in Oregon: A Call to Action, March 2004.



## Leading Sites—Cancer Incidence and Mortality, Oregon Males, 2002

Figure 2



Source: Cancer in Oregon, 2002.

## CANCER INCIDENCE

In 2002, 18,713 new cases of cancer were diagnosed among Oregonians. Nationally, Oregon men ranked 23rd for all-cancer incidence and Oregon women ranked eighth. Oregon women ranked among the nation's top 10 due to the state's high incidence rates of breast and lung cancers.

For the 10 most common cancers for males and females, Figures 2 and 3 show the number of new invasive cases and the number of deaths in Oregon, in 2002.<sup>6</sup> Overall, men have a higher incidence rate of invasive cancers and a higher mortality rate than women.

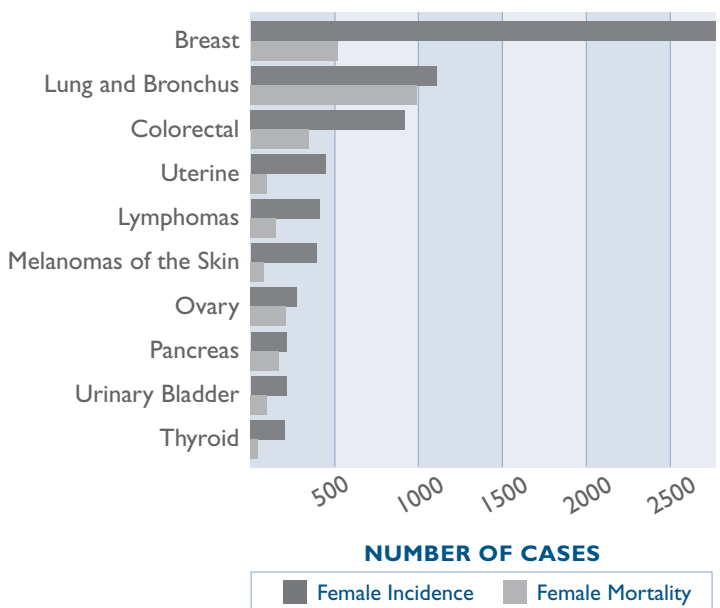
For several cancers, Oregon's incidence rates are very high. In 2002, Oregon ranked:

- Fifth in the nation for lung cancer among women.
- Third in the nation for breast cancer.

Between 1998 and 2002, female breast cancer and colorectal cancer increased 1 percent each year in Oregon, and prostate cancer increased 4 percent each year. Lung cancer decreased 1 percent each year, and colorectal cancer incidence decreased 2.6 percent each year.

## Leading Sites—Cancer Incidence and Mortality, Oregon Females, 2002

Figure 3



Source: Cancer in Oregon, 2002.

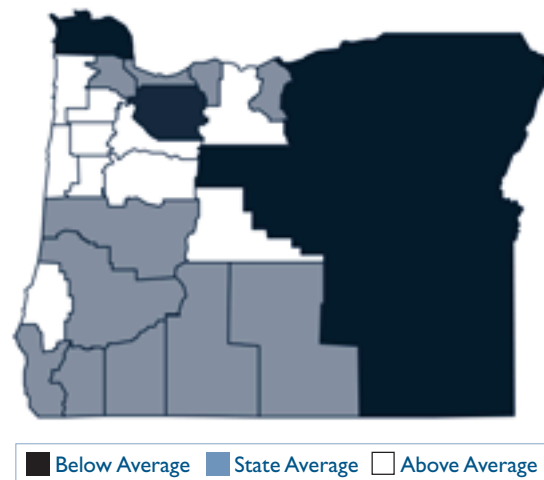
## STAGE OF DIAGNOSIS

For all the cancers diagnosed between 1998 and 2002, more were diagnosed in early stages (defined as in situ and localized stages). Diagnoses of early-stage colorectal cancer increased among women, and early-stage prostate cancer diagnoses increased among men. In situ breast cancer among women also increased, while there was a decrease in early-stage diagnosis of cervical cancer.

There were geographic differences in the stages at which cancer was diagnosed in Oregon between 1998 and 2002. Figure 4 shows that the percentage of early-stage diagnoses is generally lower in eastern Oregon and higher in western Oregon.<sup>7</sup> These differences may be attributed to differences in cancer reporting, screening practices and lifestyle behaviors.

Figure 4

### All Cancer Incidence in Oregon Percentage of Early-Stage Diagnosis Regional Variation, 1998–2002



Source: Cancer in Oregon, 2002.

<sup>6</sup> Cancer in Oregon, 2002.

<sup>7</sup> Ibid.

## Leading Causes of Cancer Deaths in Oregon

Cancer Site	No. of People
1. Lung	2,057
2. Colorectal	665
3. Breast	501
4. Prostate	435
5. Bladder	200
6. Melanoma	123

Source: Cancer in Oregon, 2002.

## CANCER MORTALITY

An estimated 7,360 individuals in Oregon will die from cancer in 2005.<sup>8</sup> Oregon's mortality rate due to cancer declined 1 percent each year since 1996, but remains higher than the national mortality rate.

In 2002, Oregon's overall cancer mortality rate was 199.2 deaths per 100,000 in population. This is 25 percent above the national Healthy People 2010 target of 159.9 deaths per 100,000. For Oregon males, the mortality rate was 246.1 per 100,000. For Oregon females, it was 173.2 per 100,000.

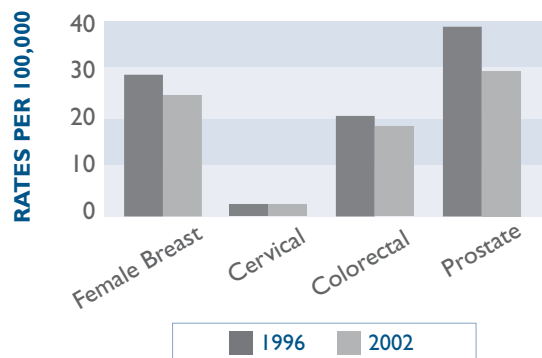
Between 1999 and 2002, Oregon's mortality rates for lung cancer and melanoma were far higher than Healthy People 2010 targets. Oregon's lung cancer mortality rate, 56.7 deaths per 100,000, was 26 percent above the Healthy People 2010 target of 44.9 deaths per 100,000. Oregon's melanoma mortality rate was the second highest in the nation.

During the five-year period between 1998 and 2002, Oregon's breast, prostate and colorectal cancer mortality rates decreased among women, and lung cancer mortality rates decreased among men. Men's mortality rates due to colorectal cancer remained stable during this period but decreased 3.6 percent each year among Oregon women. This decrease is likely due to a combination of improved screening, early-stage diagnosis and enhanced treatment.

Figure 5 shows the reduction in deaths for "screenable" cancers by comparing figures from 1996 and 2002. Only cervical cancer failed to show a decrease in mortality rate over these years.<sup>9</sup>

## Screenable Cancers Age-Adjusted Mortality Rates Oregon, 1996, 2002

Figure 5



Source: Cancer in Oregon, 2002.

## OREGON DEMOGRAPHICS: THE IMPACT ON CANCER BURDEN

Oregon's population is changing rapidly, both in age distribution and racial and ethnic composition. While the state's 3.5 million residents are mostly White (87 percent), the Hispanic population makes up 9.2 percent of Oregon's population and is expected to continue its rapid growth.<sup>10</sup> In addition, the U.S. Census predicts Oregon's Native American population will increase by 9 percent by 2010, and Oregon's African American population will grow by 11 percent.<sup>11</sup>

Given these statistics, further assessment of the impact of cancer on Oregon's population must include examination of variables such as age, gender, race, ethnicity, geographic location and the percent of Oregonians without health insurance.

### AGE

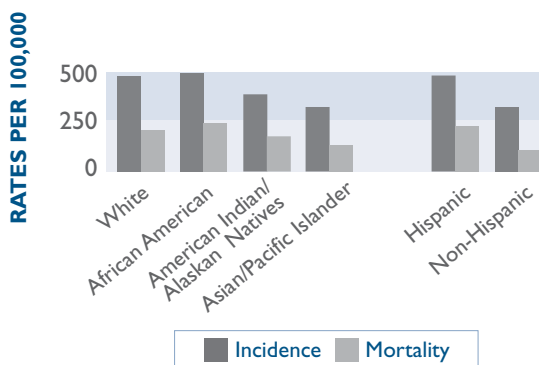
Cancer risk increases with age, and Oregon's population is rapidly aging. According to U.S. Census figures from 2003, 12.8 percent of Oregonians are age 65 or over. The size of this age group is expected to almost double by 2020, which will have serious implications for Medicaid and Medicare programs, and for the health care system as a whole.

The incidence of cancers among children in Oregon (0–14 years of age) is low compared to adults. In 2002, there were 115 invasive cancers diagnosed in Oregon children and 19 children died from cancer.

## GENDER, RACE AND ETHNICITY

Figure 6 shows cancer incidence and mortality rates by race and ethnicity. As is seen nationally, African American men in Oregon have the highest rate of cancer incidence and mortality, with Whites second. Among all racial groups, Asian/Pacific Islanders had Oregon's lowest rates of cancer incidence and mortality.

Figure 6  
**Oregon Cancer Incidences & Mortality  
Age-Adjusted Rates, 1996–2002  
Race and Ethnicity**



Source: Cancer in Oregon, 2002.

<sup>8</sup> Cancer Facts and Figures 2005.

<sup>9</sup> Cancer in Oregon, 2002.

<sup>10</sup> U.S. Census, 2003.

<sup>11</sup> Office for Oregon Health Policy and Research, January 2005.

Among Oregon men, lung cancer was the most common cause of cancer death for all racial and ethnic groups. For women, lung cancer was also the leading cause of cancer death, except among the Asian/Pacific Islander and White Hispanic populations. For women in these two groups, breast cancer was the leading cause of cancer death. Liver and bile duct cancers are among the top five cancer-related causes of death only in the Asian/Pacific Islander population.<sup>12</sup>

Whites have the highest percentage of cancers diagnosed at an early stage, while American Indian/Alaskan Natives have the lowest. Hispanics also have a lower percentage of cases diagnosed at an early stage than non-Hispanics. Oregon's Asian/Pacific Islander and Hispanic populations have lower incidences of lung, colorectal, breast and prostate cancers, and lower mortality rates for lung, colorectal, breast and prostate cancers than all other racial groups.

Historically, Oregon's American Indian/Alaskan Native (AI/AN) population has had the lowest incidence rate of cancer across all racial ethnic groups. However, when AI/AN individuals are properly classified, AI/AN incidence rates are substantially higher. OSCaR links each year with local and national tribal registries to correct racial coding. With these corrections, Oregon may have a higher AI/AN rate than those seen nationally.

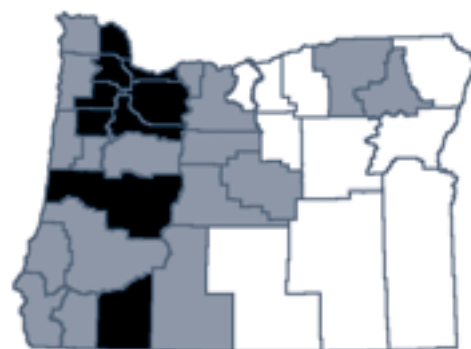
## OREGON'S RURAL GEOGRAPHY

Among Oregon's 36 counties, the Office of Rural Health designated 105 rural service areas as having unmet health care needs.<sup>13</sup> The distance to cancer screening and treatment services can impact use of recommended screening or treatment services. For example, in eastern Oregon, a woman may need to travel 120 miles to receive a mammogram.

Figure 7 shows the population designation of Oregon's 36 counties as frontier, rural or urban. A frontier county has fewer than six persons per square mile; a rural county has no city with a population of more than 50,000; and an urban county has one or more cities with more than 50,000 people or a total population of more than 100,000.

**Population Designation:  
Frontier, Rural and Urban**

Figure 7



Counties: ☐ Frontier ☒ Rural ☒ Urban

Source: Cancer in Oregon, 2002.

## HEALTH INSURANCE COVERAGE

Many factors influence health insurance rates, including the economy and employment rates. Oregon's recent high unemployment rates, increasingly expensive health insurance premiums and the shrinking of the Oregon Health Plan contribute to Oregon's growing uninsured population.

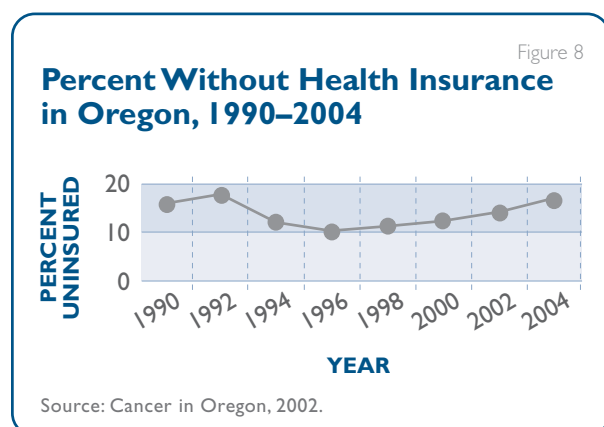
Figure 8 shows the percent of Oregon's population without health insurance between 1990 and 2004. During this 14-year period, the highest percent of the state's population without insurance was 18 percent in 1992, while the lowest was 11 percent in 1996.

Most recently, the percentage of uninsured Oregonians increased from 14 percent in 2002 to 17 percent in 2004. At 17 percent, an estimated 609,000 individuals, or one out of six Oregonians, lacked health insurance.<sup>14</sup>

## OREGON'S CALL TO ACTION

To reduce the burden of cancer among Oregonians, we need to ensure equal access to cancer prevention, screening and treatment services. We must remove barriers to cancer services across the continuum of care for Oregon's increasingly diverse communities.

The solutions lie in creative collaborations among partners at state, regional and community levels.



<sup>12</sup> Cancer in Oregon, 2002.

<sup>13</sup> Office of Rural Health, 2004.

<sup>14</sup> Office for Oregon Health Policy and Research, January 2005.

# The Oregon Partnership for Cancer Control

## CANCER CONTROL PLANNING AND IMPLEMENTATION

In 2002, a group of 12 volunteers from public health, health care, volunteer and health insurance organizations planted the seeds for the foundation of the Oregon Partnership for Cancer Control (the Partnership). In 2004, the Partnership officially formed to develop Oregon's first statewide, comprehensive cancer plan.

The steps in the planning process were as follows:

- The Partnership ([www.healthoregon.org/cancer](http://www.healthoregon.org/cancer)) was formed in March 2004, guided by a 20-member Coordinating Committee.
- Five planning workgroups drafted goals, objectives and strategies for 16 priority topics. The workgroups reviewed cancer incidence rates, mortality data and screening rates, and assessed local, state and national resources.

### The five planning workgroups:

1. Prevention and Early Detection.
2. Cancer Treatment and Quality of Life.
3. Cancer Disparities.
4. Public Policy and Legislation.
5. Data Management and Surveillance.

The workgroups selected topics based on numbers of individuals affected, availability of evidence-based interventions, existing state and local resources, and feasibility of implementation.

- More than 85 meetings were held, with 20 percent of participants coming from outside the Portland metropolitan area.
- The Coordinating Committee reviewed draft goals, which were then placed on the Web site for a public review and comment period.



**Implementation of the Cancer Plan:** This five-year cancer plan serves as a blueprint for action by individuals and organizations throughout the state. The Partnership will link individuals and organizations with mutual goals and priorities, and define short-term and long-term activities for cancer control.

The Partnership will:

- Convene implementation workgroups: Prevention and Early Detection, Cancer Treatment and Cancer Disparities.
- Form standing committees: Cancer Surveillance Advisory Workgroup (CSAW), Public Policy Committee.
- Continue to assess resources and activities of individuals and organizations.
- Develop networks for resource sharing.
- Evaluate Partnership efforts.

**Organization of the Cancer Plan:** The plan contains five sections and 16 topics.

For each topic, a brief narrative describes key issues, current efforts and remaining challenges. This is followed by information about the most current baseline measures for screening rates, health behaviors, cancer incidence and mortality rates.

Where applicable, National Healthy People 2010 objectives are noted as “Targets for Change.” Each topic concludes with a list of goals, objectives and strategies.

Implementation of this statewide cancer plan depends on effective evaluation. For this reason, we will track progress towards goals and objectives on an annual basis, and the Coordinating Committee will produce an annual report.

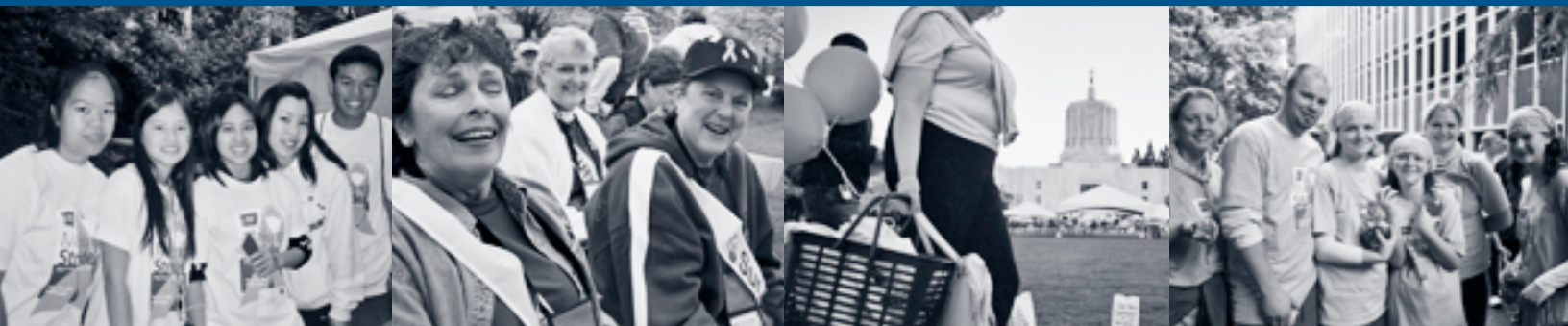
Together we can make cancer history. For more information about the Partnership, visit our Web site: [www.healthoregon.org/cancer](http://www.healthoregon.org/cancer).

# Guiding Principles for Comprehensive Cancer Control in Oregon

1. Everyone in Oregon will be touched by cancer at some time. Thus, cancer control is the responsibility of all Oregonians—public and private organizations, individual citizens, communities, families and businesses.
2. This cancer plan promotes a common vision for Oregon's cancer control activities, from prevention and early detection through treatment, rehabilitation, end of life and cancer survivorship.
3. This cancer plan is a roadmap of the efforts needed in Oregon to reduce the state's cancer burden. The plan is to be used to establish priorities for action—opportunities to work together to address the greatest needs and perform the most achievable, realistic actions.
4. This cancer plan actively supports the recommendations and strategies found in other statewide plans that address cancer-related activities, such as the Oregon Statewide Tobacco Control Plan 2005–2010, A Healthy Active Oregon Statewide Physical Activity and Nutrition Plans 2003, and Healthy Kids Learn Better.
5. The Partnership seeks to recognize and enhance the many worthwhile and effective efforts of dedicated individuals and organizations that contribute to Oregon's cancer control efforts.
6. Special emphasis in this plan will be given to Oregon's urban and rural communities, as well as underserved populations that may face cancer disparities.
7. The statewide cancer control plan will define priority activities to be implemented by a broad range of partners.
8. The Partnership understands the need for cultural competency among Oregon's health professionals and health systems to achieve effective communication and the best possible cancer care.
9. The Partnership will advocate for individual, organizational, community and environmental conditions that promote healthy behaviors to reduce cancer risk.
10. Data and evaluation are integral components of all comprehensive cancer control activities and will guide decision-making.
11. The Partnership members will seek funding sources, as needed, to implement priority activities.
12. The Partnership will establish and maintain mechanisms to share information, resources and progress of individuals and organizations throughout the state.

# Oregon's Call to Action, 2005–2010

## GOALS, OBJECTIVES AND STRATEGIES



### **SECTION I.**

**Prevention and Early Detection**

### **SECTION II.**

**Treatment and Quality of Life**

### **SECTION III.**

**Cancer Disparities**

### **SECTION IV.**

**Public Policy and Legislation**

### **SECTION V.**

**Data Management and Surveillance**

# Prevention and Early Detection

*Cancer control depends on preventing cancer whenever possible and—when cancer does occur—detecting it at the earliest possible stage.*

## KEY ISSUES

In the nine Prevention and Early Detection chapters that follow, we discuss lifestyle and behavioral changes through which we can prevent many cancers from occurring. We also discuss proven methods for early detection of cancer, such as Pap tests and mammograms.

Early detection means screening when there are no symptoms of a problem. Regular cancer screening examinations by a health professional can find cancer at its earliest stage, when treatment is most effective and the chances for survival are increased.

Screening can effectively detect breast, cervix and colon cancer. Some cancers, such as cervical and colorectal, can actually be found and treated in a pre-cancerous condition—before cancer even develops. Other cancers, such as oral cavity and skin cancers, can be found by noting changes in the look or feel of an area.

### Overall Goals

#### Prevention and Early Detection:

- Promote healthy behaviors that can reduce cancer risk.
- Promote screening for early detection of cancer.
- Reduce deaths from cancer.

## CURRENT EFFORTS

In Oregon, many efforts promote healthy behaviors that reduce cancer risk and prevent cancer-related deaths in children and adults. These efforts are outlined in the chapters that follow, each of which defines a concern and discusses key issues, current efforts and remaining challenges.

At the end of each chapter, objectives and strategies define actions that individuals and organizations in Oregon can take, such as creating supportive environments to contribute to cancer control efforts.

### Cancer Risk Factors

- Age.
- Gender.
- Lifestyle behaviors such as lack of physical activity, poor nutrition and use of tobacco and alcohol.
- Genetics.
- Environmental exposures.
- Infectious agents such as Hepatitis B and C and Human Papilloma Virus.



*“I’m sick and tired of all the talk about a cure. If we’re ever going to conquer cancer, it’s time to focus our efforts on prevention.”*

—DIANE LUND-MUZIKANT,  
9-YEAR BREAST CANCER SURVIVOR, PORTLAND

The nine Prevention and Early Detection topics in this section were selected based on:

- The number of Oregonians affected.
- The available and known interventions, such as screening to reduce cancer risk and deaths, and the identification of specific at-risk populations.

The prevention topics in this section are:

- Tobacco and Related Cancers.
- Physical Activity and Nutrition.
- Environmental Risk Factors.
- Genetics.

The early-detection topics are:

- Breast, Cancer Screening (in Women).
- Cervical Cancer Screening.
- Colorectal Cancer Screening.
- Prostate Cancer.
- Skin Protection and Melanoma Prevention.

## Key Cancer Prevention Messages

	CANCER RISK REDUCTION BENEFIT												
Prevention Strategy	Bladder	Breast	Cervical	Colorectal	Oesophageal	Kidney	Lung	Oral	Pancreatic	Prostate	Skin	Stomach	Uterus
Avoid tobacco use.	●		●	●	●	●	●	●	●			●	
Be physically active.		●		●									
Maintain a healthy weight.		●		●	●	●							●
Eat a healthy diet.	●	●		●	●		●	●	●	●		●	
Limit alcohol.		●		●	●			●					
Limit number of sexual partners and use condoms.			●										
Get appropriate cancer screening tests.		●	●	●						●			
Avoid excess sun exposure.								●			●		

Source: Modifiable Risk Factors of Cancer, C.J. Stein and G.A. Colditz, The British Journal of Cancer. Vol. 90, #2, 2004, pgs. 209–303.

# Tobacco and Related Cancers

*Tobacco use is Oregon's and the nation's leading preventable cause of disease and death. Each year, tobacco use costs Oregonians more than we can afford to pay—both in the thousands of lives lost and the billions of dollars spent on treatment and care.*

## KEY ISSUES

Simply put, tobacco use kills:

- Lung cancer is the leading cause of cancer death in Oregon, and in 2002, Oregon ranked fifth in the nation in lung cancer deaths among women.<sup>1</sup>
- Tobacco use leads to lung, oral, bladder, cervical, pancreatic and gastrointestinal cancer, among many others.
- Each year, 7,000 Oregonians die from tobacco use.
- Nationwide, tobacco use kills more people than motor vehicle crashes, suicide, AIDS and murders combined.

Despite the dangers of use, half a million Oregonians smoke cigarettes, and 75,000 chew tobacco. Three out of four smokers say they want to quit, and 27 percent say they are planning to quit within the next 30 days.<sup>2</sup>

### Lung Cancer Facts

- Lung cancer is the leading cause of cancer death among men and women in Oregon.
- In 2002, lung cancer killed 2,444 Oregonians.
- In 2002, Oregon women had the fifth-highest death rate in the U.S. for lung cancer.

Source: Cancer in Oregon, 2002.

Helping tobacco users quit, and preventing others from starting, would save lives—and millions of dollars each year:<sup>3</sup>

- Tobacco use cost Oregonians a total of \$1.8 billion in 2000.
- The direct cost of tobacco use to Oregon's health care system was nearly \$9 million in 2000.

## CURRENT EFFORTS

The 2004 Surgeon General's Report states the need for a "comprehensive approach" to cancer prevention and smoking cessation. According to the report, the best approach is "one that optimizes synergy from a mix of educational, clinical, regulatory, economic and social strategies."

### In Oregon, tobacco use is higher in these communities:

- African Americans.
- Native Americans.
- 18- to 24-year-olds.
- Some Asian/Pacific Islander groups.
- Persons of low socioeconomic status.
- Gay, lesbian, bisexual and transgender persons.
- Some rural and frontier counties.

Source: Closing the Gaps: Identifying and Eliminating Tobacco-Related Disparities in Oregon, 2002.



*“I lost my mother to lung cancer. She was only 59 years old. Please keep funding education about cancer and the effects it has on our lives.”*

—VIKKI GALANOPOULOS, TIGARD

Oregon’s comprehensive approach includes wise investment in tobacco control efforts, resulting in a dramatic reduction since 1996 in tobacco use by both adults and children. Compared to 1996, Oregon now has 75,000 fewer smokers, two billion fewer cigarettes sold each year and 63 percent fewer eighth graders who smoke.<sup>4</sup>

Oregon’s tobacco prevention activities involve private citizens, state and local coalitions, schools, businesses, health care providers and community organizations. Our current tobacco control efforts include:

- Public policies such as Ballot Measure 44, which increased the tobacco tax by 30 cents, and the Indoor Clean Air Act, which protects over 95 percent of Oregon employees from secondhand smoke at work.
- Educational efforts in schools, businesses and workplaces about the health effects of tobacco use.
- Education about how to quit smoking, through sources such as the Oregon Quit Line (1-877-270-STOP).

## REMAINING CHALLENGES

We know that to reduce tobacco use in Oregon, we must tackle the problem from several directions at once. Many factors influence a person’s decision to use tobacco, so effective tobacco prevention techniques come from many angles at once—including where people live, work and play.

Our continued success requires continued investment in a healthy Oregon. A responsible approach to tobacco control:

- Keeps kids from starting.
- Protects people from secondhand smoke.
- Helps people quit smoking.

<sup>1</sup> Cancer in Oregon, 2002.

<sup>2</sup> Oregon Behavioral Risk Factor Surveillance System (BRFSS), 2003.

<sup>3</sup> Oregon Tobacco Facts, 2003.

<sup>4</sup> Tobacco Prevention and Education Program Report, 2003–2005.



# GOAL:

Decrease the incidence and impact of tobacco-related cancers among all Oregonians.

## TOBACCO AND RELATED CANCERS

**OBJECTIVE 1:** Increase the percentage of Oregonians who do not use tobacco products.

### Baseline Measures: Tobacco

#### Youth smoking

8th graders	11%
11th graders	19%

Source: Oregon Healthy Teen Survey, 2003.

#### Adult smoking

Adult smoking	21%
Smoking in homes	17%

Source: Behavioral Risk Factor Surveillance System, 2003.

### Strategies:

- Raise tobacco taxes.
- Increase and stabilize funding for comprehensive tobacco control programs.
- Implement goals identified by the Tobacco Disparities Planning Project 2002, in “Closing the Gaps: Identifying and Eliminating Tobacco Related Disparities in Oregon” ([www.healthoregon.org/tobacco](http://www.healthoregon.org/tobacco)).
- Stabilize resources to ensure that comprehensive tobacco programs are available to every school districts in Oregon.
- Conduct a statewide tobacco control public education and awareness campaign.
- Provide tobacco cessation resources through partnerships between public agencies and private businesses.
- Increase the proportion of Oregonians who want to quit, have access to cessation resources and use available resources.

*Oregon's tobacco control community has been formally organized since 1994. Many of the goals, objectives and strategies in this plan are taken from the **Oregon Statewide Tobacco Control Plan 2005–2010**, which was developed by over 30 statewide and local tobacco control advocates, and is available at: [www.healthoregon.org/tobacco](http://www.healthoregon.org/tobacco)*

**OBJECTIVE 2:** Increase the percentage of Oregonians who are not exposed to secondhand smoke.

**Strategies:**

- Protect all workers from exposure to secondhand smoke by closing the loopholes in the Indoor Clean Air Act.
- Conduct an effective education and awareness campaign about the dangers of secondhand smoke.
- Increase resources dedicated to enforcement of the Indoor Clean Air Act.
- Increase the number of Oregonians reporting a policy against smoking in their homes and cars.

**OBJECTIVE 3:** Increase the proportion of health care providers who counsel patients about tobacco cessation.

**Strategies:**

- Educate physicians and other health care providers about the “5 A’s” for reducing tobacco use.
- Promote the widespread use of the 5 A’s in health care systems.

**OBJECTIVE 4:** Monitor the scientific literature for evidence-based cancer screening for tobacco-related cancers.

**Strategies:**

- Review the literature for advances in screening technology for disease such as lung cancer.
- Promote the use of evidence-based screening for tobacco-related cancers.

**The “5 A’s” for health care providers to help people quit smoking:**

**Ask** about tobacco use.

**Advise** to quit.

**Assess** willingness to make a quit attempt.

**Assist** in quit attempts.

**Arrange** follow-up.

Source: Treating Tobacco Use and Dependence, Clinical Practice Guidelines, 2000.

# Physical Activity and Nutrition

*Poor nutrition and physical inactivity contribute significantly to each of the leading causes of disease and death in Oregonians: cancer, obesity, heart disease and diabetes. Eating right and being physically active is more than just a good idea—it's a matter of life and death.*

## KEY ISSUES

Unhealthy eating and lack of physical activity lead to obesity, and in 2000, obesity was associated with 112,000 deaths nationwide.

The statistics, gathered in 2003, are staggering:<sup>1</sup>

- 58 percent of Oregon adults are overweight or obese.
- 23 percent of Oregon's eighth graders are overweight or at risk of becoming overweight.
- At 21 percent, Oregon's rate of adult obesity is the highest of any state west of the Rockies.
- Between 1990 and 2003, the number of overweight adults in Oregon increased 92 percent.
- Just 50 percent of Oregonians meet the Surgeon General's recommendations for physical activity.
- Only 24 percent of Oregonians eat the recommended amount of fruits and vegetables a day.

The situation is not hopeless. Changing our environment and habits can result in significant health benefits. According to the Surgeon General, you can obtain significant health benefits through moderate physical activities such as 30 minutes of brisk walking, and by eating five or more fruits and vegetables a day.

In 1997, the American Institute for Cancer Research estimated that a healthy diet and physical activity may reduce the incidence of cancer by the following percentages:

- |   |        |
|---|--------|
| • Colon, rectum                                   | 66–75% |
| • Breast  | 33–50% |
| • Stomach   | 66–75% |
| • Prostate, endometrium, cervix, bladder, thyroid | 10–20% |

*“Obesity is not just a matter of personal health—it’s a costly and deadly public health concern that affects economic productivity, state budgets, and personal and family well-being.”*

–NATIONAL GOVERNORS ASSOCIATION  
CENTER FOR BEST PRACTICES,  
ISSUE BRIEF, JUNE 13, 2002.



*“Early detection, treatment and cure is the answer to surviving cancer. We need ongoing support of screening programs and every dollar possible for cancer research.”*

—KATHY GILLESSE, SALEM

## CURRENT EFFORTS

In response to the obesity epidemic, Oregon has taken action. In 2003, Oregon produced its first statewide physical activity and nutrition plans. These plans outline strategies to address policy and environmental changes that will make healthy choices easy choices for children and adults in Oregon’s schools, worksites and communities.

In 2004, Healthy Active Oregon teams formed in rural and urban communities to address environmental and policy changes, and to promote healthy behaviors. Oregon also supports national campaigns that promote healthy eating and physical activity for children and adults, such as the 5 A Day Campaign, Walk to School Day and TV Turn-Off Week.

Bills introduced in Oregon’s 2005 legislative session include restrictions on foods sold at schools that are not part of the school lunch program, and requirements for physical education in schools.

## REMAINING CHALLENGES

The following are among the challenges we need to address:

- Many school education policies do not require adequate physical education classes for students.
- Few worksite health promotion policies exist that promote and enable physical activity and healthy eating.
- Many communities do not support and promote daily physical activity, healthy eating and maintaining a healthy weight.
- Few restaurants provide easily accessible and clear nutrition information about menu items.

<sup>1</sup> Oregon Overweight, Obesity, Physical Activity and Nutrition Facts, September 2004.

# GOAL:

Increase Oregon's community support and promotion of healthy eating, daily physical activity and healthy weight as a means of cancer prevention and risk reduction.

## PHYSICAL ACTIVITY

**OBJECTIVE 1:** Increase the percentage of Oregon youth and adults who engage in moderate, daily physical activity.

### Baseline Measures: Physical Activity

#### Percent with moderate physical activity:

Children*	8th graders	80%
	11th graders	70%
Adults**		38%

\*Source: Oregon Healthy Teen Survey, 2003.

\*\*Source: Behavioral Risk Factor Surveillance System, 2003.

### Strategies:

- Promote daily physical activity in schools by increasing the percentage of school-age youth who participate in daily physical activity through physical education classes, sports and other organized, school-based activities.
- Promote daily physical activity in worksites by increasing the percentage of worksites that support and promote opportunities for physical activity among their employees and their communities.
- Promote daily physical activity in communities by increasing the opportunities for physical activity at neighborhood community centers and through parks and recreation programs. Promote development of walking and biking trails and lanes, and walkable sidewalks.
- Promote daily physical activity in health care settings by increasing the number of health care systems and providers who support and promote physical activity among their employees, patients and communities.
- Recommend that health care professionals implement a screening protocol for cancer risk with patients who are overweight or obese.

*The goals, objectives and strategies in this plan are taken from A Healthy Active Oregon: The Statewide Public Health Nutrition Plan and The Statewide Physical Activity Plan, February 2003.*

These plans were developed by the Oregon Coalition for Promoting Physical Activity and the Nutrition Council of Oregon: [www.healthoregon.org/hpcdp/physicalactivityandnutrition](http://www.healthoregon.org/hpcdp/physicalactivityandnutrition)

**OBJECTIVE 2:** Promote environmental and policy changes to increase physical activities in Oregon communities.

**Strategies:**

- Mandate changes in elementary, middle and high school policies, requiring provision of daily physical activity not limited to physical education classes.
- Improve land-use development policies to increase the number of communities where transportation and land-use planning encourage daily physical activity.
- Improve community and environmental design policies to enable and promote facilities for recreation, green spaces, parks, walkable sidewalks and interconnected trails in all neighborhoods and communities.
- Modify insurance-industry policies to provide incentives for physical activity by reducing life- and health-insurance premiums for individuals who participate in regular physical activity.

## NUTRITION

**OBJECTIVE 1:** Increase the percentage of Oregon's youth and adults who consume at least five daily servings of fruits and vegetables.

### Baseline Measures: Nutrition

#### Percent who consume five or more fruits and vegetables a day:

Children*	8th graders	27%
	11th graders	23%
Adults**		24%

#### Percent overweight or at risk of becoming overweight:

Children*	8th graders	23%
	11th graders	22%

#### Percent overweight:

Adults**	37%
----------	-----

#### Percent obese:

Adults**	21%
----------	-----

\*Source: Oregon Healthy Teen Survey, 2003.

\*\*Source: Behavioral Risk Factor Surveillance System, 2003.

- Increase promotion of “5 A Day” messages in local public health, community, state and school nutrition and health programs through increased access to training, technical assistance and funding.
- Increase access to fruits and vegetables in schools, worksites and communities.
- Work with the Oregon 5 A Day Partnership to meet established goals.
- Use information created by the 5 A Day Program in cancer programming and events.

**OBJECTIVE 2:** Increase the percentage of youth and adults in Oregon who are at a healthy weight.

### Strategies:

- Increase public awareness of the importance of healthy eating, daily physical activity and maintaining healthy weight to reduce cancer risk; also, increase awareness of the need for supportive policies and environments.
- Increase awareness and knowledge among local and state policymakers and decision-makers about the connections between healthy eating, daily physical activity, obesity and cancer; about the impacts of these issues on health outcomes and economic costs in Oregon; and about the benefits of policy interventions.



- Encourage and recognize “healthy-weight friendly” policies and programs in public- and private-sector worksites, schools and institutions.
- Identify, provide and promote opportunities for health care providers to expand their knowledge and use of best-practice methods to help individuals reach and maintain healthy weights.
- Increase access and availability of healthy food choices in schools, worksites and communities.
- Promote and support state and local legislation and policies that create environments conducive to healthy eating, daily physical activity and healthy weight, such as limiting access to soft drinks and fast foods in schools, reducing portion size and requiring calorie, fat and sugar information on containers for soft drinks and snacks sold in convenience stores.

### **American Cancer Society (ACS) Guidelines on Nutrition and Physical Activity for Cancer Prevention**

#### **Recommendations for individual choices:**

##### **1. Eat a variety of healthful foods, with an emphasis on plant sources.**

- Eat five or more servings of a variety of vegetables and fruits each day.
- Choose whole grains in preference to processed (refined) grains and sugars.
- Limit consumption of red meats, especially those high in fat and processed.
- Choose foods that help maintain a healthful weight.

##### **2. Adopt a physically active lifestyle.**

- Adults: Engage in at least moderate activity for 30 minutes or more on five or more days of the week;

engaging in 45 minutes or more of moderate-to-vigorous activity on five or more days per week may further enhance reductions in the risk of breast and colon cancer.

- Children and adolescents: Engage in at least 60 minutes per day of moderate-to-vigorous physical activity at least five days per week.

##### **3. Maintain a healthful weight throughout life.**

- Balance caloric intake with physical activity.
- Lose weight if currently overweight or obese.

##### **4. If you drink alcoholic beverages, limit consumption.**

#### **Recommendations for community action:**

Public, private, and community organizations should work to create social and physical environments that support the adoption and maintenance of healthful nutrition and physical activity behaviors.

- Increase access to healthful foods in schools, worksites and communities.
- Provide safe and accessible environments for physical activity in schools, transportation and recreation.

Source: American Cancer Society, June 2002.

# Environmental Risk Factors

*Cancer is linked to exposure to chemicals such as pesticides and radiation in our air, food, water and soil. Much can be done to improve our understanding of Oregon's environmental risk factors and how to reduce them.*

## KEY ISSUES

About three-quarters of the nation's cancer deaths are associated with environmental factors, broadly defined to include smoking, diet and infectious disease, as well as pollution, some chemicals and radiation.<sup>1</sup>

Although much remains to be learned about links between the environment and cancer, the following is known:

- Certain racial, ethnic and socioeconomic groups are disproportionately exposed to environmental hazards.
- Known environmental carcinogens include arsenic, asbestos, benzene, diesel fuel exhaust, PCBs (polychlorinated biphenyls) and radon.
- Exposure to ionizing radiation—from sources such as diagnostic X-rays and radiotherapy, as well as nuclear waste and radioactive elements like uranium—increases the risk of leukemia, as well as thyroid, breast and lung cancers.

- Workers exposed to asbestos and silica suffer from serious lung problems, including cancer.
- Workers exposed to certain solvents are at increased risk for bladder cancer.
- A link exists between cancer and some pesticides, such as those containing arsenic.

### To prevent exposure to environmental carcinogens:

- Test for radon in homes through Oregon's Radon Indoor Air Program.
- Avoid breathing diesel exhaust.
- Use respiratory masks when varnishing and performing other tasks near dangerous chemicals.



*“Who will live healthy lives and who will be poisoned? Who shall decide? In a democracy, we can act politically to stop the poisoning of our world that erupts as cancer.”*

—MARY O'BRIEN, PHD,  
AUTHOR, CANCER SURVIVOR, EUGENE

## CURRENT EFFORTS

In Oregon, the Environmental Public Health Tracking (EPHT) Network connects health and environmental databases, encouraging research and providing information to communities about our health and the environment in which we live and work.

## REMAINING CHALLENGES

While much is known about cancer risk from tobacco use and poor diet, only a handful of the thousands of chemicals in commonly used products have been tested for their potential to cause cancer.

A number of issues make it difficult to reduce or prevent environmental risk factors:

- Some communities have reported cancer clusters suspected to be the result of common exposure to an environmental carcinogen, but it is extremely difficult to prove what caused cancer in an individual or a group.
- The public and researchers have access to limited local data and information on environmental carcinogens.
- Communities lack relevant information about their particular environmental carcinogen risks and how to reduce them.
- Current policies and regulations do not sufficiently control exposure to environmental carcinogens.

<sup>1</sup> Cancer Facts and Figures 2005.

# GOAL:

*Reduce all Oregonians' risk of cancers related to environmental carcinogens.*

## ENVIRONMENTAL RISK FACTORS

### Target for Change

**Healthy People 2010:** Reduce exposures to pesticides, heavy metals and other toxic chemicals.

**OBJECTIVE 1:** Identify and prioritize Oregon's environmental carcinogens.

#### Strategies:

- Use the Oregon State Cancer Registry (OSCaR, [www.healthoregon.org/oscar](http://www.healthoregon.org/oscar)) and other databases to prioritize carcinogens that are linked to higher-incidence cancers.
- Identify new data sources, review existing data and update priorities.

**OBJECTIVE 2:** Increase Oregonians' access to data on environmental carcinogens.

#### Strategies:

- Work with the Environmental Public Health Tracking Network (EPHT, [www.healthoregon.org/epht](http://www.healthoregon.org/epht)) and other interested parties to make data available.
- Enhance collaboration among state and local public health departments, the academic community and community organizations to further research and prevention efforts.
- Monitor sources and uses of data.
- Advocate for resources to make data available to all Oregonians.

**OBJECTIVE 3:** Identify and bridge information gaps regarding environmental carcinogens.

**Strategies:**

- Assess the health and environmental data to identify information gaps.
- Advocate for increased testing of environmental carcinogens and other resources to address information gaps.
- Work with OSCaR and other tracking systems to collect additional data elements.

**OBJECTIVE 4:** Increase public awareness of carcinogens in the environment to promote prevention activities.

**Strategies:**

- Promote collaboration among organizations to develop educational activities and disseminate information on environmental carcinogens.
- Educate Oregonians about environmental carcinogens and actions individuals can take to reduce their exposure.
- Promote individual and group action to reduce exposure to environmental carcinogens.

## ENVIRONMENTAL RISK FACTORS

**OBJECTIVE 5:** Advocate for better public policy and enforcement to protect individual health.

**Strategies:**

- Promote collaboration with public and private organizations to identify and define opportunities for policy change.
- Mobilize advocates to develop and implement strategies for improving public policies.
- Advocate for adequate resources to accomplish policy goals.

**OBJECTIVE 6:** Reduce health disparities related to environmental carcinogens.

**Strategies:**

- Identify disparate burdens of cancer among populations of specific socioeconomic status, occupation, race, ethnicity, geographic location and other demographics.
- Develop and disseminate culturally and linguistically appropriate educational materials to increase the awareness of environmental risk factors.
- Promote the development of strategies and tools for at-risk populations to reduce their exposure to environmental carcinogens.

## From the Collaborative on Health and the Environment Environmental Links of Disease Database

### TOXINS—BY STRENGTH OF EVIDENCE

CANCERS		Strong*	Good**
	Bladder	Aromatic amines (4-Aminobiphenyl, Auramine, B-Naphthalamine, Benzidine, MOCA), Benzidine-derived dyes, Chlordimeform (and its metabolite 4-COT), Coal tar, Nitrobiphenyl, Tobacco smoke, trihalomethanes (disinfection byproducts)	Arsenic, Benzo(a)pyrene (PAHs)#, Chlornaphazine, Chlorphenol, Ionizing radiation, Methylene dianiline, Organic solvents, o-Toluidines
	Breast	Estrogens/DES, Ethanol, Ionizing radiation	Aromatic amines (B-naphthylamine and benzidine), Ethylene oxide, PAHs, Tobacco smoke
	Colorectal		Acrylonitrile#, Alachlor, Aromatic amines, Ionizing radiation, Organic solvents, trihalomethanes (disinfection byproducts)
	Lung	Aluminum, Arsenic (including pesticides); Asbestos, Attapulgite, Benzo(a)pyrene (PAHs)#, Beryllium, Cadmium, Chloromethyl ethers, Chromium, Coal tars, Diesel engine exhaust, Ionizing radiation, Mineral oils, Mustard gas, Nickel, Radon, Silica, Soots, Tobacco smoke, Uranium	Acid aerosols, Acrylonitrile#, Aromatic amines, Chlorophenols, Coal dust, Copper, Dimethyl sulfate#, Formaldehyde, Solvents, Nitrosamines (NNK); PAHs (Benz(a)anthracene#, Benzo(a)pyrene#, Dibenz(a,h) anthracene#)
	Prostate		Acrylonitrile#, Aromatic amines, Cadmium, Organic solvents, PAHs
	Skin (non-melanoma)	Arsenic, Coal tar, Ionizing radiation, Mineral oils, Shale oils, UV radiation	Aromatic amines, Creosotes#, Ethylene oxide, Mineral oils; PAHs: anthracene, benzo(a)pyrene#, dibenzanthracene, dimethyl benzanthracene, methychol-anthrene; Pesticides (arsenicals)

\* The “strong evidence” category is reserved for chemicals where a causal association to disease has been verified.

\*\* The “good evidence” category is for associations of chemicals and disease drawn from smaller epidemiological studies (cross-sectional, case-series or case-control studies), or for chemicals with some human evidence and strong corroborating animal evidence of an association.

This table includes excerpts from the Collaborative on Health and the Environment (CHE) database, as compiled in April 2004 by CHE member scientists. The database summarizes representative knowledge about links between environmental exposures and human diseases. While extensive, this is not an exhaustive list.

For the full text, which includes “Limited and Conflicting Evidence,” as well as notes and references, visit the CHE Web site at [www.protectingourhealth.org/corethemes/links/2004-0203spreadsheet.htm](http://www.protectingourhealth.org/corethemes/links/2004-0203spreadsheet.htm).

# Genetics

*Like most complex diseases, cancer has major genetic and environmental components. Some cancers have simple genetic causes, but most cancers are caused by complex interactions between lifestyle factors and multiple genes.*

### KEY ISSUES

When people talk about a “family history of cancer,” they are describing either inherited or familial cancer:

- **Inherited cancers** are caused by mutations passed from parents to their children. Five to 30 percent of cancers are inherited, with the percent varying significantly by type of cancer.
- **Familial cancers** are cancers that cluster in a family more often than expected by chance. These cancers may be a sign of gene mutations, shared environmental or lifestyle risk factors, or a combination of all of these factors.

Given what we now know about the links between genetics and cancer risk, it’s not surprising that many people are seeking out genetic testing. However, genetic testing should be undertaken with great care. Anyone considering genetic testing should receive genetic counseling to learn the ramifications of testing, understand how the results will be used and receive help interpreting the test results, which can be quite complex.

We recommend the use of genetic counselors because they are a valuable resource for:

- Helping people understand the complexities of genetic testing and how a genetic test result may be used in prevention and treatment of cancer.
- Interpreting genetic test results. For instance, genetic counselors can explain why a person with a positive test result will not necessarily develop cancer, and why a negative test result does not mean that a person will not develop cancer.

### Genetic Risk

**Examples of cancers in which family history of cancer in a first-degree relative increases cancer risk:\***

Breast	Double the risk of breast cancer if a mother or a sister was diagnosed with breast cancer.
Prostate	Two- to five-fold increased risk.
Ovarian	Three-fold increased risk.
Colorectal	Two- to three-fold increased risk.
Melanoma	Eight-fold increased risk.

\*Includes immediate family members such as mothers, fathers, brothers or sisters.

Note: The level of risk varies with the age at which the affected relative was diagnosed. The younger the affected relative, the greater the risk for cancer posed to relatives.

Source: National Cancer Institute, PDQ, Genetics, March 2005 ([www.nci.nih.gov](http://www.nci.nih.gov)).





*Learning about one's genetic risk for developing cancer is frightening, and it's not information that everyone wants. But it allowed me to have surgery and prevent the cancers that I feared would eventually claim my life.*

—NANCY PROUSER, LAKE OSWEGO

## CURRENT EFFORTS

Since 2000, Oregon has addressed emerging issues in genetics and public health—including ethical, legal and social issues—through the Oregon Genetics Program.

Current priorities of the Oregon Genetics Program ([www.healthoregon.org/genetics](http://www.healthoregon.org/genetics)) include:

- Educating the public, state policy leaders and health care providers about genetics and genetic services.
- Addressing access to genetic services, including geographic, financial and cultural barriers.
- Improving quantity and quality of data about genetic health needs and services.
- Addressing public policy concerns about genetic privacy and discrimination.
- Strengthening public health capacity to address genetic issues through training and resource development.
- Understanding how complex relationships between genetic and environmental factors affect disease and health promotion.
- Integrating genetic concepts and tools into existing public health programs.

Oregon has a law to protect the privacy of personal genetic information and prevent misuse of genetic information in clinical, research, employment and insurance settings. Regular re-evaluation since its passage in 1995 ensures that the law continues to meet the goals of assuring privacy, preventing misuse of genetic information and keeping the legal environment supportive of ongoing genetic research and genetic health services in Oregon.

## REMAINING CHALLENGES

Providing genetic services across the state is a challenge. In Oregon, genetic counseling and medical genetics evaluation services are located primarily in Portland, although limited services are also available in Bend and Eugene.

It will be critical to translate and integrate the science of cancer genetics into health care delivery. This will involve many activities, such as public education; health care training; data and surveillance; and public policy to ensure and protect the health of individuals and families.

*The Oregon Genetics Program offers genetics resources for both consumers and health care providers.*

*Learn more at: [www.healthoregon.org/genetics](http://www.healthoregon.org/genetics)*

# GOAL:

*Increase awareness and knowledge of genetic factors that influence individual cancer risk among all Oregonians.*

## GENETICS

**OBJECTIVE:** Increase the proportion of Oregonians who are aware of genetic factors that increase individual cancer risk.

**Strategies:**

- Educate the public about the importance of knowing family history of cancer and sharing this information with health care providers.
- Within appropriate cancer-specific programs, include genetic components in public education and outreach to improve understanding about issues related to inherited susceptibility to cancer risk.
- Promote public awareness of the need for proper counseling prior to participating in genetic testing or research. Also promote awareness of new developments in cancer research, appropriate predictive genetic testing and clinical prevention strategies.
- Improve ability of health care providers to collect and utilize family history information to assess their patients' risk of developing cancer.
- Promote awareness among health care providers of appropriate triage and referral methods for genetic services for high-risk persons.

- Increase access to genetic services, including access for people without insurance, people who are underinsured and people who live in areas that are underserved by genetic service providers.
- Promote legislation and policies that protect individuals from discrimination based on predictive genetic testing for cancer.
- Promote legislation and policies to implement licensure of qualified genetic counselors, which will improve access to genetic counseling.
- Monitor the science and research related to genetic risk factors and testing.
- Explore data collection methods to identify individuals who have a family history of cancer or genetic susceptibility to cancer.

# Breast Cancer Screening (in Women)

*Breast cancer is the most commonly diagnosed cancer among Oregon women—but because of early detection of breast cancer, more women die each year from lung cancer.*

## KEY ISSUES

Breast cancer is the third-leading cause of cancer deaths among women, and Oregon is among the nation's top five states for incidence of breast cancer.<sup>1</sup> The good news is that while each year more Oregon women are being diagnosed with breast cancer, more women are now surviving, thanks in large part to early detection.

Although survival rates continue to increase, Oregon's statistics on breast cancer remain alarming:

- In 2002, 3,293 Oregon women were diagnosed with breast cancer. Of these women, 72 percent were diagnosed at an early stage.<sup>2</sup>
- In 2002, 501 Oregon women died from breast cancer.<sup>3</sup>
- Early-stage breast cancer diagnosis for women living in Oregon's frontier counties has increased 10 percent since 1996.<sup>4</sup>
- Mammograms in women age 50 and older can reduce deaths due to breast cancer by 20 to 30 percent.<sup>5</sup>

### Breast Cancer Risk Factors

- The two greatest risk factors for breast cancer: being a woman and getting older.
- Cancer genes BRCA 1 and 2 cause 5% of breast cancers.
- 80% of all breast cancers occur in women age 50 and older.

Source: Cancer in Oregon, 2002.

## CURRENT EFFORTS

Until more is known about prevention of breast cancer, the focus continues to be on early detection. Regular mammograms should begin at age 40 for women who have no known risk factors other than being female.

Oregon maintains a highly active network of health care, volunteer, advocacy and community-based organizations with a commitment to women's health—and to breast health, specifically. Along with many support groups and other outreach programs, Oregon's extensive network includes 101 approved mammography facilities and a mobile mammography van.

In Oregon, insurance coverage for Pap tests and mammograms has been mandated by legislation since 1994. Medicare and Medicaid also cover mammograms for eligible women.



*“Please help to renew the law on providing health insurance and free mammograms, because as a young woman with a child, I can’t afford to pay for mammograms.”*

—GABRIELA SANCHEZ, PORTLAND

In addition, Oregon has free and low-cost breast screening services available to eligible women without health insurance. These resources include:

- Family Planning clinics at county health departments.
- Planned Parenthood.
- Community health clinics.
- The Susan G. Komen Breast Cancer Foundation.
- The Oregon Breast and Cervical Cancer Program.

#### Breast cancer screening includes:

- Clinical breast exam by a trained health provider.
- Mammogram.

Breast self-examinations have not been proven to reduce deaths and should not be used alone as a screening device to detect cancer.

#### Breast screening recommendations:

The American Cancer Society (ACS) says women should begin annual mammograms and clinical breast examinations at age 40.

The U.S. Preventive Services Task Force recommends a screening mammography, with or without clinical breast examination, every one to two years for women age 40 and older.

## REMAINING CHALLENGES

Oregon’s mammography screening rate is already at the national Healthy People 2010 objective of 70 percent. To further increase long-term survival rates and to prevent deaths, we must increase regular breast screening among all women, including those with and without health insurance.

It’s particularly important that we increase our screening efforts and early detection rates for:

- Women age 40 and over who have never had a mammogram.
- Rural counties (rural and frontier) in Oregon with lower mammography screening rates than urban counties.<sup>6</sup>

To increase screening rates, we must work to remove barriers to screening, such as finances and transportation. In addition, we need to provide culturally and individually appropriate outreach, referral and service delivery.

#### Oregon’s cancer disparities for breast cancer:

- Routine mammography screening is higher in urban areas.
- Breast cancer incidence is higher along the I-5 corridor in Oregon.
- The mortality rate is highest for African American women, followed by Whites.

Source: Cancer in Oregon, 2002.

<sup>1</sup> U.S. Cancer Statistics, 2001, Incidence and Mortality.

<sup>2</sup> Cancer in Oregon, 2002.

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

<sup>5</sup> U.S. Preventive Services Task Force, February 2002.

<sup>6</sup> Oregon Behavioral Risk Factor Surveillance Survey (BRFSS), 2000–01.

# GOAL:

*Reduce the number of deaths from breast cancer among Oregon women.*

## BREAST CANCER SCREENING (IN WOMEN)

**OBJECTIVE 1:** Increase the percentage of women in Oregon age 40 and older who have had a mammogram and clinical breast examination within the previous two years.

### Baseline Measures: Breast

#### Screening rate:

Percent of women age 40 and older who have had a mammogram and clinical breast exam in the past two years:

Oregon 70%

Healthy People 2010 70% (mammogram only)

Source: Behavioral Risk Factor Surveillance System, 2002.

**Early-stage breast cancer (2002):** 70%

#### Mortality rate (per 100,000 population):

Oregon 24.7/100,000

Source: Cancer in Oregon, 2002.

### Target for Change

#### Healthy People 2010 objective 22.3/100,000:

To achieve this target, Oregon needs to reduce its breast cancer mortality rate by 10%.

### Strategies:

- Promote annual mammograms and clinical breast exams for women age 40 and over.
- Provide tailored educational messages to promote annual mammograms for women age 50 and over.
- Provide tailored educational messages to promote annual mammograms for women age 65 and over.
- Provide culturally and individually appropriate breast health education to Oregon's diverse communities of women, including but not limited to Latinas, Asian/Pacific Islanders, African Americans, American Indian/Alaskan Natives, older women, women with disabilities, lesbians, women in rural areas, the uninsured, those with low incomes and the underinsured.
- Develop and implement best-practice strategies to promote breast screening to more women.
- Promote collaboration among community organizations to reach women using culturally and individually appropriate messages about health education.
- Identify the capacity for timely breast screening services throughout Oregon.

- Explore ways to increase access to mammography screening in rural and frontier counties, such as using mobile mammography services outside the Portland area.
- Increase the number of providers who counsel women on the need for mammogram screening.
- Increase the number of primary care providers trained to perform and document proficient clinical breast examinations.
- Encourage health plan and employer/employee wellness messages that promote breast cancer screening.
- Develop a coordinated system of services and resources to provide access to breast cancer early detection, diagnosis and treatment services that ensure quality of life through the cancer continuum of care.
- Continue advocacy to increase federal funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the Breast and Cervical Cancer Prevention Treatment Act (BCCPTA).
- Continue advocacy to maintain the insurance mandate for mammography screening.

# Cervical Cancer Screening

*No Oregonian should die from cervical cancer. Cervical cancer can be prevented, and regular Pap tests will help to eliminate all deaths from cervical cancer.*

## KEY ISSUES

Cervical cancer is the fourth-leading cancer diagnosed in Oregon women. In 2002, 126 Oregon women were diagnosed with invasive cervical cancer, and 45 of these women died.<sup>1</sup> Regular Pap tests could prevent these deaths.

Pap tests not only detect cervical cancer—they actually find “pre-cancerous” conditions that can be treated before cancer ever develops, when the condition is completely curable.<sup>2</sup>

Risk factors for cervical cancer include multiple sexual partners and smoking. Women who become sexually active at an early age and have multiple sexual partners are at an increased risk for cervical cancer. This risk is related to exposure to several types of human papilloma viruses (HPVs) that can cause cervical cancer.<sup>3</sup>

Between 1998 and 2002, mortality rates for cervical cancer in Oregon increased 9 percent a year, while national rates decreased 4 percent a year. More cervical cancers are being found at an early (localized) stage in Oregon, with 55 percent diagnosed at a localized stage in 2002.<sup>4</sup>

### Cervical cancer screening includes:

**Papanicolaou (Pap) test:** The collection of cells from the cervix (the lower, narrow end of the uterus that forms a canal between the uterus and vagina) and their examination under a microscope. The Pap test can find abnormal “pre-cancerous” cells.

### Pap test recommendations:

The American Cancer Society (ACS) recommends annual Pap tests, beginning three years after a woman begins vaginal intercourse, or by age 21. After three normal Pap tests, tests should be performed every three years, unless the woman is at high risk.

In 2003, the U.S. Preventive Services Task Force recommended beginning screening within three years of onset of sexual activity or age 21 (whichever comes first), and screening at least every three years.





*“Early detection can dramatically increase survival. My mother is a cervical cancer survivor thanks to early detection. Everyone should have the same chance as her.”*

—PAHONA CARNS, PORTLAND

## CURRENT EFFORTS

Since 1994, legislation in Oregon has mandated insurance coverage for Pap tests and pelvic exams.

An extensive network of health care providers offer Pap tests for individuals with and without health insurance, and Pap tests are covered by Medicaid and Medicare.

Women seeking contraceptive services may be eligible for services through free or low-cost alternatives such as:

- Family Planning.
- Planned Parenthood.
- Community health clinics.

## REMAINING CHALLENGES

In February 2005, HPV was officially acknowledged as a known infectious, cancer-causing agent for cervical cancer, which increased awareness about cervical cancer prevention.

We need a combined effort among health care, public health and community-based organizations to implement strategies to reduce cervical cancer risk among all Oregon women.

Our challenges include:

- Limited public awareness about the risk factors for cervical cancer and about cervical cancer prevention.
- Women over the age of 55 are less likely to get Pap tests than younger women.
- The percent of Oregon women age 18 and older who had a Pap test in the past three years varies by county, from a low of 72 percent to a high of 93 percent. The national Healthy People 2010 objective is 90 percent.
- Oregon’s rural and frontier counties have lower screening rates for cervical cancer.<sup>5</sup>

<sup>1</sup> Cancer in Oregon, 2002.

<sup>2</sup> CD Summary, Screening for Cervical Cancer, Feb. 11, 2003.

<sup>3</sup> Cancer in Oregon, 2002.

<sup>4</sup> Ibid.

<sup>5</sup> Oregon BRFSS County Oversample, 2000–01.

# GOALS:

- 1) Prevent all cases of invasive cervical cancer among Oregon women.
- 2) Reduce the number of deaths from cervical cancer among Oregon women.

## CERVICAL CANCER SCREENING

**OBJECTIVE 1:** Increase awareness about cervical cancer prevention and risk reduction behaviors.

### Baseline Measures: Cervical

#### Screening rate:

Percent of women age 18 and older who had a routine Pap test within the past 3 years:

Oregon 84%

Healthy People 2010 objective 90%

Source: Behavioral Risk Factor Surveillance System, 2002.

#### Mortality rate (per 100,000 population):

Oregon 2.4/100,000

Source: Cancer in Oregon, 2002.

### Target for Change

#### Healthy People 2010 objective 2.0/100,000:

To achieve this target, Oregon needs to reduce its cervical cancer mortality rate by 20%.

### Strategies:

- Educate women age 18 and over about the importance of cervical cancer screening to prevent invasive cervical cancer.
- Provide culturally and individually appropriate cervical cancer education to reach Oregon's diverse communities of women, including but not limited to Latinas, Asian/Pacific Islanders, African Americans, American Indian/Alaskan Natives, older women, women with disabilities, lesbians, women in rural areas, the uninsured, women with low incomes and women who are underinsured.
- Promote public education and awareness about risk factors and protective behaviors for cervical cancer, including HPV and condom use.

**OBJECTIVE 2:** Increase the percentage of Oregon women age 18 and older who have had a Pap test in the last three years.

**Strategies:**

- Build collaboration among state and local organizations to promote cervical cancer prevention education and screening involving community-based, health care, business, faith-based, women's and senior organizations.
- Promote programs that focus on increasing knowledge of the importance of and means of accessing cervical cancer screening, follow-up and treatment services.
- Promote access to free or affordable, appropriate screening services.
- Develop a coordinated system of services and resources to provide access to cervical cancer prevention, early detection, diagnosis and treatment services that ensure quality of life through the cancer continuum of care.
- Continue legislative support to increase federal funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the Breast and Cervical Cancer Prevention Treatment Act (BCCPTA).
- Continue advocacy to maintain the insurance mandate for Pap test screening.
- Analyze cancer registry data to identify health disparities for cervical cancers.

# Colorectal Cancer Screening

*Every day, five Oregonians are diagnosed with colorectal cancer—a cancer that can be prevented. Routine colorectal cancer screening can reduce deaths from colorectal cancer through the early diagnosis and removal of pre-cancerous polyps.*

## KEY ISSUES

The facts about colorectal cancer are alarming:

- Colorectal cancer is Oregon's fourth most common cancer, with 1,799 new cases reported in 2002.
- Colorectal cancer is Oregon's second-leading cause of cancer deaths, with 665 deaths reported in 2002.<sup>1</sup>

### Colorectal cancer screening tests include:

- Fecal occult blood test (FOBT).
- Flexible sigmoidoscopy.
- Double-contrast barium enema.
- Colonoscopy.

### Screening recommendations:

The American Cancer Society recommends beginning screening with one of the following at age 50:

- Annual FOBT and sigmoidoscopy every 5 years.
- Double-contrast barium enema every 5 years.
- Colonoscopy every 10 years.

In 2002, the U.S. Preventive Services Task Force (USPSTF) strongly recommended that clinicians screen men and women 50 years of age or older for colorectal cancer. The USPSTF found good evidence that periodic fecal occult blood testing (FOBT) reduces mortality from colorectal cancer and fair evidence that sigmoidoscopy alone or in combination with FOBT reduces mortality. The USPSTF did not find direct evidence that screening colonoscopy is effective in reducing colorectal cancer mortality.

Eating a low-fat, high-fiber diet and not smoking may help prevent colorectal cancer. Such behavioral changes, along with screening and early detection, will help us reduce deaths due to colorectal cancer.

Since 1997, Oregon's colorectal screening rates have increased 23 percent for women and 10 percent for men.<sup>2</sup> Thanks in part to increased screening, colorectal cancer is increasingly being found at earlier, more treatable stages.

Among Oregon women, deaths from colorectal cancer decreased 4 percent a year between 1998 and 2002, while deaths were relatively unchanged among Oregon men.

In 2002, 42 percent of cancers found were early stage (in situ or localized)—that's a 20 percent increase since 1996.<sup>3</sup> Despite these advances, fewer than half of Oregonians over the age of 50 received the recommended endoscopy test (sigmoidoscopy or colonoscopy) in the past five years.<sup>4</sup>



*“I am a 29-year colon cancer survivor. I lost my father to colon cancer in 1963 because we didn’t have all the screening tests that we have today. My sister and I were more fortunate in 1972 and 1975 because of early detection from being tested.”*

—NA TASHA SEWELL, KEISER

## CURRENT EFFORTS

Promoting colorectal cancer screening is a national priority. National television advertisements and celebrity spokespersons are helping to raise public awareness about colorectal cancer through prevention messages that encourage healthy eating, exercise and screening for individuals age 50 and older.

In Oregon’s 2005 legislative session, an insurance mandate for colorectal cancer screening was introduced for the third time.

## REMAINING CHALLENGES

Colorectal cancer is preventable, and while we’ve made progress in the past five years, we need to reach many more Oregonians. With known technology and screening tests, the focus becomes ensuring access to services and actually getting individuals in for screening.

It’s uncertain at this time whether health care providers would be able to meet the demand if all Oregonians age 50 and older requested a colonoscopy in the near future. However, the fact remains that to further reduce deaths from colorectal cancer, we must promote screening for all Oregonians age 50 and older.

A comprehensive approach to prevention of colorectal cancer would:

- Increase awareness about prevention of colorectal cancer through screening and healthy behaviors.
- Provide patient information about the tests and proper preparation for them.
- Ensure access to services, especially in rural areas, where many of Oregon’s older residents live.

<sup>1</sup> Cancer in Oregon, 2002.

<sup>2</sup> Oregon Behavioral Risk Factor Surveillance System (BRFSS), 1997–2002.

<sup>3</sup> Cancer in Oregon, 2002.

<sup>4</sup> Oregon BRFSS, 2002.

# GOALS:

*Reduce deaths from colorectal cancer among all Oregonians.*

## COLORECTAL CANCER SCREENING

**OBJECTIVE 1:** Increase the percentage of Oregonians age 50 and over who have had an annual Fecal Occult Blood Test (FOBT) and a sigmoidoscopy or colonoscopy within the past five years.

### Baseline Measures: Colorectal

#### Screening rate:

Annual FOBT and sigmoidoscopy or colonoscopy within the past 5 years for adults age 50 and older:

Urban	12.2%
Rural	10.8%
Frontier	9.4%

Source: Behavioral Risk Factor Surveillance System, 2002.

**Early-stage diagnosis:** 42%

#### Mortality rate (per 100,000 population):

Oregon 17.8/100,000

Source: Cancer in Oregon, 2002.

### Target for Change

#### Healthy People 2010 objective 13.9/100,000:

To achieve this target, Oregon needs to reduce its colorectal cancer mortality rate by 28%.

### Strategies:

- Provide public education about the importance of these life-saving tests.
- Promote public awareness and acceptability of colorectal cancer screening tests.
- Promote public awareness about the role of healthy behaviors, including nutrition and physical activity, in risk reduction for colon cancer.
- Provide access to the national “Screen for Life” and Polyp Man education campaign materials.
- Identify and implement best-practice strategies to reach Oregonians age 50 and over.
- Provide culturally and individually appropriate colorectal cancer education to reach Oregon’s diverse communities of women and men, including but not limited to Asian/Pacific Islanders, African Americans, American Indian/Alaskan Natives, Hispanics and Latinos, individuals age 50 and over, people with disabilities and people who live in rural areas.

- Assess the capacity for endoscopy services in Oregon.
- Adopt, disseminate and monitor screening guidelines.
- Promote history-taking to identify individuals at increased risk for colorectal cancer.
- Promote evidence-based interventions such as reminder systems and multiple education strategies for patient education.
- Provide culturally and linguistically appropriate education about sigmoidoscopy and colonoscopy test preparation and screening.
- Promote provider recommendation of screening for Oregonians age 50 and over.
- Develop a coordinated system of services and resources to provide access to colorectal cancer prevention, early detection, diagnosis and treatment services that ensure quality of life through the cancer continuum of care.
- Encourage utilization of the Health Employer Data and Information Set (HEDIS) established by the National Commission of Quality Assurance.
- Advocate for an insurance mandate for colorectal cancer screening tests.

# Prostate Cancer

*Prostate cancer is Oregon's fourth-leading cause of cancer death. Screening for prostate cancer is controversial—what's certain is the need for men to consult with their physicians about this potentially life-and-death issue.*

## KEY ISSUES

Prostate cancer, which affected 2,517 Oregon men in 2002, is the second most common cancer in Oregon men, behind only lung cancer. Fortunately, Oregon's incidence and mortality rates are declining.

Between 1998 and 2002, the incidence of prostate cancer declined 1.9 percent annually in Oregon, despite nationwide increases. Over those same years, the prostate cancer mortality rate decreased nationally and declined by 3.7 percent each year in Oregon.

Although screening efforts remain controversial, 84 percent of prostate cancers among Oregon men were diagnosed in an early stage. This represents a 6 percent increase in Oregon's early-stage diagnosis since 1996.<sup>1</sup>

Prostate cancer does not affect all men equally. The mortality rate for African American men in Oregon is more than twice that of all Oregon men. However, no divide appears to exist in early-stage diagnosis in Oregon's urban versus rural areas.

### The risk for prostate cancer is highest among:

- Older males (risk increases as men age).
- African American and Jamaican men of African descent.
- Men with first-degree relatives who developed prostate cancer at an early age.

### Screening for prostate cancer includes:

- Prostate-specific antigen (PSA) test (a blood test).
- Digital Rectal Examination (DRE).

In 2005, the American Cancer Society (ACS) recommended an annual PSA and DRE, beginning at age 50 for men who have a life expectancy of at least 10 more years. Men at high risk (African American men and men with a strong family history of cancer) should begin testing at age 45.

In 2002, the U.S. Preventive Services Task Force (USPSTF) concluded that insufficient evidence exists to recommend for or against routine screening for prostate cancer using PSA testing or DRE.





*“I am a prostate cancer survivor. Without early detection, I would probably be living a lower quality of life. But surviving without the full function of the prostate leaves me without a full life. Stopping prostate cancer without stopping the prostate should be the goal.”*

—DONALD R. COLLINS, SALEM

## CURRENT EFFORTS

Routine screening for prostate cancer is controversial. Most cancers occur in older men, grow slowly and do not affect survival. And the side effects of treating these tumors can affect a man’s quality of life. Unfortunately, current screening methods cannot reliably distinguish aggressive from slow-growing tumors.<sup>2</sup>

Despite these controversies, it is agreed that all men should be given clear and accurate information about the benefits, limitations and harms of prostate screening and treatment. This minimizes confusion and frustration, and allows each individual to make well-informed decisions based on personal values.

## REMAINING CHALLENGES

Several large clinical trials are underway to examine early detection and treatment of men with prostate cancer. The results, expected in 2006, may enlighten the debate and lead to a comprehensive prevention and early-detection program for prostate cancer.

### **Cancer disparity for prostate cancer in Oregon:**

Oregon’s prostate cancer mortality rate is highest for African American men, more than twice the rate for all races.

<sup>1</sup> Cancer in Oregon, 2002.

<sup>2</sup> CD Summary, January 29, 2002.

# GOALS:

- 1) Reduce deaths from prostate cancer among all Oregon men.
- 2) Increase informed and shared decision-making between men and their health care providers regarding the risks and benefits of prostate cancer screening and treatment.

## PROSTATE CANCER

**OBJECTIVE 1:** Increase the proportion of Oregonians who receive accurate, evidence-based information about prostate cancer screening and treatment.

### Baseline Measures: Prostate

#### Mortality rate (per 100,000 population):

Oregon	29.4/100,000
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Source: Cancer in Oregon, 2002.

### Target for Change

#### Healthy People 2010 objective 28.8/100,000:

To achieve this target, Oregon needs to reduce its prostate cancer mortality rate by 2%.

### Strategies:

- Develop a comprehensive educational message regarding major issues related to prostate cancer.
- Provide education about prostate screening to men at high risk, specifically African American men and men with a family history of prostate cancer.
- Identify and develop effective education programs and materials, including appropriate communication strategies about prostate cancer screening.
- Provide culturally sensitive and linguistically appropriate education materials about prostate cancer screening risks and benefits, treatment options and quality of life issues.
- Increase adherence to proven prostate cancer treatment modalities.

**OBJECTIVE 2:** Increase the proportion of health care providers who receive accurate and scientifically sound education about prostate cancer screening.

### Strategies:

- Develop methods to assess provider knowledge and understanding about prostate cancer screening issues.
- Provide education to primary care providers about the risks and benefits of prostate cancer screening.

**OBJECTIVE 3:** Monitor research in primary, secondary and tertiary prevention.

**Strategies:**

- Provide education to health care providers and men about clinical trials.
- Interpret and translate research findings about prostate screening and treatment to the public.
- Continue to monitor scientific research and recommendations of professional organizations for prostate cancer screening and treatment.

**OBJECTIVE 4:** Establish a blue-ribbon committee of health care, business and community organizations, along with cancer survivors and others, to define the agenda for prostate cancer education, screening and treatment in Oregon.

**Strategies:**

- Provide a forum for discussions about prostate cancer screening and treatment.

# Skin Protection and Melanoma Prevention

*Don't let Oregon's reputation for cloudy skies fool you: Oregonians are among the nation's leaders in melanoma incidence rates. Occurrences of melanoma—the most serious form of skin cancer—may be reduced through early detection and prevention efforts.*

## KEY ISSUES

Oregon's melanoma-related statistics are startling:

- Malignant melanoma is the fifth most common cancer among Oregonians, with 1,612 total cases diagnosed and 123 deaths in 2002.<sup>1</sup>
- Oregon's melanoma incidence rate was 22 percent higher than the national average in 2002, one of the highest melanoma incidence rates in the nation.<sup>2</sup>
- In 2002, Oregon's melanoma mortality rate was 27 percent higher than the national average.<sup>3</sup>
- In 1999, 38 percent of Oregonians reported getting a sunburn within the last 12 months.<sup>4</sup>
- Melanoma is most common in people with white skin. The incidence rates are more than 10 times higher in Whites than in African Americans.
- Melanoma can be found early, when it is curable. In 2002, 95 percent of all melanomas were found in an early stage.<sup>5</sup>

### Skin Cancer

Skin cancer includes basal-cell and squamous-cell cancers. Most, but not all, of these cancers are highly curable. The most serious form of skin cancer is melanoma, which is more likely to spread to other parts of the body.

Source: National Cancer Institute, PDQ, Prevention, 2004.

Unfortunately, the melanoma problem in Oregon appears to be increasing. Since 1996, melanoma incidence and mortality rates increased for Oregon's men and women, with the greatest increase among women.<sup>6</sup>

Both prevention and early detection strategies can help to address Oregon's melanoma problem. Exposure to sunlight (ultraviolet radiation) causes almost all cases of basal-cell and squamous-cell skin cancer and is a major cause of skin melanoma.

Skin cancer prevention includes adopting "sun-safe behaviors" such as:

- Avoiding the sun between 10 a.m. and 4 p.m.
- Wearing sun-protective clothing.

### Melanoma Risk Factors

- Prior melanoma.
- Family history of one or more family members with melanoma.
- Large moles.
- Sun-sensitive skin (skin that sunburns easily, common in people with natural blond or red hair color).
- History of excessive sun exposure and sunburns in childhood.
- Exposure to tanning booths.



*“As a new mother at 31, I was diagnosed with invasive melanoma and told the majority of the skin damage occurred in my childhood. I now advocate to every parent I meet the importance of sunscreen and protective clothing for their children because early education may save their lives.”*

—SABRINA PRILL, SHERWOOD

- Using sunscreen with a sun-protective factor (SPF) of 15 or higher.
- Avoiding artificial sources of ultraviolet (UV) light, such as tanning booths.
- Reducing work-related UV exposure.

Routine skin cancer screening by health care providers has not been proven to reduce deaths. However, skin examinations during routine health exams and self-examination of the skin can help detect a change in the skin or a mole.

### **Skin Cancer Prevention**

#### **The American Cancer Society recommends:**

- Self-examination once a month.
- Examination by a health care professional as part of a routine cancer-related check-up.

In April 2001, the U.S. Preventive Services Task Force (USPSTF) concluded that the evidence is insufficient to recommend for or against routine screening for skin cancer; using a total-body skin examination for the early detection of cutaneous melanoma, basal-cell cancer or squamous-cell skin cancer.

### **CURRENT EFFORTS**

While national sun-safe campaigns exist, Oregon has no known coordination of efforts at this time. However, Oregon does hold skin clinics in collaboration with the American Dermatological Society, and Oregon has a state regulation for tanning booth operation, training and inspection that serves as a model for other states.

### **REMAINING CHALLENGES**

Individuals and organizations can adopt sun-safe behaviors. Opportunities exist for policy and environmental change to incorporate sun-safety practices in outdoor occupations, as well as sites such as Oregon’s schools, child-care centers and outdoor recreation facilities. Actions taken to reduce UV exposure among children and youth can help reduce deaths from melanoma in the future.

<sup>1</sup> Cancer in Oregon, 2002.

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

<sup>4</sup> Oregon Behavioral Risk Factor Surveillance System (BRFSS), 1999.

<sup>5</sup> Cancer Facts and Figures 2005.

<sup>6</sup> Cancer in Oregon, 2002.

# GOALS:

- 1) Reduce skin cancer among all Oregonians.
- 2) Reduce deaths from melanoma among all Oregonians.

## SKIN PROTECTION & MELANOMA PREVENTION

**OBJECTIVE 1:** Prevent skin cancer by increasing the proportion of Oregonians who report regular use of at least one sun-safe behavior to reduce unprotected ultraviolet (UV) exposure.

### Baseline Measures: Melanoma

#### Mortality rate (per 100,000 population):

Oregon	3.1/100,000
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Source: Cancer in Oregon, 2002.

### Target for Change

#### Healthy People 2010 objectives:

- Increase the proportion of persons who use at least one of the sun-safe behaviors.
- Increase the proportion of adolescents in the ninth through 12th grade who follow protective measures.
- Increase the proportion of adults age 18 and older who follow protective measures that may reduce the risk of skin cancer.

#### Healthy People 2010 objective 2.5/100,000:

To achieve this target, Oregon needs to reduce its melanoma cancer mortality rate by 24%.

### Strategies:

- Utilize education resources from the National Council on Skin Cancer Prevention ([www.skincancerprevention.org](http://www.skincancerprevention.org)) to promote skin cancer awareness and cancer prevention efforts.
- Promote awareness in schools about sun-protective behaviors for children.
- Identify strategies to involve parents and family members in skin cancer prevention activities.
- Promote the use of sun-safety education campaigns among employers; parks and recreation facilities; and business, health care and community organizations.
- Identify celebrities as spokespersons to encourage individuals to adopt sun-safety practices.
- Provide education to health care professionals about sun-safe behaviors and skin cancer prevention.

- Encourage providers to promote sun-safe behaviors for individuals at high risk for skin cancer.
- Encourage providers to promote skin self-examination to their patients to detect skin changes.
- Increase the number of organizations that participate in the American Dermatology Association's annual skin cancer screening activities.
- Develop and implement policy changes to increase the use of sun-safe behaviors in sites including schools, workplaces and outdoor park and recreation areas.
- Promote strict adherence to registration, licensure and inspection requirements for all tanning facilities in Oregon, as described at [www.dhs.state.or.us/publichealth/rps/tanpkt.cfm](http://www.dhs.state.or.us/publichealth/rps/tanpkt.cfm).
- Explore and identify ways to collect data about sun-protective behaviors, such as the Behavioral Risk Factor Surveillance System and Oregon Healthy Teen Survey.

## Treatment and Quality of Life

*Nobody wants to hear those three fateful words: “You have cancer.” The reality is that thousands of Oregonians will be diagnosed with cancer, which underscores the importance of treatment, follow-up care and long-term management.*

### KEY ISSUES

Nearly half of all males (46 percent) and about two of every five females (38 percent) will be diagnosed with cancer at some point in their lifetime.<sup>1</sup> In 2002, 18,713 Oregonians were diagnosed with cancer—that’s approximately 50 new cancers diagnosed each day.

Cancer is a complex disease, and increasingly it is viewed as a chronic condition that includes issues such as follow-up care and self-management, along with initial treatment.

Among the cancer treatment issues to consider:

- Cancers in children and young adults often require different services and resources than cancers impacting people over the age of 65.
- Cancer treatment involves complicated

choices. Patients and families need individually appropriate information and support to take charge of their health and make informed decisions, both short-term and long-term.

- Without proper understanding of all the issues, patients may not receive the recommended treatment or follow-up care.

This Treatment and Quality of Life chapter incorporates both short-term and long-term needs of individuals, their families and caregivers, as well as the health care system. The chapter’s key components are:

- Access to quality cancer treatment services.
- Symptom management, follow-up and rehabilitation services.
- Survivorship services.
- Timely palliative and end-of-life care, as needed.

*“When my daughter was diagnosed four years ago, we went through a very scary and trying time. We were so fortunate to have a happy ending to our story.”*

—MOTHER OF 7-YEAR-OLD,  
ST. HELENS





*“I am a cancer survivor. They gave me three days to live and that was six years ago. Many more can survive if their cancer is detected early enough.”*

—WARREN BENNETT, MEDFORD

## CURRENT EFFORTS

Oregon has 21 accredited cancer programs, including the OHSU Cancer Institute, a National Cancer Institute–designated cancer center. In addition, many hospitals, outpatient clinics and health care facilities provide a wide range of cancer-related treatment and follow-up services.

Oregon’s 21 accredited cancer programs provide:

- Access to quality care as close to home as possible.
- Comprehensive care, including a range of state-of-the-art services and equipment.
- A multidisciplinary team approach that coordinates individually appropriate assessment, treatment and referral, as needed.
- Information about cancer clinical trials, education and support.
- Lifelong patient follow-up through a cancer registry that collects data on treatment results, type and stage of cancer, and an annual follow-up that determines patient status.
- Ongoing monitoring and improvement of patient care.

## REMAINING CHALLENGES

Oregon’s economic, geographic and demographic factors present challenges for health care in general. Ensuring the highest quality of life for all individuals with cancer requires coordination of many services over time.

Oregon’s health care delivery system must continue to address patient, family and caregiver needs such as:

- Access to quality services.
- Effective communication.
- Financial, physical, social and spiritual support.
- Incorporation of complementary therapies.
- Education.

We need to address health care system factors like:

- Equal access to quality cancer services.
- Effective communication.
- Ongoing assessment of patient and family needs.
- Advocacy for patient resources.
- Continuity of cancer care and follow-up services.
- Timely and appropriate referrals.
- Coordination between oncology providers and primary care providers.

<sup>1</sup> National Cancer Institute, SEER Cancer Statistic Review, 1975–2001, Table II-8.

## Access to Quality Cancer Treatment

*When asked to name Oregon's top three health care problems, Oregonians didn't name specific diseases. Instead, they said the leading problems are: 1) access to health care; 2) cost of health care; and 3) cost of health insurance.<sup>1</sup>*

### KEY ISSUES

Access to health care involves more than just getting in the door for services. For cancer care, it means assuring that all Oregonians have access to quality treatment and follow-up care that is culturally and individually appropriate, and available when needed. Barriers to cancer services can be geographic, financial, individual or systemic.

### CURRENT EFFORTS

In Oregon, 21 cancer centers serve the state's insured and uninsured populations. In 2004, Oregon's uninsured population rose to 17 percent.<sup>2</sup>

The harsh reality in Oregon and the nation is that where people live, their education and cultural background, and their health insurance status can greatly impact their ability to access cancer screening and treatment services.

*"Quality Cancer Care is defined to mean the provision of evidenced-based, patient-centered services throughout the continuum of care in a timely and technically competent manner, with good communication, shared decision-making and cultural sensitivity, with the aim of improving clinical outcomes, including patient survival and health-related quality of life."*

—NATIONAL CANCER INSTITUTE:  
PLANS AND PRIORITIES 2004,  
IMPROVING THE QUALITY OF CANCER CARE.



*“Access to quality treatment can be a reality when people begin working together.”*

—CELESTE WHITEWOLF,  
STAGE III BREAST CANCER SURVIVOR,  
DIAGNOSED IN AUGUST 1998

In order to ensure equal access to cancer care, a comprehensive plan must provide:

- Timely access to cancer care services.
- Access to quality cancer care services.
- Individualized financial assessment and support.
- Transportation options.
- Ongoing assessment of patient and family information, support, needs and wishes.
- Culturally and individually appropriate services.
- Prompt referrals to psychosocial support and other rehabilitation services or therapies.
- Patient navigator systems to ensure that patients don’t “fall through the cracks” in the health care system.

## REMAINING CHALLENGES

Currently, we have few systematic ways to define Oregon’s gaps in cancer care. We have yet to gather data on the quality of cancer care or the quality of life of cancer patients and their families. In addition, we need to define a method to assess patient satisfaction and to clarify cancer patient and family financial burdens over time.

A comprehensive approach to cancer care in Oregon would include both adjustments to public policy and expanded collaboration among health care providers. The benefit to individuals with cancer and their families, as well as to health care providers, would be immense.

*“I was diagnosed with prostate cancer in January of 1993. I’ve had surgery, radiation and several medical and drug treatments, but the cancer continues to grow, and I’m now looking for another treatment plan to extend my life.”*

—72-YEAR-OLD MAN, AUMSVILLE

<sup>1</sup> Oregon Health Values Survey, 2004.

<sup>2</sup> Ibid.

# GOAL:

*Ensure that all Oregonians have access to quality cancer treatment and information services that are culturally and individually appropriate by age, financial situation and geographic location.*

## ACCESS TO QUALITY TREATMENT

**OBJECTIVE 1:** Increase the proportion of Oregon's cancer patients treated according to established national guidelines.

### Strategies:

- Develop strategies for assessing and monitoring the quality of cancer care.
- Increase by 10 percent the number of individuals enrolled in clinical trials in Oregon.
- Encourage investigators to develop research projects that address quality-of-life issues.
- Increase by 20 percent the number of hospital cancer programs certified by the American College of Surgeons (ACOS).  
Provide an ACOS liaison to promote the benefits of certification to hospitals with more than 200 new cancer cases a year.
- Develop partnerships to facilitate access to specialty services for rural patients and providers through methods such as teleconferencing and telemedicine.
- Promote and support health care professionals traveling to rural community facilities to deliver care, education and follow-up services.

**OBJECTIVE 2:** Increase the proportion of Oregonians who are offered comprehensive multicultural education and support services.

**Strategies:**

- Develop methodology for identifying barriers to accessing and receiving culturally competent care.
- Explore the development of patient navigator programs state-wide, especially in underserved and under-certified areas of the state.
- Advocate for resources to address patient transportation and related barriers to culturally competent care.
- Explore the feasibility of a Web-based database of multicultural cancer treatment resources by county across the state.
- Advocate for simplified versions of the most frequently used National Cancer Institute (NCI) and American Cancer Society (ACS) pamphlets to enhance patient participation in their own care and decision-making.

**OBJECTIVE 3:** Reduce the personal financial burden for patients and their families who are unable to access cancer services because of inability to pay.

**Strategies:**

- Explore options to enhance health insurance coverage and reimbursement for cancer care and treatment.
- Advocate for the return of the Oregon Health Plan (Medicaid) to its maximum scope of coverage.
- Provide physicians' office staffs with simple instructions to access free or discounted medications for patients.

# Symptom Management

*To fully manage the symptoms and side effects of cancer and its treatment, the health care system must be able to anticipate patient needs, individually assess clients and refer people to appropriate services. This requires an interdisciplinary cancer care team as well as an established network of supportive services.*

### KEY ISSUES

The goal of health care providers is to prevent or reduce short-term and long-term side effects of cancer and its treatment. When prevention of symptoms is not possible, aggressive management should be expected.

This management, as assessed by health care providers, may include services and referrals for:

- Pain management.
- Nutrition counseling.
- Fatigue and nausea.
- Cognitive and memory changes related to treatment.
- Exercise therapy.
- Physical therapy.
- Complementary and alternative medicine.
- Spiritual support.
- Psychosocial interventions.

### CURRENT EFFORTS

Successful symptom management requires the collaboration of cancer care teams. Such coordination, including appropriate referrals, forms a critical component of quality cancer care.

Pain can be a side effect of the cancer itself as well as its treatment. The Oregon Legislature formed the Pain Management Program in 1999 as a result of patient advocacy efforts about the need to adequately control pain.

The Oregon Legislature also created the Oregon Pain Commission ([www.dhs.state.or.us/pain](http://www.dhs.state.or.us/pain)) and mandated continuing education on pain management for all health care providers in the state, effective January 2006.

*“The only true continuity of care is the patient and family.”*

—SUE FRYMARK, RN



*“The symptoms are the reality of the disease. They need to be managed.”*

—LILLIAN NAIL, PHD, RN,  
THREE-TIME CANCER SURVIVOR

## REMAINING CHALLENGES

To promote the highest quality of life for cancer patients, comprehensive cancer treatment must include:

- Assessment of patient and family needs.
- Provider awareness and education about the broad scope of symptom management options.
- Adequate and timely referrals to supportive services.
- Advocacy for patients—helping individuals have a voice in their own treatment.
- Adequate health care reimbursement.
- Understanding of cultural, ethnic and religious issues related to pain, symptom management, cancer treatment, communication and decision-making.

### 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 and other health care professionals.
- **Have your pain thoroughly assessed** and promptly treated.
- **Be informed** by your health care provider about what may be causing your pain, the possible treatments, and the benefits, risks and costs of each.
- **Participate actively in decisions** about how to manage your pain. 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, have time to make decisions and be able to refuse a particular type of treatment if you choose.

Source: (c) 2003 American Pain Foundation  
([www.painfoundation.org](http://www.painfoundation.org)).

# GOAL:

*Ensure that all Oregonians with cancer receive information and treatment for the effective management of the side effects and symptoms of their cancer treatment. This information and treatment should be culturally and individually appropriate by age, financial situation and geographic location.*

## SYMPTOM MANAGEMENT

**OBJECTIVE 1:** Increase the proportion of Oregon cancer patients whose pain is adequately controlled.

### Strategies:

- Incorporate pain management in patient education and provider in-service programs.
- Widely disseminate National Comprehensive Cancer Network (NCCN) Guidelines on cancer pain to all case managers, senior-center coordinators and health coordinators at assisted living facilities.
- Promote awareness of the American Pain Foundation's Pain Care Bill of Rights.

**OBJECTIVE 2:** Increase the proportion of Oregon cancer patients whose cancer and cancer treatment–related side effects are recognized and treated early, or prevented.

### Strategies:

- Strongly encourage doctors and registered nurses (RNs) to use the Holland Distress Scale in a routine manner at all cancer treatment evaluations.
- Educate office RNs on the appropriate interventions based on the Distress Scale and the NCCN Guidelines on Distress.
- Promote knowledge of and access to complementary therapies that are proven to reduce cancer treatment–related side effects.



**OBJECTIVE 3:** Increase the proportion of health care professionals who collaborate to enhance knowledge, opportunities and resources that can assist with improving cancer patients' quality of life.

**Strategies:**

- Develop collaboration between Oregon's licensed dietitians and cancer care providers to address nutritional needs of people with cancer, based on the American Institute for Cancer Research (AICR) and American Cancer Society (ACS) guidelines.
- Provide insurance case managers with information on the benefits of early intervention with physical and psychosocial support, and incorporate current symptom management interventions into all in-services with case managers.
- Coordinate with licensed physical therapists and researchers to disperse recent findings and strategies on using exercise interventions to reduce cancer-related fatigue and nausea.
- Survey Oregon members of the Association of Oncology Social Work to identify the psychosocial and financial assistance services available in their individual areas of practice, along with local barriers to accessing quality cancer care. Use data to confirm gaps and provide referral strategies.
- Provide intercultural agencies with NCCN Guidelines on pain; nausea and vomiting; cancer-related fatigue and anemia; fever and neutropenia; distress; and advanced cancer and palliative care for patients and their family members.

# Survivorship

*For cancer survivors and their families, legal, financial, physical and emotional challenges don't end when the disease disappears. Improving follow-up and long-term management will help the increasing number of cancer survivors live longer, happier lives.*

### KEY ISSUES

More people are surviving cancer and living longer. In fact, about 62 percent of all cancer survivors are expected to live for at least five years after diagnosis.<sup>1</sup> With that good news comes an added responsibility to ensure that cancer survivors receive follow-up and long-term care that promotes the highest possible quality of life.

Long-term survivorship issues include:

- Psychological and emotional well-being, including management of depression.
- Side effects of treatment.
- Physical fitness and nutrition.
- Financial issues for individuals with and without health insurance.
- Long-term health implications, including cognitive changes, falls and fractures.
- Discrimination, such as denial of health benefits and life insurance.

#### Cancer survivors are:

People diagnosed with cancer who are living with, through or beyond cancer from the moment of diagnosis. The term also includes family members, friends and caregivers.

Source: Cancer Facts and Figures 2005.

Other survivorship issues are specific to particular groups. For instance, survival rates for all childhood cancers have improved markedly over the past 30 years—from a survival rate of less than 50 percent before 1970 to more than 70 percent in the late 1990s.<sup>2</sup>

Childhood and young adult cancer survivors face unique issues related to their cancer treatment. They may, for example, have needs related to fertility, personal empowerment, cognitive functioning and discrimination.

*“Today, there are nearly 10 million people living with cancer. Decades of investment in research are paying off—more and more people are winning the battle against cancer. It’s time to deal with the issues they face.”*

—LANCE ARMSTRONG FOUNDATION, 2005

*“Hope, the best four letter word! I’m a survivor and glad to be here!”*

—WOMAN IN HER 50s,  
LEBANON



*“I think it’s great for patients who are in or out of cancer treatment to stay active. This program helped me meet some special people and I had the added benefit of accomplishing some of my fitness goals.”*

–JOAN HEIMBIGNER (RIGHT), BREAST CANCER SURVIVOR,  
WITH LISA DOMENICO,  
“MOVING FORWARD” FACILITATOR, PORTLAND

## CURRENT EFFORTS

Oregon’s extensive network of cancer support groups includes many groups that target individual cancer sites and other groups that focus on cancer in general. Hospitals and local voluntary organizations often coordinate these support groups.

Nationally, researchers’ efforts include working to enhance the body of knowledge and identify services available to improve cancer survivors’ quality of life.

### Five-Year Survival Rates

Survival rates for cancers found in early stages and that have not spread:

Breast	98%
Cervical	Almost 100%
Colorectal	38%
Melanoma	91%
Prostate	Almost 100%

Source: Cancer Facts and Figures 2005.

## REMAINING CHALLENGES

Once cancer treatment ends and survivors return to their primary care providers, new sets of challenges emerge.

The health care, allied health and social systems must be able to assess, anticipate and respond to the long-term needs of cancer survivors. That means each cancer patient must have a long-term life plan to prevent or reduce long-term side effects of cancer treatment.

Survivorship needs can include:

- Education and awareness of health care providers about the long-term needs of survivors.
- Assessment and documentation of physical, emotional, social, vocational and financial needs.
- Assessment and referral for appropriate follow-up care, rehabilitation and social services.
- Awareness among the general public, policymakers and health care providers about the needs of cancer survivors.

<sup>1</sup> Cancer Facts and Figures 2005.

<sup>2</sup> Ibid.

# GOAL:

*Improve cancer survivors' quality of life through services that address the physical, emotional, social and vocational challenges of survivorship.*

## SURVIVORSHIP

### Target for Change

**Healthy People 2010:** Increase the proportion of cancer survivors who are living five years or longer after diagnosis.

**OBJECTIVE 1:** Increase the proportion of cancer survivors, significant others and health care professionals who use cancer survivor resources.

#### Strategies:

- In conjunction with Partnership member organizations, create and maintain a multicultural database that includes therapy and rehabilitation services; support and education groups; and other cancer care resources at local, state and national levels.
- Provide information from multicultural databases to physicians' offices in print or CD format.
- Conduct outreach strategies to promote the availability of information to patients, caregivers and survivors.

**OBJECTIVE 2:** Increase the proportion of cancer patients who use rehabilitation services to reduce or prevent long-term effects of cancer and its treatment.

#### Strategies:

- Develop and implement an assessment tool to identify primary access, rehabilitation and psychosocial needs of cancer survivors.
- Increase primary care provider (PCP) awareness of strategies and resources to prevent or reduce long-term side effects of cancer treatment.
- Promote to professionals the use of the American Psychosocial Oncology Society (APOS) core curriculum, "Multidisciplinary Curriculum in Psycho-Oncology," available at [www.apos-society.org](http://www.apos-society.org).
- Enhance public and provider awareness of interventions to prevent and treat physical de-conditioning during and following cancer treatment.

- Increase use of dietary and nutritional consultation to maximize recovery and long-term health.
- Collaborate with private insurance and government-sponsored insurance plans to improve reimbursement for exercise, nutritional and psychological services.

**OBJECTIVE 3:** Increase the proportion of cancer patients who are informed and participate with their provider in their long-term follow-up care plan.

**Strategies:**

- Develop appropriate long-term follow-up plans through collaboration between cancer patients and their primary health care providers.
- Expand awareness and use of existing follow-up guidelines by oncology and primary care physicians and patients.
- Promote collaboration with disease-specific organizations to disseminate guidelines to patients and caregivers.
- Monitor and incorporate emerging information on cancer survivorship into the Partnership's plans as they are developed.

**OBJECTIVE 4:** Eliminate disparities affecting survivors from underserved communities.

**Strategies:**

- Partner with multicultural agencies to provide survivorship services within diverse communities.
- Increase the enrollment of underserved populations in clinical trials by developing community-based partnerships that work with culturally diverse and underserved communities.

# Palliative Care and End-of-Life Issues

*Oregon is a national leader in providing palliative and hospice care—comfort care that is delivered with dignity and respect for the patient and family.*

## KEY ISSUES

Many of us don't like to talk about death and dying. The process is complex and sometimes painful, involving many ethical, legal and spiritual facets.

Key issues in end-of-life care include:

- Education about hospice: what hospice means and what it provides to both health care providers and the general public.
- The need for earlier identification of individuals within the health care setting who may benefit from hospice care.
- The need to protect autonomy and dignity for patients and their family members, as well as health care providers.

*"I couldn't have managed the care of my daughter who died of a brain tumor without the support of the hospice nurse, social worker and chaplain."*

—MOTHER OF A 22-YEAR-OLD,  
BEND

## CURRENT EFFORTS

Oregon is nationally known for its efforts to promote comfort care, patient autonomy and informed decision-making, especially concerning end-of-life issues. Examples include the Oregon Death With Dignity Act of 1994 and the legislation forming the Oregon Pain Management Program and Commission in 1999.

In Oregon, more than 50 Medicare-certified facilities provide hospice services. These services

### Definitions

**Palliative Care:**\* The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of illness in conjunction with anti-cancer treatment.

**Hospice Care:**\*\* Comprehensive palliative medical care and supportive social, emotional and spiritual services to the terminally ill (defined as less than six-month life expectancy) and their families, primarily in the patient's home. The hospice interdisciplinary team, composed of professionals and volunteers, coordinates an individualized plan of care for each patient and family. Hospice reaffirms the right of every person and family to participate fully in this final stage of life's journey.

\*Source: World Health Organization (WHO).

\*\*Source: Hospice Association of America.



*“I’m grateful to the hospice nurses who helped provide my mom, who had melanoma cancer, the pain and symptom control she needed to live out the rest of her life as comfortably as possible.”*

—GEENA PARK, TIGARD

can be provided in any safe environment for the patient. Options include private homes, inpatient hospices, nursing homes, foster cares, residential care facilities and assisted living facilities.

Physicians, registered nurses, home health aides, social workers and therapists provide hospice services. In addition, Oregon facilities offer pastoral, caregiver and volunteer programs and services.

### Hospice Services

**Survey data from Oregon hospice facilities provides a glimpse at hospice services in Oregon:**

- Clients: Average age 76.8; 45% male; 55% female.
- Days of care: The median number of days of hospice care is 15, similar to the national average.
- Cancer patients: Cancer patients compose about half of all hospice deaths (8,910 in 2002).
- Funding resources: 84% Medicare; 11% insurance; 4% Oregon Health Plan.
- Place of death: Almost 60 percent of clients died at home.
- Primary caregiver for clients:
  - About 30% spouse/partner
  - About 30% other family member
  - About 38% paid caregiver
  - About 2% friend
  - About 1% none

Source: Oregon Hospice Association, 2002 Survey Data.  
(Data collection is voluntary.)

### REMAINING CHALLENGES

While Oregon has extensive hospice resources, improvements need to be made to enhance the existing systems.

Improvements should include:

- Adequate reimbursement by public and private insurers.
- Culturally relevant, patient-oriented education materials for adults and children. The information should be comprehensive and accurate.
- Use of best-practice guidelines as standards of care for treatment of physical and psychological symptoms. Nationally recognized accreditation bodies should encourage application of these guidelines.
- Enhancement of data systems through cancer control registries.
- Increased public awareness about death and dying issues.
- Increased provider education and training.
- Increased timely referrals to hospice.
- Increased use of palliative care services.

# GOAL:

*Ensure that all Oregonians have access to and utilize high-quality hospice and palliative care that is culturally and individually appropriate by age, financial situation and geographic location.*

## PALLIATIVE CARE AND END-OF-LIFE ISSUES

**OBJECTIVE 1:** Increase the proportion of Oregonians who, in a timely manner, are offered and have access to end-of-life care.

### Strategies:

- Monitor access and utilization of hospice services as a basis for evaluation of interventions.
- Improve reimbursement streams (Oregon Health Plan, Medicare, private health plans and employer-based health plans) to ensure financial viability of hospices, especially in rural areas.
- Support efforts to broaden service areas of existing hospices.
- Improve access to palliative care services in inpatient settings and homes.
- Support efforts to broaden the range of services offered by hospices, home health agencies, hospitals and long-term-care facilities.
- Support efforts to develop new palliative care services and palliative-care programs within existing hospices.



- Support efforts to include adequate palliative care benefits under Medicare, Oregon Health Plan, private health plans and employer-based health plans.
- Increase proportion of utilization of hospice and palliative care for populations including pediatric, adult, geriatric and special-needs patients such as the developmentally disabled and ethnically diverse populations.
- Evaluate existing sources of data to identify unserved and underserved populations or regions.
- Develop and implement strategies to meet the needs identified in the assessment.

## PALLIATIVE CARE AND END-OF-LIFE ISSUES

**OBJECTIVE 2:** Increase the proportion of health care providers in Oregon who receive education and training related to end-of-life care.

**Strategies:**

- Identify existing or develop new end-of-life care education and training modules that include cultural competence.
- Host conferences and seminars about end-of-life issues, options and resources.
- Support efforts to enhance health care providers' use of effective education concerning pain and symptom management.
- Provide tools and strategies for practicing health care professionals to use in addressing end-of-life issues with patients and families.
- Educate providers about effective communication strategies for discussing death and dying.
- Support adequate funding of health care educational and training institutions.

**OBJECTIVE 3:** Increase public awareness of death and dying, and of end-of-life issues and resources.

**Strategies:**

- Provide patients with complete and accurate information regarding all legal and ethical end-of-life care options, including: hospice and palliative care services; pain and symptom management; advance directives and physician orders for life-sustaining treatment; right to refuse and discontinue treatment; and the Death With Dignity Act.
- Encourage patients and families to ask about hospice and end-of-life care.
- Provide opportunities for open discussion about death and dying.
- Provide Oregonians with information and tools needed to advocate for themselves and their loved ones during a life-threatening illness.
- Encourage patients and their families to give permission to health care professionals to be open and honest about their condition and prognosis throughout the disease process.
- Encourage a variety of approaches to public education on death and dying.
- Systematically evaluate the use of Physician Orders for Life-Sustaining Treatment (POLST) forms and compliance to patient wishes.

# Cancer Disparities

*Cancer does not impact all segments of Oregon’s population in the same way. Addressing these disparities should be a priority in our increasingly diverse state.*

## INTRODUCTION

The 1999 Institute of Medicine report, “The Unequal Burden of Cancer,” states that despite dramatic scientific gains, not all segments of the U.S. population have benefited to the fullest extent from advances in the understanding of cancer.

Unless ALL Oregonians have access to quality cancer care throughout the cancer continuum, Oregon will be unable to significantly alter the cancer disparities affecting minorities and medically underserved populations.

The complexity of this problem becomes further compounded when we consider Oregon’s rapidly growing racial/ethnic minority and elderly populations. For many minorities, language and cultural barriers inhibit access to health care. Oregon also has one of the fastest-growing populations of people over the age of 65, and these people are at a higher risk for being diagnosed with cancer.

Throughout this plan, cancer disparities are defined as “differences in the incidence, mortality and burden of cancer and related health conditions that exist among specific population groups in Oregon.”

For example, some Oregonians are disproportionately affected by cancer. These include, among others, people living in our rural communities, our older residents, the increasing number of racial and ethnic minorities, people with disabilities, and the gay, lesbian, bisexual and transgender communities.

### Determinants of Cancer Disparities

- Gender.
- Geography.
- Cultural Values/Beliefs.
- Language.
- Race/Ethnicity.
- Socioeconomic Status/Insurance.
- Urban vs. Rural.
- Disability.
- Age.
- Occupation.
- Sexual Orientation.



*“I was diagnosed with breast cancer in 2001. I was fortunate to have it caught in an early stage. Unfortunately, due to the cancer I was unable to keep working. [I ended up] homeless again. I had to continue to try to keep my Oregon Health Plan Plus in order to continue my cancer treatments and medication.”*

—CRUCITA WHITE, SALEM

## KEY ISSUES

The following are among Oregon’s cancer disparities:

- The incidence rate for prostate cancer among African American men is more than double that for Whites.<sup>1</sup>
- The colorectal cancer screening rate for Asian Americans is 30 percent, compared to 50 percent in the general population.<sup>2</sup>
- People over the age of 65 are the fastest-growing age group in Oregon. It’s projected that this age group will double in size in 20 years, which will have significant implications for cancer resources.<sup>3</sup>
- A study of primary care capacity of 102 rural areas concluded that 35 percent of these areas met less than a quarter of their primary health care needs.<sup>4</sup>
- The prevalence of smoking by lesbian, gay, bisexual and transgender (LGBT) Oregonians is 34 percent, while overall adult prevalence is 21 percent.<sup>5</sup>
- In 2002, 31 percent of Hispanics were uninsured, compared to 14 percent of the overall Oregon population.<sup>6</sup>

- For all cancers combined, both men and women in high-poverty areas have the lowest rates of cancer survival.
- Oregonians with disabilities are more likely to be diagnosed at later stages for screenable cancers (breast, cervical and colorectal).<sup>7</sup>

Data collection and analysis are central to reducing cancer disparities. In order to create supportive policies and allocate resources to eliminate disparities in the continuum of cancer care, Oregon needs to use a more routine and reliable method to collect and analyze data pertaining to racial and ethnic minorities.<sup>8</sup>

Current data issues include:

- Most national surveys such as the Behavioral Risk Factor Surveillance Survey (BRFSS) are conducted only in English and Spanish, and by land-line phones. This results in responses only from highly acculturated racial and ethnic minorities.

<sup>1</sup> Cancer in Oregon, 2002.

<sup>2</sup> Oregon Behavioral Risk Factor Surveillance System (BRFSS), 2000–2001.

<sup>3</sup> Office for Oregon Health Policy and Research (OOHPR), January 2005.

<sup>4</sup> Oregon Office of Rural Health, 1998.

<sup>5</sup> Oregon BRFSS, 2003.

<sup>6</sup> OOHPR, Spring 2003.

<sup>7</sup> Disability and Health Quarterly, March 2004.

<sup>8</sup> OOHPR, 2005, pg. 83.

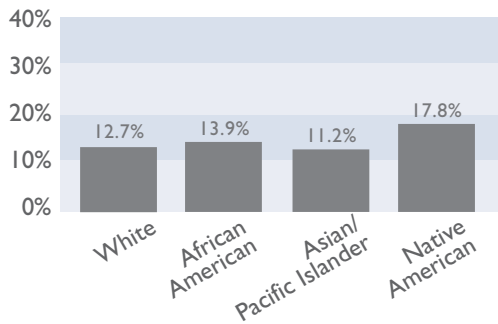
- No national cancer registries collect data based on sexual orientation or gender identity, even though there is a need for data on the incidence and prevalence of various forms of cancer among LGBT individuals.<sup>9</sup>
- Standardized data collection of race, ethnicity, socioeconomic status, primary language use and sexual orientation is needed to better inform public policy and the monitoring, evaluation and design of cancer care programs in Oregon.
- We need to enhance state cancer registries to collect data pertaining to the role of the environment in relation to cancer.
- Oregon is one of the few states that includes questions about sexual partners, sexual orientation and harassment based upon perceived sexual orientation in its Youth Risk Behavior Survey (YRBS) and Behavioral Risk Factor Surveillance System (BRFSS).<sup>10</sup>
- Many of Oregon's academic institutions, the Oregon Department of Human Services and health care systems are collaborating to identify and address issues of cancer disparities for the underserved.
- The Tobacco Prevention and Education Program has a special populations network to identify best practices for tobacco prevention and cessation.
- The Oregon Health Services Office of Multicultural Health provides community resources to improve the health status of underserved Oregonians through multicultural and culturally competent approaches that influence the way health services are designed and delivered.

### **CURRENT EFFORTS**

Oregon's current efforts include:

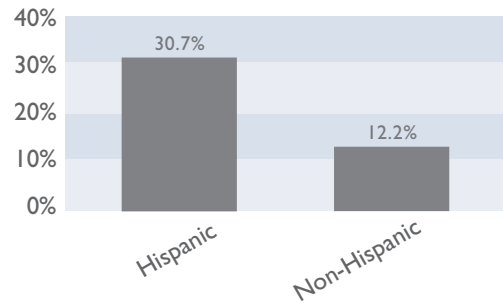
- Expanded access for Medicare and Medicaid (Oregon Health Plan) is offered through 23 Federally Qualified Health Centers in over 100 sites. Together, these sites comprise Oregon's health care safety net.

### Percentage of Uninsured Oregonians by Race–2002



Source: OOHPR, Spring 2003.

### Percentage of Uninsured Oregonians by Ethnicity–2002



Source: OOHPR, Spring 2003.

- Funding is available at federal, national and local levels to address cancer disparities. For example, the Susan G. Komen Breast Cancer Foundation and the Northwest Health Foundation offer grants to underserved communities.

Lack of insurance is one barrier to cancer education, prevention and treatment services. The above graphs show the percent of uninsured Oregonians by race and ethnicity.<sup>11</sup>

### REMAINING CHALLENGES

Among the remaining challenges in Oregon are the following:

- Lack of culturally and individually appropriate cancer resources for ethnic minorities and other underserved populations.
- Need for education for health professionals about cancer disparities and the resulting differences in health outcomes in underserved populations. For example, the lack of

screening recommendations specific to people with disabilities.

- We need more minority and rural health care providers, especially because they are more likely to serve in minority and medically underserved communities.
- The uninsured are:
  - Less likely to have a regular primary-care doctor.
  - Less likely to get routine health care.
  - More likely to be hospitalized for preventable conditions.
  - More apt to die from needless complications.<sup>12</sup>
- Oregonians reported that access for all, cost of health care and affordable health insurance are the top three health problems for the state to resolve.<sup>13</sup>
- There are many geographic barriers to accessing accredited cancer care facilities in rural Oregon.

<sup>9</sup> Healthy People 2010: Lesbian, Gay, Bisexual and Transgender Health, pg. 104.

<sup>10</sup> Bassett et al., Clinical Research and Regulatory Affairs, 2002, pg.195.

<sup>11</sup> OOHPR, Spring 2003.

<sup>12</sup> OOHPR, 2005, pg. 80.

<sup>13</sup> Oregon Health Values Survey, 2004.

# GOAL:

*Eliminate cancer disparities in Oregon through incremental reductions.*

## CANCER DISPARITIES

**OBJECTIVE 1:** Increase the proportion of Oregonians who have access to culturally and linguistically appropriate cancer information throughout the cancer continuum of care.

**Strategies:**

- Identify and deliver to all Oregonians consistent cancer education messages at appropriate literacy levels.
- Identify and utilize best-practice strategies for health communication and interventions to reach underserved Oregonians.
- Educate Oregonians about populations affected by cancer disparities and the impact that these disparities have on the system and communities at large.
- Establish collaborative relationships with key stakeholders to pool resources and enhance education efforts to eliminate cancer disparities. Such stakeholders include government agencies, academic institutions, businesses, health care agencies and community-based organizations serving underserved communities.
- Educate the public regarding the importance of participation in clinical trials, with special emphasis on addressing the concerns of underserved populations.

**OBJECTIVE 2:** Increase the proportion of cancer research conducted in Oregon to understand and eliminate determinants of cancer disparities.

**Strategies:**

- Develop and implement an assessment tool to identify primary access issues, rehabilitation and psychosocial needs of cancer survivors.



- Establish a statewide cancer disparities advisory committee to support community-based research on understanding the extent and impact of cancer disparities in diverse communities.
- Disseminate research findings and recommendations on cancer disparities from national, state and local organizations to all Oregonians in appropriate formats.
- Identify and analyze barriers to the low utilization of cancer services (for example, screening, hospice care and clinical trials) by underserved Oregonians.
- Explore and identify opportunities to conduct research and demonstration projects to reduce cancer disparities.

**OBJECTIVE 3:** Increase the data collection and analysis specific for underserved Oregonians.

**Strategies:**

- Educate health care professionals and administrations in clinic and hospital settings about the importance of capturing data related to diverse communities.
- Enhance data collection systems in clinic and hospital settings to include demographic indicators for cancer disparities (for example, country of origin, level of education, socioeconomic status, health insurance status, primary language, sexual orientation, gender identification and disability status).
- Establish a disparities subcommittee of the Cancer Surveillance Advisory Workgroup (CSAW) to address data collection and standardized classification and reporting mechanisms.
- As data collection improves, include race- and ethnicity-specific cancer data and analysis for the most common cancer sites (breast, colorectal, cervical, lung, prostate) in the Oregon State Cancer Registry (OSCaR) annual report.
- Ensure availability of datasets to the public via downloadable, de-identified datasets. (De-identified datasets do not include information that can identify a particular person.)

## CANCER DISPARITIES

**OBJECTIVE 4:** Increase the proportion of professional education activities aimed at reducing access barriers to cancer services throughout the cancer continuum of care.

**Strategies:**

- Educate health care professionals about barriers to cancer screening and treatment among underserved Oregonians.
- Provide Continuing Education credits in cultural competency for health care professionals who serve underserved Oregonians.
- Educate all health care professionals on evidence-based screening and treatment guidelines specific to all Oregon populations.
- Increase the availability of training opportunities to health care providers from diverse backgrounds and different racial and ethnic groups.
- Increase continuing education opportunities for rural providers through telemedicine and online classes.
- Include cultural competency training for health care professionals and allied health professionals, and for students through medical school curricula.

**OBJECTIVE 5:** Improve access to and utilization of cancer screening, prevention, treatment, end-of-life and survivor care services among underserved Oregonians.

**Strategies:**

- Partner with federal, state, local and tribal institutions to identify and eliminate barriers to accessing cancer care.
- Encourage health insurance plans to promote awareness of cancer prevention and screening using diverse languages and varied media formats.

- Develop and test hospice outreach to racial, ethnic, low-income, rural and other underserved Oregonians.
- Support the formation of a regional foundation to help pay premiums for uninsured, underinsured and uninsurable cancer patients.
- Increase resources for culturally sensitive social workers, medical translators and interpreters in clinic and hospital settings.
- Assess needs and establish opportunities for coordination of transportation services that minimize the barriers in accessing cancer care services throughout the cancer continuum of care.

**OBJECTIVE 6:** Enforce existing policy and legislation, and introduce new policies and legislation to ensure equitable cancer care for all Oregonians.

**Strategies:**

- Partner with and support state and local legislators and advocates to ensure increased access for all Oregonians to the cancer continuum of care.
- Increase accessibility in accord with Americans with Disabilities Act guidelines.
- Create and encourage use of a standardized, culturally and linguistically appropriate form for patient data collection in clinic and hospital settings.
- Increase access to public insurance programs like the Oregon Health Plan and Medicare.
- Advocate for enhanced health care benefits to include all Oregonians.
- Advocate for increased and sustained funding for OSCaR, specifically for better data collection on underserved populations.

# Public Policy and Legislation

*Public policy may be understood as the choices made by our government—choices that greatly affect Oregon society. Cancer-related public policy includes specific statutes and rules, as well as the allocation of resources that impact cancer prevention, diagnosis, treatment and health outcomes.*

### KEY ISSUES

As we each go through our day, we do so with expectations about the safety and security of many of our activities, particularly those related to health. Our feeling of security is due in large part to governmental public health policies.

For example, as Oregonians we assume that our children's schools are not laden with known cancer-causing agents such as radon or asbestos, and we assume that health care specialists such as oncologists are certified and trained. These protections and securities, along with many others, are largely the result of cancer-control public policy.

### What is public policy?

In short, public policy is what governments choose to do or not to do. Good public policy provides the greatest level of protection and service to the whole of society, within the context of society's overall needs.

Public policy is an integral tool in the fight against cancer. One example is Ballot Measure

44, which Oregon voters approved in 1996. This measure increased the state's tobacco tax and dedicated a portion of the revenue to a new tobacco prevention and education program. Since this program's inception, Oregon's per-capita cigarette consumption has declined 40 percent, and smoking among eighth graders has declined 51 percent.<sup>1</sup> Simply put, this public policy has helped to lower Oregonians' risk of cancer, especially lung cancer.

Guiding the Partnership's public policy decisions is the belief that public policy should:

- Be consistent with the Partnership's vision and mission.
- Address public issues or concerns important to cancer control and with consideration of the broader public and private interests.
- Relate to cancer control issues that fall within benchmarks and populations determined by the Coordinating Committee.
- Address cancer control in relation to the economic toll cancer takes on our state and society as a whole.



*“Early detection is so important for cancer survival, and as a new voter who just turned 18, I want to make sure that we protect cancer research and detection for a long time.”*

—AMANDA KEEFER, BEAVERTON

## CURRENT EFFORTS

While much has been accomplished in cancer-related public policy, much remains to be done.

Political responsibility for public health belongs to the state of Oregon, including responsibility for the fight against cancer. The Partnership, through its Public Policy Committee, will advocate for policies promoting the most effective use of cancer resources for the benefit of all Oregonians.

The Public Policy Committee will serve as a resource and a bridge between all stakeholders, including government agencies, providers and provider organizations, as well as Oregonians with cancer, their relatives and friends.

Most importantly, the Partnership and its Public Policy Committee will be a resource to government decision-makers, sharing information with them about effective policy strategies for cancer control, along with providing personal stories of Oregonians who have experienced cancer.

## REMAINING CHALLENGES

To frame cancer control policy issues, we must define the scope and seriousness of the problem and define and prioritize solutions given current political and economical realities.

We need political and social action at the local and national level to enact policies and legislation that will:

- End disparities in cancer.
- Protect Oregonians from environmental cancer risks.
- Ensure equal access to quality prevention, early detection, treatment and survivor services.
- Help children avoid developing unhealthy behaviors by providing healthy food choices and physical education in our schools.
- Fund evidence-based and population-based programs to reduce cancer risk factors and promote early detection.

<sup>1</sup> Oregon Tobacco Facts, September 2004.

# GOAL:

*Achieve the public policy objectives of Oregon's Comprehensive Cancer Plan.*

## PUBLIC POLICY AND LEGISLATION

**OBJECTIVE 1:** Develop and implement a three-tiered foundation for cancer control advocacy.

**Strategies:**

- Develop a statewide cancer control Public Policy Committee of stakeholders to focus political action on the Partnership's public policy objectives.
- Develop a cancer control caucus of legislators to support and move statewide legislation through the political process.
- Develop a grass-roots network that will advocate for public policy on cancer control.

**OBJECTIVE 2:** Develop and implement public policy strategies for cancer prevention.

**Strategies:**

- Fully fund the Tobacco Prevention and Education Program at the voter-mandated level.
- Raise Oregon's Cigarette Tax.
- Remove all exceptions in the Oregon Indoor Clean Air Act.
- Use 10 percent of Master Settlement Agreement dollars to fund the Tobacco Prevention and Education Program.
- Promote policies that create environments conducive to healthy eating in Oregon public schools.
- Require physical education and activity at all grade levels in Oregon public schools.
- Improve land-use policy to ensure more active-living policies in our communities.
- Enact school policies to increase the use of sun-safe behaviors.

**OBJECTIVE 3:** Develop and implement public policy strategies for early cancer detection.

**Strategies:**

- Continue insurance coverage for mammography screenings.
- Continue insurance coverage for Pap test screening.
- Implement a colorectal cancer screening insurance mandate.

**OBJECTIVE 4:** Develop and implement public policy strategies for cancer treatment and end-of-life care.

**Strategies:**

- Advocate for return of the Oregon Health Plan to its maximum coverage for Oregon's medically underserved populations.
- Advocate for increased federal funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP).
- Advocate for expanded funding and eligibility for the Breast and Cervical Cancer Medical (BCCM) Program.

**OBJECTIVE 5:** Develop and implement public policy strategies for cancer control data collection.

**Strategies:**

- Secure stable funding for the Oregon Healthy Teens Survey.
- Advocate for funding for the Behavioral Risk Factors Surveillance Survey (BRFSS) and the Medicaid BRFSS.
- Maintain funding for the Oregon State Cancer Registry.
- Secure supplemental funds to enhance cancer registry operations.
- Explore options for a standardized data collection form.
- Advocate for funding to address data gaps.

# Data Management and Surveillance

*Cancer is a complex disease that affects thousands of Oregonians in unique ways. Tracking and understanding the disease requires extensive collaboration in data management and surveillance.*

## KEY ISSUES

For public health purposes, surveillance is “the ongoing, systematic collection, analysis, interpretation and dissemination of data.”<sup>1</sup> Surveillance involves collection of cancer-related data, which are used to reduce morbidity and mortality rates, and to improve the overall health of Oregonians.

A surveillance system is a means to an end. It must be the answer to some question, provide the means for making a decision or be the means for using another answer effectively. Otherwise, it is a waste of time and money.

A distinction exists between a one-time or intermittent determination of a health-related event and an ongoing system of operation. Only the latter is considered surveillance.

The cancer data derived from surveillance systems are essential to cancer control planning, implementation and evaluation.

Data gathered from surveillance are used to:

- Describe the burden of cancer.
- Establish priorities.
- Guide the allocation of resources.
- Target research and public health efforts.
- Recognize cancer disparities.
- Evaluate the effectiveness of interventions.

## CURRENT EFFORTS

Oregon’s data on cancer occurrence and risk factors come from a variety of sources. Cancer surveillance systems that collect data in the state can be divided into three broad segments:

- Population-based data systems.
- Representative sample data systems.
- Subpopulation data systems.

In addition, although not considered surveillance, special studies and other intermittent methods of data collection also provide useful information.





*“As a person who was treated for cancer in 1995, I provided testimony in support of the legislation to create the Oregon State Cancer Registry. This was a critical step in moving Oregon’s cancer research agenda forward.”*

—WENDY RANKIN, PORTLAND

A number of data resources already exist in Oregon. These resources are summarized at the end of this section, in Table 1, Oregon Cancer-Related Data Resources, which includes a description of potential uses and limitations of the data.

#### Uses of cancer surveillance data:

- **Compare cancer rates over time or among groups of people.** Oregon consistently ranks among the top few states in the nation for breast cancer incidence.
- **Identify groups at risk.** Cervical cancer is higher among Hispanic women.
- **Set priorities and direct resources.** Health problems due to tobacco use in pregnant women led to the development of the Smoke-Free Mothers and Babies Program.
- **Generate hypotheses to guide risk factor research.** The high incidence of lung cancer among shipyard workers helped generate recognition of asbestos as a cause of occupational cancer.
- **Evaluate public health interventions and programs.** The number of early-stage cancers increased after implementation of the Oregon Breast and Cervical Cancer Medical Program.
- **Track changes in medical practices.** The use of endoscopy as a colorectal cancer screening tool has increased.

#### Population-Based Data Systems

##### The Oregon State Cancer Registry (OSCaR)

is a population-based reporting system that collects and analyzes data about all reportable cancers diagnosed in Oregon. Established by the 1995 Oregon Legislature, OSCaR began full operation in January 1996, and is located in the Oregon Department of Human Services, Health Promotion and Chronic Disease Prevention.

Information reported to OSCaR comes from sources such as hospital cancer registries, hospital medical records departments, ambulatory surgical centers, physician offices, Oregon Vital Statistics, pathology laboratories and other state cancer registries.

Data collected by OSCaR are used to characterize cancer occurrence in Oregon and can provide useful information to cancer prevention programs, clinicians, cancer researchers, policymakers and the general public. Data include the type and characteristics of the cancer, patient demographics and details of the diagnosis.

<sup>1</sup> Morbidity and Mortality Weekly Report (MMWR), v50/No.RR-13, July 27, 2001.

**Oregon Vital Statistics**—part of the Oregon Department of Human Services, Center for Health Statistics and Vital Records—collects information on all deaths that occur in Oregon, including cancer deaths. Mortality data are available in electronic form from 1989 forward.

Either a funeral director or the first person to assume responsibility for a body generally files a death certificate. A physician completes the medical portion of the death certificate, and hospital medical records personnel help to ensure that all certificates are complete and accurate.

The Center for Health Statistics produces annual vital statistics reports that include cancer deaths by sex, race and age, as well as unadjusted cancer mortality rates, tobacco-related deaths and other cancer-specific mortality measures.

### **Representative Sample Data Systems** **The Behavioral Risk Factor Surveillance System (BRFSS)**

is a collaborative project between the Centers for Disease Control and Prevention (CDC) and individual states in the U.S. that collect data. The program was initiated in 1984, and Oregon began participating in 1988.

BRFSS is a cross-sectional telephone survey conducted annually by the Oregon Department of Human Services, Center for Health Statistics and Vital Records. The survey is administered to adults age 18 and older living in households.

The primary objective of BRFSS is to collect standardized data on risk factors and preventive health practices that may be linked to chronic diseases like cancer, as well as to injuries or preventable infectious diseases. The collected cancer-related topics include tobacco use, history of mammograms and Pap tests, and frequency and duration of physical activity.

**The Oregon Healthy Teens Survey (OHT)** is administered by the Oregon Department of Human Services, Center for Health Statistics and Vital Records, in an effort to monitor the health and well-being of Oregon's adolescents. The first administration of the OHT survey occurred during the 2000–2001 school year, and the survey has been conducted annually ever since.

The OHT survey collects information among eighth graders and 11th graders drawn from a random, statewide sample of schools. Participation is voluntary. Cancer-related topics addressed in the OHT survey include tobacco access and use, diet and exercise, health conditions and access to care.

The OHT survey incorporates two previous youth surveys: the Youth Risk Behavior Survey (YRBS) and the Student Drug Use survey. YRBS data are available for odd-numbered years from 1991 through 1999, and Student Drug Use survey data are available for even-numbered years from 1996 through 2000.

### **Subpopulation Data Systems**

**The Oregon Medical Assistance Program (OMAP)** Database collects Medicaid encounter data and health care utilization information for Medicaid clients. Medicaid, a state and federal health insurance program, provides access to health services for persons below a certain income level. Data are available from 1997 forward.

OMAP receives claims associated with delivered health care services, including information on diagnosis and procedures. Data collected by OMAP may be useful for monitoring cancer diagnoses and treatments among the Medicaid population.

### **Special Studies or Intermittent Data Collection Using BRFSS**

**Northwest Tribal BRFSS**, conducted by the Northwest Portland Area Indian Health Board, provides behavioral risk factor data for American Indians in seven participating tribes in Idaho, Oregon and Washington.

Unlike the national BRFSS conducted by the CDC and participating states, which is administered by telephone, the Tribal BRFSS was administered through face-to-face interviews. The Tribal BRFSS was conducted over several years and used a slightly modified 2001 national BRFSS questionnaire.

The tribal survey's primary purpose was to provide information on risk factors and preventive health practices that may be linked to chronic diseases, injuries and preventable infectious diseases. Cancer-related topics included tobacco use, history of cancer screening, and frequency and duration of physical activity.

**Oregon BRFSS Racial/Ethnic Oversample**, conducted periodically through the BRFSS, collects health information among various racial and ethnic groups. This provides information about the prevalence of chronic diseases and related risk factors among these populations—information that cannot be obtained through the interviews included in the standard BRFSS. The oversample was conducted in 2000–2001, and a similar oversample will be conducted in 2005.

**The Oregon Medicaid Health Risk and Health Status Survey** is a random telephone survey of Oregon Medicaid Recipients conducted by OMAP. This survey, patterned after the BRFSS, collects information about cancer screening behaviors as well as cancer-related risk factors such as tobacco use, nutrition and physical activity. One such survey, completed in October 2004, included interviews with 2,700 adult respondents.

## REMAINING CHALLENGES

Currently, cancer surveillance in Oregon and nationally involves a variety of disparate systems that separately collect and store data. Many of these systems work independently of one another, have different objectives and use different methods of data collection and analysis. This results in deficiencies, or gaps, in Oregon's current cancer surveillance system.

This comprehensive cancer plan addresses some of these gaps, such as the Public Policy Committee's objective to develop and implement public policy strategies for cancer control data collection. Another data gap involves our need to identify measurable indicators for all cancer plan objectives.

Still other gaps are systemic problems without easy solutions, and they continue to hamper cancer control activities. For instance, inconsistent collection of race and ethnicity data hinders cancer control activities in diverse groups.

We must continue to evaluate the status of Oregon's cancer surveillance system, identifying gaps in the system and prioritizing efforts to address those gaps.

# GOAL:

*Fully implement cancer surveillance—the collection, analysis, dissemination and utilization of cancer information—for Oregon’s Comprehensive Cancer Plan.*

## DATA MANAGEMENT AND SURVEILLANCE

**OBJECTIVE 1:** Establish a statewide Cancer Surveillance Advisory Workgroup (CSAW) to promote quality assurance in cancer surveillance efforts and utilization of cancer data.

**Strategies:**

- Identify and recruit a diverse group of individuals and organizations that can contribute to the goal of fully implemented cancer surveillance for Oregon’s Comprehensive Cancer Plan.
- Establish a mission statement, goals and objectives for the CSAW that are consistent with needs identified in Oregon’s Comprehensive Cancer Plan.

**OBJECTIVE 2:** The CSAW will develop a work plan to address data management and surveillance issues including but not limited to: quality assurance; standardizing methods of collecting, analyzing and reporting cancer data; evaluating existing data systems; and evaluating training opportunities.

**Strategies:**

- Oversee the formation of one or more workgroups that will coordinate efforts to improve the quality and completeness of cancer data for Oregon’s diverse communities.
- Work with other affiliates of the Partnership to identify priorities for Comprehensive Cancer Plan implementation.

**OBJECTIVE 3:** Identify at least one measurable indicator for all of Oregon's Comprehensive Cancer Plan objectives.

**Strategies:**

- Complete an evaluation of available sources of cancer-related data in Oregon.
- Categorize indicators based on the availability of data sources: data are available and accessible; data are available but additional steps are required; or data are not currently available.

**OBJECTIVE 4:** The CSAW will develop and enact a plan to track all indicators identified for Oregon's Comprehensive Cancer Plan.

**Strategies:**

- Identify and document the data source and data collection mechanism for all Comprehensive Cancer Plan indicators for which such mechanisms currently exist.
- Identify gaps in availability of data sources and address these gaps through the development of new cancer surveillance systems; modification of existing systems; or planning and implementation of relevant special studies.

Table 1

## Oregon Cancer-Related Data Resources

	Population-Based Data Systems:		Representative Sample Data Systems:
Database/System Contact Phone No. Web site for Reports and/or Data	<b>Oregon State Cancer Registry (OSCaR)</b> DHS/Oregon Health Services, Health Promotion and Chronic Disease Prevention Program Phone: 503-731-4858 Web site: <a href="http://www.healthoregon.org/oscar">www.healthoregon.org/oscar</a>	<b>DHS Vital Statistics</b> Data DHS/Oregon Health Services, Center for Health Statistics Phone: 503-731-4354 Web site: <a href="http://www.dhs.state.or.us/publichealth/chs/index.cf">www.dhs.state.or.us/ publichealth/chs/index.cf</a>	<b>Behavioral Risk Factor Surveillance System (BRFSS)</b> DHS/Oregon Health Services/ Center for Health Statistics Phone: 503-731-4478 Web site: <a href="http://www.ohd.hr.state.or.us/chs/brfss.cfm">www.ohd.hr.state.or.us/chs/ brfss.cfm</a>
Main Purpose	To track cancer incidence and mortality, and reduce the burden of cancer and benign tumors among Oregonians.	To administer birth and death certification and summarize mortality statistics for administrative and public health use.	To collect population-based behavioral health data about chronic diseases, injuries and lifestyle issues that affect morbidity and mortality.
Demographic and Geographic Coverage	Among Oregon residents, all reportable cancers diagnosed or treated in Oregon.	All births and deaths among Oregon residents.	7,000 telephone interviews of Oregon adults age 18 and over, in English/Spanish.
Years of Available Data	1996–Current	1993–Current	1988–Current
Data Availability	Aggregate data and statistics available; case-based data released only with patient consent and DHS Institutional Review Board approval.	Aggregate data available. County-level data available for most jurisdictions.	Results by question are on DHS Web site, CDC Web site. For 2000–2001 and 2004–2005, county-level and more complete regional data are available.
Examples of Data Collected	Cancer site, stage, age and county at diagnosis, sex, histology, initial treatment.	Age, race, ethnicity, sex, marital status, residence, occupation, cause and manner of death, link to tobacco if any.	Reported rates of colorectal, cervical and breast cancer screening among Oregon adults. BMI from reported height and weight.
Comparability with U.S. and Other State Reports on Cancer Outcomes	Data collected and analyzed based on national registry standards.	Comparable to National Vital Statistics System of the CDC/ Centers for Health Statistics and to state vital statistics systems.	BRFSS surveys nationally and in other states.
Notes/Limitations	No scheduled follow-up (annual follow-up plan under consideration). Monthly death clearance being conducted.	Causes of death reported by providers are not verified.	Data based on self report. Only given in English and Spanish. Increased cell phone use and call monitoring may affect completeness.

\* International Classification of Diseases, 9th Revision, Clinical Modification.

\*\* Current Procedural Terminology.



**Special Studies or Intermittent Data  
Collection (using BRFSS):**

**Oregon Healthy Teens  
Survey**

DHS/Oregon Health Services/  
Center for Health Statistics  
Phone: 503-731-4478  
Web site:  
[www.dhs.state.or.us/  
publichealth/chs/yrbsdata.cfm](http://www.dhs.state.or.us/publichealth/chs/yrbsdata.cfm)

To collect population-based  
behavioral health data among  
adolescent Oregonians.

Paper survey of 6,000 8th and  
4,500 11th graders from a  
random sample of schools  
throughout Oregon.

1991–Current

Results by question are on  
DHS Web site.

Smoking prevalence, level of  
physical activity, alcohol use.

Partially overlaps with the  
national Youth Risk Behavioral  
Survey and Student Drug Use  
Survey.

Data based on self-report.  
Not designed expressly to  
track cancer risk factors.

**Oregon BRFSS Racial/  
Ethnic Oversample.**

DHS/Oregon Health Services/  
Center for Health Statistics  
Phone: 503-731-4478

To collect population-based  
data about illnesses and their  
risk factors among Oregonians  
of African American, Asian/  
Pacific Islander, Latino and  
Native American heritage.

Oversampling conducted by  
telephone in areas of the state  
with higher proportions of  
persons from the group being  
surveyed.

2000–2001, 2004–2005 (Data  
collection will be completed at  
end of 2005.)

Databases reside at DHS/  
Center for Health Statistics.

Smoking prevalence; rates of  
breast, cervical cancer  
screening; levels of physical  
activity, body mass index.

BRFSS surveys nationally and in  
other states.

Self-reported data; sampling  
strategy may affect  
generalizability of results.

**Oregon Medicaid Health  
Risk and Health Status  
Survey**

DHS/OMAP  
Phone: 503-945-6929

To collect population-based  
data about illnesses and their  
risk factors among Oregon  
Medicaid recipients.

Oregon Health Plan/Medicaid  
recipients.

1999, 2004

A report of results will be  
available from the Office of  
Medical Assistance Programs in  
mid-2005.

Smoking prevalence, rates of  
cancer screening.  
BRFSS surveys nationally and in  
other states.

Questions were predominantly  
from Oregon and National  
BRFSS surveys.

Self-reported data. Sampling  
strategies in 1999, 2004 were  
different; comparisons should  
be made with caution.

**Northwest Tribal  
Behavioral Risk Factor  
Surveillance System  
Project**

NW Portland Area Indian  
Health Board  
Phone: 503-228-4185  
Web site:  
[www.npaihb.org/epi/brfss/  
webpage\\_brfss.htm](http://www.npaihb.org/epi/brfss/webpage_brfss.htm)

To collect population-based  
behavioral health data among  
American Indians/Alaska  
Natives in the Northwest.

Random sample of 1,107  
members from seven  
Northwest tribes, two of them  
in Oregon.

2001

Aggregate data available for 6  
of 7 tribes at NPAIHB Web  
site.

Smoking prevalence, rates of  
cancer screening; prevalence  
for lung, breast, cervical,  
prostate and colorectal cancer.

Similar to National and  
Oregon BRFSS surveys.

Self-reported data. Includes  
tribes from ID, WA; Oregon-  
based tribes that are included  
are limited; may not be  
representative.

Table 1 *continued***Oregon Cancer-Related Data Resources**

	Subpopulation Data Systems:	Other Data Collection:	
Database/System Contact Phone No. Web site for Reports and/or Data	<b>Database for Oregon Medical Assistance Program (OMAP),</b> DHS/ OMAP Phone: 503-945-6929	<b>Oregon Hospital Discharge Database</b> Oregon Association of Hospitals and Health Systems (OAHHS). Phone: 503-636-2204	<b>Oregon Hospice Association Database,</b> Oregon Hospice Association Phone: 503-228-2104 Web site: <a href="http://oregonhospice.org">http://oregonhospice.org</a>
Main Purpose	To collect medical, administrative and billing data to monitor Medicaid financial transactions.	To provide data about hospital discharges, related expenses and diagnoses.	To track hospice patient-specific data regarding cause of death, lengths of stay, services utilized, place of death, age, race, gender, caregiver, etc.
Demographic and Geographic Coverage	Oregon Health Plan/Medicaid recipients.	Includes reports from all but 2 of Oregon's 57 acute care hospitals. Reporting is not mandated.	State of Oregon, although not all hospices provide patient-specific data.
Years of Available Data	1980s–Current	1995–Current	1988–Current
Data Availability	Aggregate data available. County-level data available for most jurisdictions.	Access to unidentified data can be arranged through OAHHS.	Data runs available through third-party agency.
Examples of Data Collected	Demographics, disease prevalence (ICD-9-CM*); CPT** codes for medical management.	Dates of hospitalization. Race/ethnicity not included; ICD-9-CM* and CPT** codes.	To track hospice patient-specific data regarding cause of death, lengths of stay, services utilized, place of death, age, race, gender, caregiver, etc.
Comparability with U.S. and Other State Reports on Cancer Outcomes	Comparable to Medicaid administrative databases nationally and in other states.	Similar to the National Hospital discharge survey and to hospital discharge databases of other states.	The National Hospice and Palliative Care Organization (NHPCO) collects hospice data that is not patient-specific.
Notes/Limitations	Has not been used much for this purpose in past. Complex data structure.	Does not include Veterans hospitals, participation is voluntary.	Special data runs cost \$50 per hour.

\* International Classification of Diseases, 9th Revision, Clinical Modification.

\*\* Current Procedural Terminology.

# Appendices



**References**

**Glossary of Cancer-Related Terms**

**Acronyms**

**National Comprehensive Cancer Control Partners and Resources**

**Partnership Vision, Mission, Roles and Values**

**Partnership Membership Form**

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# Glossary of Cancer-Related Terms

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## **Accredited cancer program**

A cancer program certified, according to established standards, by the Commission on Cancer ([www.facs.org](http://www.facs.org)).

## **Age-adjusted rate**

Because cancer rates tend to vary with age, and populations vary with respect to their age distributions, incidence and mortality rates are age-adjusted to allow for comparison of rates between different populations. All age-adjusted rates included in this plan are adjusted to the 2000 U.S. standard population, are expressed per 100,000 individuals per year and include invasive cancers only.

## **Behavioral Risk Factor Surveillance System (BRFSS)**

A telephone survey conducted each year that asks people about health behaviors. Some questions are part of the national BRFSS while others are unique to Oregon. BRFSS is conducted by the Office of Vital Statistics, Department of Human Services, Health Services.

## **Body Mass Index (BMI)**

The calculation of weight (kilograms) divided by height squared (meters). This index is used to categorize adults as underweight, normal, overweight or obese.

## **Cancer**

A group of diseases characterized by uncontrolled growth and spread of abnormal cells.

## **Cancer survivor**

According to the National Cancer Institute, a person living with, through or beyond cancer from the moment of diagnosis, as well as family members, friends and caregivers.

## **Carcinogen**

A substance scientifically proven to cause cancer.

## **Clinical trials**

Research studies that test new diagnostic and treatment regimens and compare them to current, standard treatments. Before a new treatment is used on humans, it is studied in a scientific lab. If lab studies suggest the treatment is effective, it is tested for patients.

## **Colonoscopy**

An examination of the entire colon with a flexible tube that allows a doctor to see and closely inspect the inside of the entire colon for signs of cancer or polyps.

## **Complementary medicine**

Practices often used to enhance or complement standard treatment that are not recognized as standard or conventional medical approaches. May include dietary supplements, mega-dose vitamins, herbal preparations, special teas, acupuncture, massage therapy, spiritual health practices and medications.

## **Comprehensive cancer control**

Defined by the Centers for Disease Control and Prevention as: “An integrated and coordinated approach to reducing cancer incidence, morbidity and mortality through prevention, early detection, treatment, rehabilitation and palliation.”

### **Cultural competence**

A set of behaviors, attitudes and policies that come together in a system, agency or among professionals that enables effective work in cross-cultural situations. “Culture” refers to patterns of human behavior. “Competence” implies having the capacity to function effectively as an individual and an organization within the context of cultural beliefs, behaviors and needs presented by consumers and their communities.

### **Current trend**

A trend or pattern based on the most recent five years of cancer data. Trends can be determined for measures such as cancer incidence, stage of diagnosis and mortality.

### **Early-stage diagnosis**

Defined as in situ and local cancers.

### **Environmental risk factors**

Broadly defined, environmental factors include smoking, diet and infectious disease, as well as chemicals and radiation that are estimated to cause three-quarters of all cancer deaths in the United States. In this plan, environmental risk factors refer to cancer-causing agents in the environment, such as chemicals and toxins.

### **Ethnicity**

In general, the Census Bureau defines ethnicity as the heritage, nationality group, lineage or country of birth of a person, or the person’s parents or ancestors before their arrival in the United States. People who identify their origin as Spanish, Hispanic or Latino may be of any race. In this plan, cancer incidence and mortality rates that are based on ethnicity relate to Hispanic origin only.

### **Fecal Occult Blood Test (FOBT)**

A chemical test to detect for blood in the stool that is used as a screening test for colorectal cancer.

### **Frontier county**

Rural counties with a population of fewer than 6 people per square mile.

### **Healthy People 2010**

Healthy People 2010 is the prevention agenda for the United States. It is a statement of national health objectives designed to identify the most significant preventable threats to health. It establishes national goals to reduce these threats, such as lowering the death rate from colorectal, breast, lung, cervical and prostate cancers. ([www.health.gov/healthypeople](http://www.health.gov/healthypeople)).

### **High risk**

An individual may be considered to be at increased or high risk for a particular cancer due to specific factors such as family history of cancer among first-degree relatives (mother, father, sister or brother), personal history of cancer, race, age or exposure to cancer-causing agents.

### **Hospice care**

This type of care is designed to help people with cancer as well as their families during the final stages of illness. Services concentrate primarily on maintaining comfort. Care may be provided in a free-standing hospice, a hospice connected to a hospital or in the patient’s home.

### **Incidence**

The number of new cases of a given type of cancer diagnosed during a specified time period. Cancer incidence is not the same as the number of Oregonians diagnosed with cancer because one person could be diagnosed with more than one cancer.



### **Incidence rate**

The number of new cases per 100,000 population during a particular period of time.

### **In situ cancer**

An in situ cancer is a tumor that does not invade or penetrate surrounding tissue. With the exception of in situ bladder cancer, in situ cancers are not included in the calculation of incidence rates and thus are not presented in incidence tables. However, in situ cancers are classified as early stage and are included in the sections presenting stage at diagnosis.

### **Invasive cancer**

This involves a malignant tumor that has penetrated surrounding tissue. Invasive cancers are diagnosed in the local, regional or metastatic stages. There are no in situ diagnoses, with the exception of urinary bladder cancers.

### **Late-stage diagnosis**

A cancer diagnosed at a regional or distant stage. The cancer has spread beyond the original site.

### **Lifetime risk**

The probability that individuals will develop or die from cancer over the course of their lifetimes.

### **Localized**

A cancer of localized stage cancer involves a tumor that is invasive but remains restricted to the site of origin. Localized cancers are classified as early-stage cancers.

### **Malignant**

A tumor made up of cancer cells of a type that can spread to other parts of the body.

### **Mammography**

Mammographies involve use of X-rays to create a picture of the breast (mammogram) that can show signs of breast cancer before it can be felt. A mammography is a special X-ray examination of the breast and is the most effective method available for detecting breast cancer at an early stage, when successful treatment is more likely ([www.fda.gov/cdrh/mammography/certified.html](http://www.fda.gov/cdrh/mammography/certified.html)).

### **Metastatic/distant**

This is the most advanced stage of disease, in which cells from the original tumor travel to other parts of the body and continue to grow. These cancers are classified as late-stage cancers.

### **Moderate exercise**

Defined in the Behavioral Risk Factor Surveillance System (BRFSS) as “brisk walking, bicycling, vacuuming, gardening or anything else that causes small increases in breathing or heart rate.”

### **Mortality rate**

The number of deaths per 100,000 population during a particular period of time. Mortality rates in this plan refer to one-year time periods.

### **Obesity**

Body Mass Index (BMI) calculated to be 30.0 or greater.

### **Oncologist**

A doctor who specializes in the diagnosis, treatment and rehabilitation of individuals diagnosed with cancer.

### **Oncology**

A specialty of medicine concerned with the diagnosis and treatment of cancer.

### **Oregon Health Plan**

Oregon's expanded medicaid program, serving individuals with low income since 1994.

### **Oregon State Cancer Registry (OSCaR)**

A group established by the Oregon Legislature in 1995 to conduct statewide cancer surveillance and guide cancer control planning.

### **Overweight**

Body Mass Index (BMI) calculated to be between 25.0 and 29.9.

### **Pain management services**

These services can be provided by multi-disciplinary pain management teams, which can include oncologists, anesthesiologists, neurosurgeons, nurses, pharmacists, psychologists and social workers who work together to help patients receive pain relief.

### **Palliative care**

The active, total care of patients whose disease is not responsive to curative treatment. Controlling pain and other symptoms, as well as helping with psychological, social and spiritual problems, is paramount. The goal of palliative care is to achieve the best quality of life for patients and their families.

### **Papanicolaou (Pap) test**

The collection of cells from the cervix (the lower, narrow end of the uterus that forms a canal between the uterus and vagina) and their examination under a microscope. The Pap test can find abnormal "pre-cancerous" cells.

### **Prevention programs**

Educational programs aimed at preventing the onset of cancer through behavioral and lifestyle changes.

### **Prostate-specific antigen (PSA) test**

A blood test used to detect a substance made by the prostate.

### **Quality of life**

Personal satisfaction (or dissatisfaction) with the conditions under which a person lives.

### **Race**

The Census Bureau complies with the Office of Management and Budget's (OMB) standards for maintaining, collecting and presenting data on race. As of 1997, the minimum categories for race are: American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; and White.

### **Regional stage**

An invasive, malignant tumor that has spread to adjacent organs or tissues. Regional lymph nodes may also be involved. Regional cancers are classified as late-stage cancers.

### **Rehabilitation services**

Comprehensive rehabilitation services can help with psychological adjustment, improving physical functioning, and providing help with resuming work and recreational activities. The multidisciplinary team can include physicians, physical therapists, occupational therapists, enterostomal therapists and others.

### **Rural county**

A county without a major city (50,000 people or more), not in an urbanized area with a population of at least 100,000 and with a population density greater than 6 persons per square mile.

### **Screening (cancer)**

Examinations for individuals of average cancer risk, without signs or symptoms of cancer. The purpose of screening is to find a cancer at the earliest possible stage. Examples of screening include mammograms, Pap tests and endoscopy services.

### **SEER (Surveillance, Epidemiology and End Results)**

A program of the National Cancer Institute, SEER is an authoritative source of information on cancer incidence and survival in the United States.

### **Sigmoidoscopy**

An exam of the rectum and lower part of the colon with a thin, flexible, lighted scope to find polyps, abnormal areas and tumors.

### **Stage at diagnosis**

The extent to which a cancer has spread from the organ of origin at the time of diagnosis. Stages include in situ, localized, regional and distant.

### **Support services**

Services provided to aid and assist the cancer patient and family with the diagnosis, treatment and survival of cancer. Services may be focused on emotional, behavioral, physical and financial needs.

### **Surveillance**

Public health surveillance is the ongoing, systematic collection, analysis, interpretation and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health.

### **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. In this plan, this term generally refers to five-year survival periods.

### **Urban county**

A county with at least one major city (50,000 people or more) or an urbanized area with a population of at least 100,000. Counties that experience a high degree of social and economic “attachment” to a metropolitan area are also considered part of that metropolitan area.

### **U.S. Preventive Services Task Force (USPSTF)**

An independent panel of experts in primary care and prevention that systematically reviews evidence of effectiveness and develops recommendations for clinical preventive services. USPSTF provides access to scientific evidence, recommendations on clinical preventive services and information on how to implement recommended preventive services in clinical practice ([www.preventiveservices.ahrq.gov](http://www.preventiveservices.ahrq.gov)).

### **Vigorous activity**

Defined by the American Cancer Society as “running, aerobics, heavy yard work, or anything else that causes a large increase in breathing or heart rate.”

Sources: Cancer in Oregon, 2002, and Glossary of Terms, American Cancer Society.

# Acronyms

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**ACOS** American College of Surgeons

**ACS** American Cancer Society

**AICR** American Institute for Cancer Research

**BCCM** Breast and Cervical Cancer Medical (BCCM) Program

**BCCPTA** Breast and Cervical Cancer Prevention and Treatment Act of 2000

**BMI** Body Mass Index

**BRFSS** Behavioral Risk Factor Surveillance System

**BSE** Breast Self-Exam

**CBE** Clinical Breast Exam

**CDC** Centers for Disease Control and Prevention

**CIS** Cancer Information Service

**CMS** Center for Medicare and Medicaid Services

**COC** Commission on Cancer

**CSAW** Cancer Surveillance Advisory Workgroup

**DHS** Oregon Department of Human Services

**DRE** Digital Rectal Exam

**EPHT** Environmental Public Health Tracking

**HEDIS** Health Employer Data and Information Set

**HP** Healthy People

**HPV** Human Papilloma Virus

**ICC** Intercultural Cancer Council

**LAF** Lance Armstrong Foundation

**NBCCEDP** National Breast and Cervical Cancer Early Detection Program

**NCCAM** National Center for Complementary and Alternative Medicine

**NCCCP** National Comprehensive Cancer Control Program

**NCCN** National Comprehensive Cancer Network

**NCI** National Cancer Institute

**NHPCO** National Hospice and Palliative Care Organization

**NPAlHB** Northwest Portland Area Indian Health Board

**NTCCP** Northwest Tribal Cancer Control Project

**OHA** Oregon Hospice Association

**OHP** Oregon Health Plan (Medicaid)

**OHSU** Oregon Health & Sciences University

**OHT** Oregon Healthy Teen Survey

**OMAP** Office of Medical Assistance Programs

**OOHPR** Office for Oregon Health Policy and Research

**OPCC** Oregon Partnership for Cancer Control

**OSCaR** Oregon State Cancer Registry

**PSA** Prostate-Specific Antigen

**SPF** Sun Protective Factor

**TPEP** Tobacco Prevention & Education Program

**USPSTF** U.S. Preventive Services Task Force

**UV** Ultraviolet

**WHO** World Health Organization

# National Comprehensive Cancer Control Partners and Resources

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## **NATIONAL COMPREHENSIVE CANCER CONTROL PARTNERS**

These national organizations are working together to promote, coordinate and leverage comprehensive cancer control efforts and resources at the state and local levels.

American Cancer Society:  
[www.cancer.org](http://www.cancer.org)

American College of Surgeons (ACoS), Commission on Cancer: [www.facs.org](http://www.facs.org)

Association of State and Territorial Health Officials (ASTHO): [www.astho.org](http://www.astho.org)

C-Change (formerly the National Dialogue on Cancer): [www.ndoc.org](http://www.ndoc.org)

Chronic Disease Directors (CDD):  
<http://chronicdisease.org>

Health Resources and Services Administration (HRSA): [www.hrsa.gov](http://www.hrsa.gov)

Intercultural Cancer Council:  
<http://iccnetwork.org>

Lance Armstrong Foundation:  
[www.laf.org](http://www.laf.org)

National Cancer Institute:  
[www.cancer.gov](http://www.cancer.gov)

National Comprehensive Cancer Control Program (NCCCP), Centers for Disease Control and Prevention (CDC):  
[www.cdc.gov/cancer/ncccp](http://www.cdc.gov/cancer/ncccp)

National Conference of State Legislatures (NCSL): [www.ncsl.org](http://www.ncsl.org)

National Governors Association (NGA):  
[www.nga.org](http://www.nga.org)

North American Association of Central Cancer Registries (NAACCR): [www.naaccr.org](http://www.naaccr.org)

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## **NATIONAL CANCER RESOURCES**

This list is not intended to be a complete listing of cancer resources. Rather, it is a listing of organizations that were referenced during the development of this cancer plan. Topics included relate to cancer prevention; screening and early detection; cancer treatment; and patient services.

American Pain Foundation:  
[www.painfoundation.org](http://www.painfoundation.org)

American Social Health Association:  
[www.ashastd.org](http://www.ashastd.org)

Cancer PLANET (Plan Planet):  
<http://cancercontrolplanet.cancer.gov>

Center to Reduce Cancer Health Disparities:  
<http://crchd.nci.nih.gov/chd>

The Collaborative on Health and the Environment: [www.cheforhealth.org](http://www.cheforhealth.org)

The Community Guide:  
[www.thecommunityguide.org](http://www.thecommunityguide.org)

Hospice Association of America:  
[www.hospice-america.org](http://www.hospice-america.org)

National Center for Complementary and Alternative Medicine: [www.nccam.org](http://www.nccam.org)

National Cervical Cancer Coalition:  
[www.nccc-online.org](http://www.nccc-online.org)

National Coalition for Cancer Survivorship:  
[www.nccs.org](http://www.nccs.org)

National Comprehensive Cancer Network (NCCN): [www.nccn.org](http://www.nccn.org)

National Hospice and Palliative Care Organization: [www.nhpco.org/templates/1/homepage.cfm](http://www.nhpco.org/templates/1/homepage.cfm)

National Institute of Environmental and Health Sciences: [www.niehs.nih.gov](http://www.niehs.nih.gov)

National Skin Cancer Primary Prevention and Awareness: [www.cdc.gov/cancer/nscpep/awareness.htm](http://www.cdc.gov/cancer/nscpep/awareness.htm)

Patient Advocate Foundation:  
[www.patientadvocate.org](http://www.patientadvocate.org)

Put Prevention into Practice:  
[www.ahrq.gov/clinic/ppipix.htm](http://www.ahrq.gov/clinic/ppipix.htm)

The Susan G. Komen Breast Cancer Foundation: [www.komen.org](http://www.komen.org)

U.S. Preventive Services Task Force (USPSTF):  
[www.preventiveservices.ahrq.gov](http://www.preventiveservices.ahrq.gov)

US Too, Prostate Cancer Education and Support Network:  
[www.ustoo.com/About\\_UsTOO.asp](http://www.ustoo.com/About_UsTOO.asp)

Women's Cancer Network: [www.wcn.org](http://www.wcn.org)

# Oregon Partnership for Cancer Control

## VISION, MISSION, ROLES AND VALUES\*

### **Our vision is for the State of Oregon to be a place where:**

- Stakeholders take an integrated and coordinated approach in order to maximize and achieve desired cancer control outcomes.
- Efforts include population-based prevention approaches for cancer.
- Individuals do not get preventable cancer.
- Those individuals with detectable cancers are diagnosed in the earliest stage of the disease.
- Those individuals with treatable cancers receive the highest-quality, state-of-the-art care and rehabilitation necessary to optimize their survival and quality of life.
- Those individuals in the end stages of incurable cancers receive care that maximizes the quality of their life and death.
- Full support is given to research directed toward understanding the causes of cancers and toward improving prevention, early detection, treatment, rehabilitation and palliation.
- There is respect for family and friends who are caregivers of persons with cancer.
- Health care providers have access to resources so they can provide evidence-based comprehensive care.

### **Our mission is to:**

- Enhance cancer prevention activities.
- Reduce cancer morbidity and mortality.
- Increase equity in access to appropriate preventive, diagnostic, medical, rehabilitative and palliative care.

- Maximize the quality of life for individuals affected by cancer.
- Promote cancer-related research.
- Educate consumers, providers, payers and policymakers on cancer issues.
- Utilize and promote accurate and complete cancer control data.

### **Our role is to provide leadership in and advocacy for:**

- Assuring adequate prevention programs and strategies.
- Identifying and prioritizing needs.
- Identifying resources and interventions.
- Catalyzing and coordinating activities.
- Assuring availability of health workforce, equipment and service.
- Assuring availability of financial resources.

### **We value a process that encourages broad participation and is:**

- Prevention-oriented.
- Integrated and coordinated.
- Science-based.
- Data-driven.
- Committed to reducing health disparities.
- Culturally respectful.
- Patient-informed.
- Outcome-oriented.
- Comprehensive in nature.
- Respectful of individual autonomy and rights.

\* Adopted by the Oregon Partnership for Cancer Control Core Planning Committee, September 2003. The Committee gives thanks and acknowledgement to the Washington State Comprehensive Cancer Control Partnership (WA CCCP) for its Vision, Mission, Roles and Values document.





# Oregon Partnership for Cancer Control

## MEMBERSHIP FORM — YES, PLEASE SIGN ME UP!

Please fax this form to the Partnership at 503-731-4082, or mail it to:  
OPCC, Project Staff  
800 NE Oregon Street, Suite 730  
Portland, OR 97232

The purpose of the Partnership is to develop and implement the first cancer control plan for Oregon. The Partnership invites individuals and organizations that would like to work with others to help reduce the burden of cancer on Oregon's communities.

By completing this form, you will be added to the Partnership listserv and will receive information about meetings and Partnership activities. Please visit our Web site at [www.healthoregon.org/cancer](http://www.healthoregon.org/cancer) for more information.

Name: \_\_\_\_\_

Credentials and Title: \_\_\_\_\_

Organization: \_\_\_\_\_

Address: \_\_\_\_\_

Phone/Fax: \_\_\_\_\_

E-mail address: \_\_\_\_\_

☐ Yes, I'd like to attend future Partnership meetings.

☐ My particular interest is (please note area(s) and specific topic, if you wish):

- |  |   |
|--|---|
| <input type="checkbox"/> Prevention and Early Detection_____       | <input type="checkbox"/> Public Education   |
| <input type="checkbox"/> Cancer Treatment and Quality of Life_____ | <input type="checkbox"/> Patient Education  |
| <input type="checkbox"/> Public Policy and Legislation_____        | <input type="checkbox"/> Provider Education |
| <input type="checkbox"/> Cancer Disparities_____                   | Other, please note:_____                    |
| <input type="checkbox"/> Data Management and Surveillance_____     | _____                                       |

☐ No, I cannot attend meetings but I am interested. Check all that apply:

- ☐ I'd like to be on the mailing list only.
- ☐ I'd like to get more information about the Partnership.

I recommend you contact (Name, Contact Information): \_\_\_\_\_

Comments: \_\_\_\_\_

## NOTES

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