

A photograph of a beach with waves crashing onto the shore under a cloudy sky. The text is centered over the image.

**Rhode Island  
Comprehensive Cancer Control Plan  
2007**

**RHODE ISLAND  
COMPREHENSIVE CANCER CONTROL PLAN  
2007**



**A publication of the Partnership to Reduce Cancer in Rhode Island.**

An electronic version of this plan is available on the Internet at [www.health.ri.gov](http://www.health.ri.gov)

Special acknowledgement to: Nancy Libby Fisher, Rhode Island Department of Health; Barbara Baldwin, the Partnership to Reduce Cancer in Rhode Island; and Jennifer Kawatu & Josie Halpern-Finnerty, John Snow, Inc., for facilitating the development and production of this plan.

Copyright Information:

All material in this report is in the public domain and may be reproduced or copied without permission; citation as to source, however, is appreciated.

*This publication was produced with funding from the Rhode Island Department of Health, fully supported by Cooperative Agreement Number U55/CCU121976 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the Partnership to Reduce Cancer in Rhode Island and do not necessarily represent the official views of the Centers for Disease Control and Prevention or any other participating entity.*

## Table of Contents

3	Executive Summary
5	Introduction
6	The Burden of Cancer in Rhode Island
11	Prevention
19	Detection and Screening
26	Treatment
30	Workforce Issues
33	Clinical Trials
35	Palliative Care
39	Survivorship
42	Surveillance and Evaluation
45	Committee Members and Contributors
47	References

# Executive Summary

## CANCER IN RHODE ISLAND

Cancer is the second leading cause of death in Rhode Island. About four out of every 10 people in Rhode Island will develop cancer sometime in the course of their lives, and half of them will die of the disease. At any one time, it is estimated that over 33,000 Rhode Islanders are living with cancer or are cancer survivors. We have all been personally affected by someone who has struggled or is struggling with the physical, emotional, and financial challenges of this disease. In 2007, an estimated 6,360 new cancer cases will be diagnosed, and an estimated 2,370 Rhode Islanders will die of the disease.

## THE PARTNERSHIP TO REDUCE CANCER IN RHODE ISLAND

The mission of the Partnership to Reduce Cancer in Rhode Island is to reduce the burden of cancer for the residents of Rhode Island by working collaboratively to: educate and advocate on cancer issues; to ensure Rhode Islanders have access to care, prevention, early detection, treatment, support services; and to promote research. The Partnership is a broad based, coalition of partners who have come together to provide input in planning and implementation of programs and services around comprehensive cancer control. A main priority of the Partnership and aim of this plan is to address issues of health disparities and to include a diverse representation of the population in the collaborative process.

Comprehensive cancer control can be defined as a collaborative process through which a community and its partners organize

to promote cancer prevention, improve cancer detection, increase access to health and social services, and reduce the burden of cancer.

The Partnership to Reduce Cancer in Rhode Island has six work groups: Prevention; Detection and Screening; Treatment; Palliative Care; Survivorship; and Surveillance and Evaluation. These work groups collectively created the Rhode Island Comprehensive Cancer Control Plan and will continue to work during the implementation phase of the planning process.

The 2007 Rhode Island Comprehensive Cancer Control Plan's goals are to:

- 1. Reduce cancer risk through changes in behavior, policies and environment that promote healthy lifestyles.**

The priorities are to focus on reduction of tobacco, obesity, and sun exposure as well as an increase in the rates of physical activity, the HPV vaccine coverage, breastfeeding and physical activity as prevention measures.

- 2. Increase proven, science-based cancer screening rates among all segments of the population in Rhode Island.**

Increasing colorectal cancer screening rates through increased access and affordability is the priority for screening in RI. Breast, cervical, prostate and skin cancer screening are also important in reducing the burden of cancer through early detection.

- 3. Ensure access to cancer care for all residents of Rhode Island.**

Increased access to healthcare and cancer treatment for all Rhode Islanders is essential for decreasing cancer mortality and disparities.

**4. Improve the quality of cancer treatment provided in Rhode Island.**

RI is working to have 100% of the acute care RI hospitals approved by the American College of Surgeons Commission on Cancer (ACoS CoC) approved.

**5. Enhance the treatment experience for cancer patients.**

The treatment experience for cancer patients can be enhanced through linguistically and culturally appropriate educational and support services.

**6. Reduce workforce gaps and ensure an adequate supply of diverse and highly trained professionals in all aspects of cancer care and control.**

A diverse and well-trained workforce is essential for providing cancer prevention, early detection, treatment and support services.

**7. Increase awareness, access, and participation in cancer clinical trials by Rhode Island residents.**

In order to improve participation in clinical trials, this plan proposes a baseline assessment of cancer clinical trials, and activities that will increase public and provider awareness of clinical trials in RI.

**8. Improve access to palliative care for all patients seeking end-of-life care due to cancer in Rhode Island.**

Cancer patients seeking end-of-life care should be informed about and have access to a palliative care team and hospice care if desired.

**9. Promote the well being and quality of life of Rhode Islanders who are living with, through and beyond cancer.**

A new recognition of the importance of survivorship services focuses on assessing the current services, gaps, and a plan for improvement for the growing number of cancer survivors and their caretakers.

**10. Assure the use of timely, complete, and accurate cancer surveillance data in the planning, management and evaluation of cancer control programs.**

In order to make informed decisions, track progress, and evaluate success, it is essential to maintain the integrity of the data surveillance systems in the state.

The Rhode Island Comprehensive Cancer Control State Plan is a reflection of the community's priorities, current efforts, and the vision of what can and should be done in Rhode Island to conquer cancer, and is intended to serve as a "blueprint" to address cancer control in the state. It was developed by a broad coalition of stakeholders who will work toward its implementation.

The objectives for each section are measurable. The Partnership work groups will work toward the implementation of the State Plan priorities, review them at the Partnership's annual meetings, and use them to create an action agenda for subsequent years. Through collective effort and coordinated approach laid out in this plan, we *can* reduce the burden of cancer in Rhode Island.

# Introduction

The Comprehensive Cancer Control State Plan is a reflection of the community's priorities, current efforts, and the vision of what can and should be done in Rhode Island to conquer cancer, and is intended to serve as a "blueprint" to address cancer control in the state. It was developed under the auspices of a broad coalition of stakeholders who will work toward its implementation.

Comprehensive Cancer Control has been defined as a collaborative process through which a community and its partners organize to promote cancer prevention, improve cancer detection, increase access to health and social services, and reduce the burden of cancer. The state's cancer coalition of stakeholders was formed to facilitate this collaborative process and is named the Partnership to Reduce Cancer in Rhode Island.

## **THE PARTNERSHIP TO REDUCE CANCER IN RHODE ISLAND**

The mission of the Partnership to Reduce Cancer in Rhode Island is to reduce the burden of cancer for the residents of Rhode Island by working collaboratively to: educate and advocate on cancer issues; to ensure Rhode Islanders have access to care, prevention, early detection, treatment, rehabilitation, palliative care, support services; and to promote research. The Partnership is a broad based coalition of partners who have come together to provide input in planning and implementation of programs and services.

Membership is open to any organization that is interested in working toward reducing the burden of cancer in Rhode Island whose mission is not in conflict with the purpose of the Partnership. The Partnership has six work groups including: Prevention;

Detection and Screening; Treatment; Clinical Trials; Workforce; and Surveillance and Evaluation. The development of the Comprehensive Cancer Control State Plan was done through the participation of individuals who served on one or more of the six work groups.

Included in the Partnership and in the planning process to develop and implement the State Plan are representatives from public health programs, other government agencies, professional associations and organizations, academic and medical institutions, business and industry, community-based organizations, survivors and individuals with an interest and commitment to reduce the burden of cancer in Rhode Island.

## **HEALTH DISPARITIES**

The issue of health disparities was a major concern to those participating in the development of the State Plan. The decision was made at the outset that rather than create a separate section, each work group would address disparities and disparate populations within the context of their topic and use this information to shape goals, objectives, and strategies. Health disparities and limitations in information systems that may inaccurately depict reported disparities are presented throughout the document.

This plan is organized into topical sections, each supported by specific strategies and measurable objectives when possible. The Partnership work groups will work toward the implementation of the State Plan priorities, review them at the Partnership's annual meetings, and use them to create an action agenda for subsequent years.

# The Burden of Cancer in Rhode Island

Cancer is the second leading cause of death in Rhode Island. About four out of every 10 people in Rhode Island will develop cancer sometime in the course of their lives, and half of them will die of the disease. At any one time, it is estimated that over 33,000 Rhode Islanders are living with and through cancer. Almost every one of us has been personally affected by someone who has struggled or is struggling with the physical, emotional, and financial challenges of this disease. In 2007, an estimated 6,360 new cancer cases will be diagnosed, and an estimated 2,370 Rhode Islanders will die of the disease.<sup>1</sup>

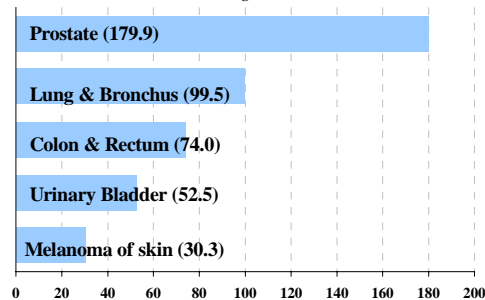


## CANCER INCIDENCE IN RHODE ISLAND

Cancer **incidence** is the number of new cases of cancer during a particular time period. The five most common cancers responsible for new cases in Rhode Island are those of the prostate, lung and bronchus, female breast, colon and rectum, and urinary bladder. Together, these cancers represent almost two-thirds of all cancers to be diagnosed in the state during 2007 (a breakdown of the most common cancers by gender is provided in Figures 1. and 2.).<sup>2</sup>

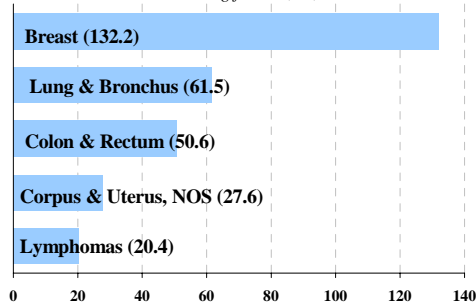
More detailed statistics can be found in the “Cancer in RI” report available on the Rhode Island Department of Health website. <http://www.health.ri.gov>

**Figure 1. Leading male cancer sites**  
Cancer incidence rates\* among males, RI, 1999-2003.



\* Rates are age-adjusted to the year 2000 US standard population, expressed as cases per 100,000 population. Source: RICR, HEALTH; calculated with SEER\*Stat.

**Figure 2. Leading female cancer sites**  
Cancer incidence rates\* among females, RI, 1999-2003.



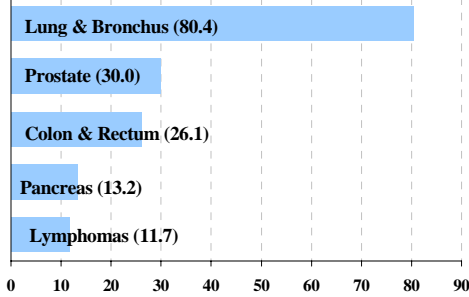
\* Rates are age-adjusted to the year 2000 US standard population, expressed as cases per 100,000 population. Source: RICR, HEALTH; calculated with SEER\*Stat.

## CANCER DEATHS IN RHODE ISLAND

Cancer **mortality** is the measure of the number of deaths in the population. Four of the five most common cancers (cancers of the lung and bronchus, colon and rectum, female breast, and prostate) are also among the top five causes of cancer deaths, accounting for almost half – of all cancer deaths projected for Rhode Island in 2007.<sup>3</sup>

**Figure 3. Leading male cancer deaths**

Cancer mortality rates\* among males, RI, 1998-2002.

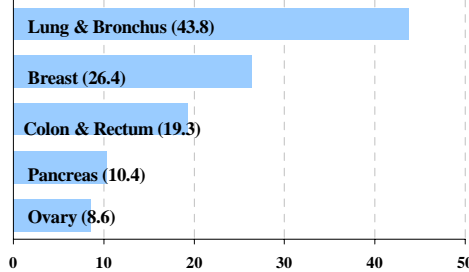


\* Rates are age-adjusted to the year 2000 US standard population, expressed as deaths per 100,000 population. Source: Office of Vital Records, HEALTH; calculated with SEER\*Stat.



**Figure 4. Leading female cancer deaths**

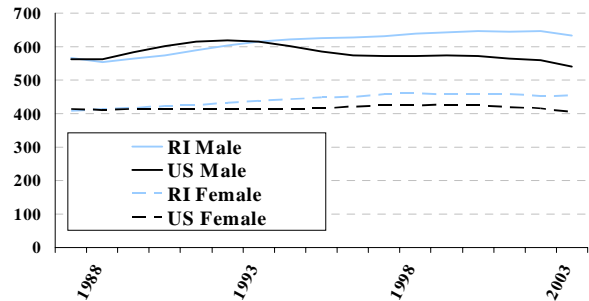
Cancer mortality rates\* among females, RI, 1998-2002.



\* Rates are age-adjusted to the year 2000 US standard population, expressed as deaths per 100,000 population. Source: Office of Vital Records, HEALTH; calculated with SEER\*Stat.

**Figure 5. Cancer incidence by year for all cancers combined**

Annual invasive\* all-cancer incidence rates\*\* by gender, RI and US, 1987-2003.



\* Invasive includes the following stages of disease at diagnosis: local, regional, distant, and unknown.

\*\* Rates are age-adjusted to the year 2000 US population, expressed as cases per 100,000 population.

Source: RICR, HEALTH; SEER Public-Use 1973-2003 Data; calculated with SEER\*Stat.

## CANCER TRENDS

Over the past decade, the incidence of all cancers combined increased among both Rhode Island men and women. The number of new cases of cancer is higher in Rhode Island than in the United States as a whole and this gap has widened in the past ten years.

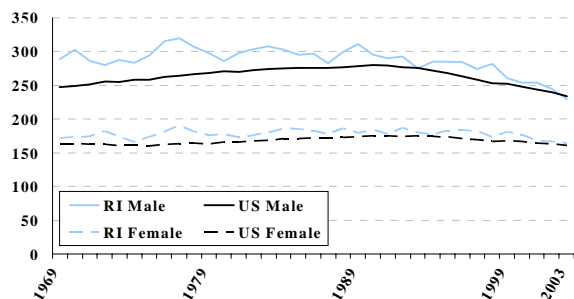
The increase in cancer incidence rates can be partly attributed to the development and widespread use of cancer screening techniques which are effective in finding certain types of cancer at early stages.

Rhode Island has experienced significantly higher cancer death rates than the nation over a period of at least five decades. From 1969-1996 cancer mortality rates stayed around 300 per 100,000 but the difference between Rhode Island and U.S. cancer mortality rates has gotten smaller over time. Currently, RI and US cancer mortality rates are almost the same. For 1999 to 2003 the RI rate is 200.2 versus the US rate of 195.7.<sup>4</sup>



**Figure 6. Cancer mortality by year for all cancers combined**

Annual all-cancer mortality rates\* by gender, RI and US, 1969-2003.



\*Rates are age-adjusted to the 2000 US standard population, expressed as deaths per 100,000 population. Source: Office of Vital Records, HEALTH; SEER US Mortality 1969-2003 Data; calculated with SEER\*Stat.

## DISPARITIES

Anyone can develop cancer. Cancer is not, however, equally distributed across the population. Health disparities are described as differences in the incidence (new cases), prevalence (all existing cases), mortality (death), and burden of cancer and related adverse conditions that exist among specific population groups. These population groups may be characterized by gender, age, ethnicity, education, income, social class, disability, geography or sexual orientation.<sup>5</sup>

## GENDER

In both Rhode Island and the nation as a whole, the burden of cancer is higher among men than women. This disparity is largely attributable to cancers of the prostate, colon-rectum, lung-bronchus, and urinary bladder.

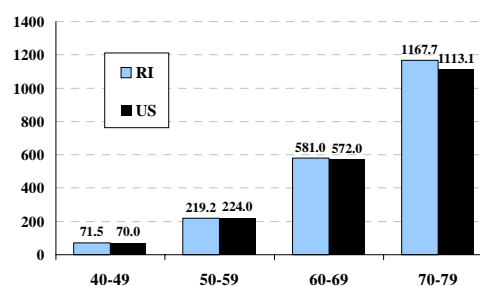
## AGE

Although some cancers are more common among children, the incidence of most cancers increases with age. Due to both internal factors, such as normal aging processes, and external factors, such as prolonged exposure to carcinogens, cancer is largely a disease of age. Over 77% of all cancers occur in people over 55.<sup>6</sup> RI ranks

8<sup>th</sup> in the nation for percent of population over 60, with 18.2% of the population in this category. With a population that is both growing and aging, even if cancer rates remain stable, the number of people diagnosed with cancer is expected to increase.

**Figure 7. Cancer incidence by Age**

Average annual cancer incidence rates\* by race and sex for all cancers combined, RI and US, 1987-2000.



## RACIAL AND ETHNIC DISPARITIES

Racial and ethnic disparities appear to have decreased over time but have not been eliminated. (See Figure 8. and 9.) African Americans have the highest death rates in the state. The data on race and ethnicity for Rhode Island is limited, however, due to the small numbers.

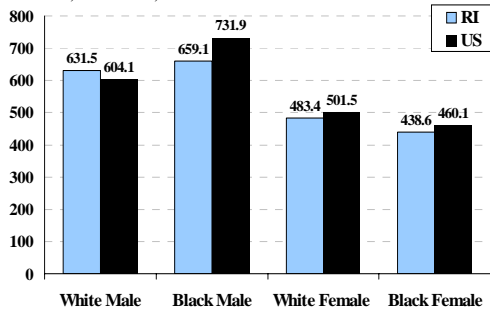


Cancers of the colon, rectum, breast, and cervix are found more often at advanced stages among African American and Hispanic Rhode Islanders, decreasing the likelihood of survival. This profile suggests that non-Hispanic Whites have greater access to many cancer screening tests than other groups.<sup>7</sup> Cancer prevention and control efforts may not have effectively reached minority populations.



**Figure 8. Cancer incidence by race and sex for all cancers combined**

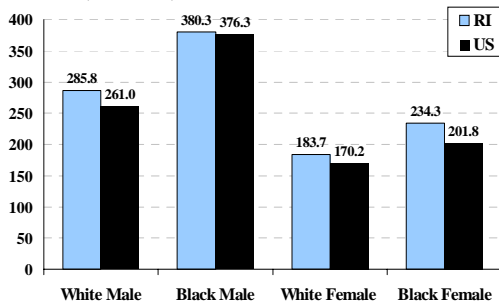
Average annual cancer incidence rates\* by race and sex for all cancers combined, RI and US, 1987-2000.



\* Rates are age-adjusted to the year 2000 US standard population, expressed as cases per 100,000 population. Source: RICR, HEALTH; SEER Public-Use 1973-2000 Data; calculated with SEER\*Stat.

**Figure 9. Cancer mortality by race and sex for all cancers combined**

Average annual cancer mortality rates\* by race and sex for all cancers combined, RI and US, 1987-2000.

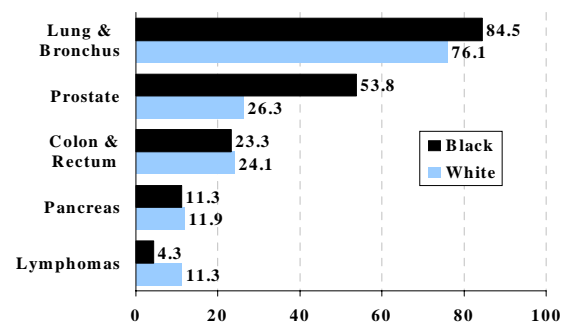


\* Rates are age adjusted to the year 2000 US standard population, expressed as deaths per 100,000 population. Source: Office of Vital Records, HEALTH; SEER US Mortality 1969-2000 Data; calculated with SEER\*Stat.

Prostate cancer death rates for African American men are more than twice that of white men. Even though the greatest decrease in cancer mortality rates has been among African American men, they still have the highest cancer mortality rates of any racial / ethnic category with a death rate of 287 out of 100,000 in Rhode Island.<sup>8</sup> New cases of breast cancer are higher in white women, but the death rate from breast cancer is higher among black women.

**Figure 10. Leading male cancer deaths**

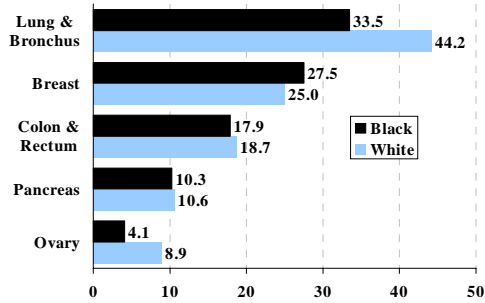
Cancer mortality rates\* among males, RI, 2000-2003.



\* Rates are age-adjusted to the year 2000 US standard population, expressed as deaths per 100,000 population. Source: Office of Vital Records, HEALTH; calculated with SEER\*Stat.

**Figure 11. Leading female cancer deaths**

Cancer mortality rates\* among females, RI, 2000-2003.



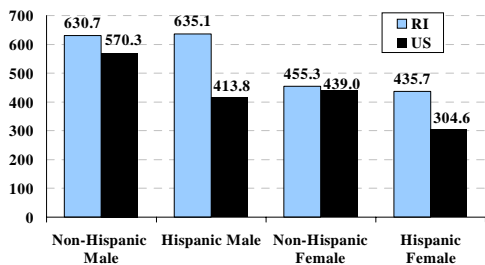
\* Rates are age-adjusted to the year 2000 US standard population, expressed as deaths per 100,000 population..

Source: Office of Vital Records, HEALTH; calculated with SEER\*Stat.

In Rhode Island, Hispanics have a higher cancer incidence, but lower cancer mortality rate than US rates. There is considerable speculation, however, about the accuracy of Hispanic ethnicity data. The problem of under-identification may be resolved through increased compliance with the Office of Management and Budget’s (OMB) Statistical Policy Directive No. 15 concerning Race and Ethnic Standards for Federal Statistics and Administrative Reporting.<sup>9</sup>

**Figure 12. Cancer incidence by ethnicity and gender for all cancers combined**

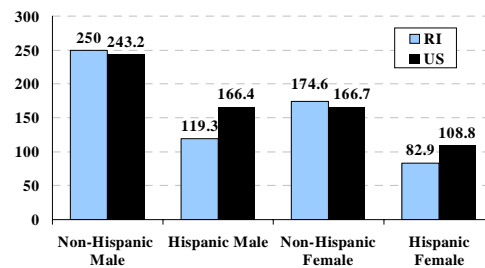
Average annual cancer incidence rates\* by race and gender for all cancers combined, RI and US, 1999-2003.



\* Rates are age-adjusted to the year 2000 US standard population, expressed as cases per 100,000 population. Source: RICR, HEALTH; SEER Public-Use 1973-2003 Data; calculated with SEER\*Stat.

**Figure 13. Cancer mortality by ethnicity and gender for all cancers combined**

Average annual cancer mortality rates\* by race and gender for all cancers combined, RI and US, 1999-2003.



\* Rates are age adjusted to the year 2000 US standard population, expressed as deaths per 100,000 population.

Source: Office of Vital Records, HEALTH; SEER US Mortality 1969-2003 Data; calculated with SEER\*Stat.

## SOCIO-ECONOMIC STATUS

Access to quality healthcare is most closely linked to socio-economic status, which includes level of income and education. Compared to people with health insurance coverage, those without health insurance have more difficulty accessing personal health services such as cancer screenings, use less medical services, and receive less outpatient and inpatient care.<sup>10</sup> They often seek care at a later or more advanced stage of disease, leading to higher death rates.<sup>11</sup> Lack of access to a regular source of healthcare including screening tests, early detection, and preventive health messages all contribute to these disparities.

## COST

In addition to the cost in terms of lives and emotional turmoil, cancer also costs a lot of money. Cancer costs Rhode Island about \$881 million per year, about \$312 million in direct medical costs, \$74 million for cost of lost productivity due to illness, and about \$499 million in lost productivity due to premature death.<sup>12</sup>

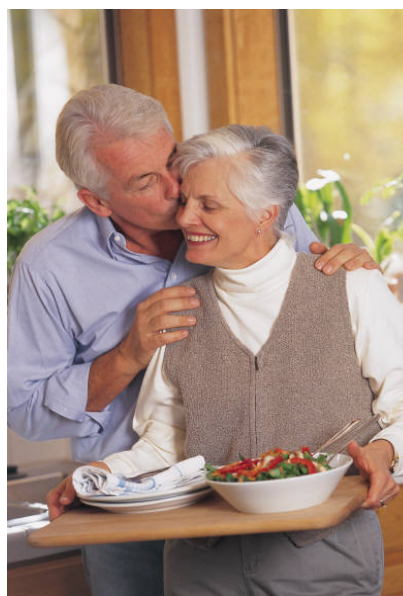
## Prevention

Lifestyle choices and environmental factors profoundly affect cancer incidence and mortality. Current research supports several lifestyle modifications that affect risk for cancer. Approximately one-third of cancer-related deaths can be linked to diet, sedentary lifestyles and being overweight or obese. Smoking is responsible for an additional 30% of cancer-related deaths.<sup>13</sup> Reducing known risk factors such as smoking, exposure to ultraviolet light, environmental toxins and the human papillomavirus is a top priority for cancer control in Rhode Island. Increasing healthy habits in individuals and communities such as diet improvement, exercise and increased breastfeeding help to prevent cancer before it starts.

### TOBACCO

Tobacco smoking is responsible for 30% of cancer-related deaths and 87% of lung cancer deaths. Tobacco use also increases the risk for acute leukemia, as well as cancers of the pancreas, uterus, cervix, kidney, bladder, stomach, head and neck.<sup>14</sup> Researchers conservatively estimate that reductions in tobacco smoking over the past 50 years as a result of tobacco control strategies account for at least 40% of the decrease in cancer mortality among males between 1991 and 2003.<sup>15</sup> As of 2005, 19.8% of adults and 16% of high school students in Rhode Island were current smokers.<sup>16</sup> According to the Behavioral Risk Factor Surveillance System (BRFSS), a United States national health survey that looks at behavioral risk factors, Whites in RI have the highest smoking rate of any racial or ethnic group. Smoking rates are higher

among those with lower educational and income levels; the rate is three times higher among those Rhode Islanders with less than a high school education compared to those with a college degree.<sup>15</sup>



Nationally, around 3,000 non-smokers also die from lung cancer each year as a result of breathing second-hand smoke.<sup>17</sup> A primary cancer control strategy in Rhode Island, therefore, is to reduce the prevalence of smoking and exposure to second hand smoke. The 2005 Smokefree Workplace Law, which banned smoking in most indoor public spaces and workplaces, is an invaluable first step in this effort. This piece of legislation is one of the most important strategies in the reduction of smoking and exposure to second-hand smoke in Rhode Island. The objectives and strategies regarding tobacco in this plan have been coordinated with the *Rhode Island Tobacco Control Program Annual Action Plan 2005 – 2006*. These objectives aim to promote



smoking cessation, reduce smoking initiation, reduce exposure to second hand smoke and eliminate disparities in tobacco use.

## NUTRITION

Nutrition plays an important role in cancer prevention. Nutrition and levels of physical activity have the potential to influence cancer risk individually and through their relation to body weight. As previously noted, one-third of cancer-related deaths can be attributed to nutrition, sedentary lifestyle and overweight/obesity.<sup>18</sup> In 2004, 37% of Rhode Island adults were overweight and 19% were obese; this means that, in 2004, 56% of Rhode Island adults had a weight-related risk factor for cancer.<sup>19</sup> Weight has become a problem for younger Rhode Islanders as well. In Rhode Island, 47% of 6-11 year olds are overweight or at risk for becoming overweight.<sup>20</sup> There are many factors that contribute to this epidemic, including increased consumption of fat and sugar in our diets. Over the last three decades, fast food consumption quadrupled for adults and quintupled for children.<sup>21</sup> In

**“Over the last three decades, fast food consumption quadrupled for adults and quintupled for children.”**

than tripled among adolescents between 1977 and 1994, increasing from 7 to 22 ounces per day.<sup>23</sup> Weight gain and body mass index (BMI) are associated with sugar sweetened beverage and fast food consumption; reducing consumption are evidence-based strategies for obesity prevention and control. Maintenance of a healthy weight can be promoted by

Rhode Island, 29% of families report eating at fast food restaurants at least once per week, and 21% report more than once per week.<sup>22</sup> Soft drink consumption more

encouraging Rhode Islanders to follow guidelines for nutrition including consuming recommended quantities of fruits and vegetables, consuming whole grains, and reducing consumption of red and processed meat. Meeting these guidelines can be facilitated by making healthy food choices more available in the work place, schools, and in communities throughout Rhode Island. The goal is to increase the proportion of adults, adolescents and children who reduce excessive caloric intake by improving the nutritional quality of their diets. Communities that have been identified as target communities in which there are nutrition-related disparities include Warwick, Newport and Central Falls.<sup>24</sup> The objectives and strategies in this plan related to nutrition, physical activity and breastfeeding are coordinated with *Rhode Island’s Plan for Healthy Eating and Active Living: 2006 – 2012*.



## PHYSICAL ACTIVITY

Physical activity has been associated with a decrease in cancers of the breast and colon, among others.<sup>25</sup> As noted above, physical activity, along with healthy diet, is important for maintaining a healthy weight and preventing against the cancer risk factors of overweight and obesity. In 2004, 24% of Rhode Islanders reported that they had not been physically active in the past month.<sup>26</sup> Screen time, such as television, computers and video games, can displace physically

active time. Research suggests that children who spend the most time in front of a screen are the least active.<sup>27</sup> Rhode Islanders are encouraged to pursue the physical activity guidelines established by the Centers for Disease Control and American College of Sports Medicine and detailed in the Surgeon General's 1996 report: engaging in at least 30 minutes of moderate-intensity activity (the equivalent of a brisk walk) on at least 5 days each week, or engaging in at least 20 minutes of vigorous-intensity activity (the equivalent of a jog) on at least 3 days each week.<sup>28,29</sup> Rhode Islanders will be better able to meet these guidelines if more work sites and schools support and encourage physical activity and if there is greater access to safe, well-lit public spaces in which to be active. Although many affluent communities have attractive options for exercise and physical activity, lower-income communities may have limited options. Interventions designed to increase opportunity for physical activities should specifically target lower income neighborhoods with limited options.

## BREASTFEEDING



Although the public may be less aware of breastfeeding as a strategy for cancer prevention, research has demonstrated that each year a woman breastfeeds reduces her risk of developing breast cancer by 4.3%.<sup>30</sup> Some studies suggest that women who were breastfed as babies may be at lower risk of developing breast cancer than women who

were not breastfed.<sup>31</sup> For women who are able to breastfeed, the effects may be protective for both the mother and the child. This is an important aspect of cancer prevention, as breast cancer is the most commonly diagnosed cancer in women with over 212,000 new cases of invasive breast cancer expected in the United States and 780

***“Breastfeeding rates in Rhode Island are the lowest in New England.”***

new cases expected in Rhode Island in 2006.<sup>32</sup>

Breastfeeding rates in Rhode Island are the lowest in New England, with only

32% of mothers breastfeeding at 6 months.<sup>33</sup> The aim is to make the environment in Rhode Island supportive of breastfeeding and increase awareness of breastfeeding as a strategy for cancer prevention.

## HPV VACCINE

In June 2006, the Food and Drug Administration licensed the first vaccine to prevent cervical cancer caused by certain strains of human papillomavirus (HPV), the major cause of cervical cancer.<sup>34</sup> In 2006, it was estimated that 5,900 women in the United States would be diagnosed with cervical cancer. Although cervical cancer used to be the most common cause of cancer death among American women, due to the widespread use of the pap test and treatment of pre-cancerous abnormalities, the impact has dropped dramatically. Currently, Hispanic/Latina women have the highest cervical cancer rate in the United States.<sup>35</sup> The new vaccine offers an exciting opportunity to eradicate the disease and decrease further incidence and mortality of cervical cancer. The CDC recommends that the HPV vaccine be administered to females prior to the initiation of sexual activity—before females may have become exposed to HPV—in order to be most effective.<sup>36</sup>

## SKIN PROTECTION

Exposure to ultraviolet light— from the sun and other sources such as tanning beds and sun lamps— is responsible for the majority of skin cancers. As the “Ocean State,” Rhode Islanders have a love of the ocean, the summer, and the sun. It is important for Rhode Island residents, especially those with

***“I would love to see a siren that goes off every couple of hours at beaches and pools to remind people to reapply their sunscreen.”***

fair skin, to protect themselves from excessive exposure to ultraviolet light.

Over one million basal and squamous skin cancers are diagnosed yearly in the United States, making this the most common form of cancer. In addition, in 2006, it was estimated that over 62,000 cases of a more deadly form of skin cancer, melanoma, would be diagnosed in the United States— 240 of those in Rhode Island. It was also estimated that over 7,900 people in the United States would die from melanoma in 2006, or about 165 in RI.<sup>37</sup> Skin cancers can be prevented, however, through the use of a number of skin protection strategies.



## ENVIRONMENTAL TOXINS

It is estimated that approximately 4% of cancer-related deaths are due to occupational exposure to cancer-causing agents (such as asbestos and radon) and 2% to environmental pollutants in the air, water and soil (for example, from the combustion of oil or gas). Although these environmental factors only account for 6% of cancer-related deaths, even this small fraction of cancer mortality translates into 33,900 preventable deaths in the United States each year. Lower-income workers and communities bear a disproportionate burden from these occupational and environmental pollutants, contributing to disparities in cancer incidence.<sup>38</sup> Radon exposure is second only to tobacco smoke as a risk factor for lung cancer. The current average Radon level in Rhode Island is 3.5 pCi/L, which is nearly 3 times the national average. Over 1 in 4 homes tested in Rhode Island has Radon levels exceeding the EPA action level.<sup>39</sup>

**Goal: Reduce cancer risk through changes in behavior, policies and environment that promote healthy lifestyles.**

## TOBACCO

### OBJECTIVE A:

- **By 2010, reduce smoking prevalence in adolescents from 16% to a maximum of 10% and in adults from 19.8% to 15%.<sup>40</sup>**

### STRATEGIES:

1. Promote strategies as outlined in the *Rhode Island Tobacco Control Program Annual Action Plan 2005-2006*.
2. Discourage the sale of tobacco products through increased sales tax.
3. Reduce youth access to tobacco products by enforcing existing regulations.
4. Ensure that schools have resources to address youth tobacco use and curricula that prevent initiation and promote cessation.
5. Continue to raise public awareness about the health hazards of tobacco and promotion of quitting.
6. Increase funding for state prevention and cessation initiatives including smoking cessation support services.
7. Identify and promote strategies to decrease disparities among populations at high risk for tobacco use.

### OBJECTIVE B:

- **By 2010, reduce the proportion of non-smokers exposed to environmental tobacco smoke in homes, community settings and worksites from 38% to 20%.<sup>41</sup>**

### STRATEGIES:

1. Support the strategies as outlined in the *RI Tobacco Control Program Annual Action Plan* to reduce exposure to environmental tobacco smoke.
2. Increase enforcement and compliance with the 2005 'Smokefree Workplace and Public Place Law.'
3. Educate key decision makers about the importance of enforcement of the Smoke Free Workplace Law.



## NUTRITION

### OBJECTIVE C:

- **By 2010, increase from 27% to 35% the proportion of adults, and adolescents and children who eat five or more servings of fruits and vegetables per day.<sup>42</sup>**

### STRATEGIES:

1. Support the strategies of *Rhode Island's Plan for Healthy Eating & Active Living 2006-2012*.
2. Increase options for obtaining healthy foods in low-income communities, targeting Warwick, Central Falls and Newport.
3. Promote the development of and increased use of Farmer's Markets in all communities.
4. Encourage schools and daycare providers to provide safe and healthy foods, including increased fruits and vegetables.



5. Increase the number of communities that have community garden programs.

**OBJECTIVE D:**

- **For children and adolescents in Rhode Island, decrease to 40% the proportion who report eating at a fast food restaurant once per week or more and average consumption of sugar-sweetened drinks to eight ounces per day by 2010.**<sup>43</sup>

**STRATEGIES:**

1. Advocate for state-endorsed policy language for nutrition that includes nutrition guidelines for all competitive foods available in schools and a corresponding approved foods list.
2. Assist in training childcare providers on menu planning.
3. Provide training for food service providers at worksites regarding how to determine and post key nutrient information.
4. Encourage schools to develop policies that limit unhealthy foods and beverages on campus.



**PHYSICAL ACTIVITY**

**OBJECTIVE E:**

- **By 2012, increase from 49% to 67% the proportion of adults, ages 18 years or older, who engage in moderate physical activity for at least 30 minutes on at least five days of the week.**<sup>44</sup>

**STRATEGIES:**

1. Support the strategies to increase physical activity as outlined in the *Rhode Island's Plan for Healthy Eating and Active Living: 2006 – 2012*.
2. Educate employers about the positive aspects of offering benefits that reduce the cost of physical activity (e.g., reduced sick time).
3. Educate the public on the importance of weight maintenance and physical activity and their role in cancer prevention.
4. Develop and disseminate worksite physical activity toolkit.
5. Encourage communities to provide free or low-cost opportunities for structured physical activity.
6. Advocate for communities to have land management systems that support physical activity.

**OBJECTIVE F:**

- **By 2012, increase from 24% to 40% the proportion of adolescents and children, ages 17 years or younger, who engage in moderate physical activity for at least 60 minutes daily.**<sup>45</sup>

**STRATEGIES:**

1. Advocate for strengthened physical education requirements in schools.
2. Require opportunities to integrate physical activity into regular classes throughout the school day.

3. Require daily recess at all elementary schools.
4. Require school playground accessibility to all students at recess.
5. Require after-school programs to provide opportunities for physical activity
6. Promote an increase in the proportion of adolescents and children, ages 17 years or younger, who spend two or fewer hours per day in front of a screen (TV, Videogames, Computer).



## BREASTFEEDING

### OBJECTIVE G:

- **By 2010, increase the proportion of women breastfeeding their babies for at least 6 months from 33% to 50% and for at least 12 months from 17% to 25%.<sup>46</sup>**

### STRATEGIES:

1. Support the *Healthy Eating and Active Living* plan strategies to increase the percentage of mothers who breastfeed by targeting worksites, community settings, health care systems and safety net providers.

2. Promote the establishment of breastfeeding-friendly environments in community settings.
3. Advocate for the increased availability of breast pumps through WIC local agencies.
4. Promote *Ten Steps to Successful Breastfeeding*.
5. Identify community-based intervention programs for employer outreach.

## HPV VACCINE

### OBJECTIVE H:

- **By 2012, at least 75% of 13 year old girls in Rhode Island will have received the HPV vaccine according to the CDC guidelines.**

### STRATEGIES:

1. Support the Federal Advisory Committee on Immunization Practices (ACIP) recommendations regarding HPV vaccination—i.e., that females aged 11 to 12 be routinely vaccinated and that “catch up” vaccines be provided to females aged 13 to 26 who have not been previously vaccinated.
2. Educate the public and health care providers about HPV vaccination recommendations.
3. Support the tracking and promotion of the HPV vaccine through VFC/AFIX (Vaccines for Children quality improvement program) site visits.
4. Support the efforts of health care insurers to educate providers and members about the HPV vaccine.
5. Improve access to the vaccine for the uninsured.

## SKIN PROTECTION

### OBJECTIVE I:

- **Increase the number of Rhode Islanders who use skin protection strategies from 65% to 75% by 2010.**<sup>47</sup>

### STRATEGIES:

1. Provide education about sun protection (e.g., “covering up,” or using SPF of at least 15) in recreational/tourist settings.
2. Support the enforcement of Rhode Island legislation requiring parental permission for those under 18 years of age to use a tanning bed or booth.
3. Provide signage (e.g., by emailing a PDF file) to sites offering tanning booths/beds that includes the required warnings.
4. Develop reporting at non-hospital sources (e.g., pathology labs, free-standing medical oncology clinics and radiation therapy centers) to identify missed cases of non-invasive melanoma.



## ENVIRONMENTAL TOXINS

### OBJECTIVE J:

- **Increase from 8% to 10% the proportion of persons who live in homes tested for radon concentrations by 2010.**<sup>48</sup>

### STRATEGIES:

1. Promote increased radon testing and mitigation of existing housing by the public through public outreach and education.
2. Increase the testing of radon during residential real estate transactions.
3. Increase access to testing and mitigation of radon for low to moderate income homeowners.

### OBJECTIVE K:

- **By 2012, establish more stringent vehicle emissions standards in Rhode Island that are on par with those in California.**

### STRATEGIES:

1. Support policies that would increase the available options for public transportation and provide incentives for car pooling.
2. Inform key decision makers and encourage policies that would reduce greenhouse gas emissions.

## Detection and Screening

Screening the general population for some types of cancers can lead to early detection and an increased likelihood that treatment will be successful. Screening is testing for a specific disease across a defined population when there are no clinical indications of illness. There is general consensus in the scientific community that breast, cervical, and colorectal cancer screening reduce mortality and are cost effective. There is also some evidence that prostate and skin cancer screening may be helpful in early detection and reduced mortality, although definitive research is unavailable at this time.

Rhode Island has a relatively high rate of preventive cancer screening coverage compared to the U.S. as a whole (see Figure 14). According to the RI Behavioral Risk Factor Surveillance System (BRFSS), Rhode Island was able to meet the national Healthy People (HP) 2010 goal for mammograms and colorectal cancer screening. Cervical cancer screening was only 1% below its goal in 2004.<sup>49</sup> The high screening rates for breast, cervical, and colorectal cancer can be attributed, at least in part, to the success of public health efforts in the state.



**Figure 14. Rhode Island Screening Rates Compared to U.S. Rates and Healthy People 2010 Targets**

	Rhode Island	U.S.	HP 2010 Target
<b>Mammogram</b> (In the past 2 years, Women 40+)	<b>82.4</b>	<b>74.9</b>	<b>70</b>
<b>Pap Test</b> (In the past 3 years, Women 18+)	<b>89</b>	<b>86</b>	<b>90</b>
<b>Colorectal Screen</b> (Ever had a Sigmoidoscopy or Colonoscopy, Adults 50+)	<b>61.7</b>	<b>53.5</b>	<b>50</b>

From: Behavioral Risk Factor Surveillance System, United States, 2004 *MMWR* Vol 55, No SS-07 (July 14, 2006).

Although public health efforts to promote and provide access to screening have worked well in Rhode Island, the rising numbers of uninsured people pose a challenge to continued screening successes. Rhode Island has historically had a relatively low number of uninsured people, but that number is rising. In 2004, the CDC found that 12% of RI adults reported having no health insurance.<sup>50</sup> The safety net in Rhode Island is dominated by a network of Community Health Centers that provide primary care services to a wide range of patients – both insured and uninsured. The numbers of uninsured seen by the Health Centers increased by 29% from 2003 to 2004, while the numbers of insured patients treated increased by only 1.5%.<sup>51</sup> The number of uninsured is rising without clear options for meeting their health care needs. Rhode Island hospitals provide a growing amount of care free of charge, straining already tight



budgets. The RI Free Clinic is the only facility in RI where the uninsured are welcomed to receive care at no charge. This clinic, operated by volunteer providers, saw a 28% increase in the number of patients seen between 2004 and 2005.<sup>52</sup> Without a regular source of primary care, many people do not or cannot access routine health services such as cancer screening tests.

## **SCREENING FOR COLORECTAL CANCER**

The Rhode Island Detection and Screening work group set colorectal cancer in RI as its number one screening priority with the greatest potential for improvement. Colorectal cancer is the second most common cause of cancer deaths for men and women in Rhode Island. Screening with colonoscopy can result in the detection and removal of colorectal polyps before they become cancerous as well as the detection of cancer that is at an early stage. Because screening can save lives, coverage for colorectal cancer screening for all Rhode Island residents, regardless of healthcare coverage status or ability to pay has become a high priority. The Rhode Island mortality rate from colon and rectal cancer is higher than the national average, (21.1 v. 20.0) despite higher than average screening rates. According to the BRFSS, about 61.7% of adults 50 and older in RI have ever had a sigmoidoscopy or colonoscopy compared to just 53.5% nationwide.<sup>53</sup> The USPSTF recommends screening with fecal occult blood testing (FOBT) yearly in combination with sigmoidoscopy every 5 years, a double-contrast barium enema every 5 years, or colonoscopy every 10 years starting at age 50; with colonoscopy being the preferred method of screening.<sup>54</sup> The American College of Gastroenterology calls for screening of African Americans starting at age 45 due to increased risk.<sup>55</sup>

There are several barriers to colorectal cancer screening that must be addressed in order to increase compliance with the guidelines. Colonoscopy, the preferred test, is an expensive test with *or* without insurance. This is the most expensive of the screening tests recommended for the early detection of cancer, the insurance co-pay is as high as \$500 for one procedure. For those without insurance, the out of pocket expense is often prohibitive. A survey conducted by the Rhode Island Cancer Council found that other common barriers to endoscopic screening included: fear of the procedure, procrastination, the intent to test in the near future, the need to give priority to existing medical problems, and lack of time required for the prep and procedure.<sup>56</sup> Despite Rhode Island screening rates being higher than nationwide rates, almost 40% of the population have still never been screened for one of the most significant causes of cancer death in Rhode Island.



## **SCREENING FOR BREAST CANCER**

Rhode Island's strong commitment to early screening continues to make a difference in the area of mammography and helped the state reach the national HP 2010 goal. That goal was to assure that at least 70% of women 40 years or older have been screened in the past two years. In fact that goal was met for every race, ethnicity, and income. Physician education, public education and programs such as the Rhode Island Women's Cancer Screening Program,

funded by the CDC's National Breast and Cervical Cancer Early Detection Program, have resulted in high rates of mammography screening among women 40 and older.<sup>57</sup> It has been shown that mammograms can reduce mortality from breast cancer by approximately 20% for women 40 to 49

***"I encourage women to have regular exams. Early detection saved my life."***

years of age and 20-35% for women 50-69. While national mammography rates have been declining, Rhode Island rates have seen a modest but steady increase from 81% in 2000 to 86% in

2004 for women over 50.<sup>58</sup> RI has made tremendous strides against breast cancer. In 1969, the female breast cancer death rate was 21% higher in RI than in the U.S. as a whole. This gap has decreased dramatically. In 1999-2003, the female death rate in Rhode Island was 25.0 (age adjusted, per 100,000) compared to 26.0 for the U.S.<sup>59</sup> The U.S. Preventative Services Task Force (USPSTF) currently recommends a mammogram with or without a clinical breast exam every 1-2 years for women 40 and older.<sup>60</sup>

## **SCREENING FOR CERVICAL CANCER**

In addition to mammography, the state's strong commitment to early screening has made a difference in the area of cervical cancer screening. The Women's Cancer Screening Program, RIte Care (Rhode Island's Medicaid Managed Care Program), Title X, and private efforts have resulted in high cervical cancer screening rates. The USPSTF recommends initiating screening with a pap test within three years of onset of sexual activity or age 21, whichever comes first and then repeating the test one to three years thereafter, depending on the

individual.<sup>61</sup> Follow-up care for abnormalities may require colposcopy and removal of pre-cancerous lesions, to prevent the progression of the disease. It is important, then, that follow-up care also be widely available.



## **SCREENING FOR PROSTATE CANCER**

According to the BRFSS in 2004, about 54% of RI males over 40 had a prostate specific antigen (PSA) test, a screening test for prostate cancer, in the previous two years.<sup>62</sup> Prostate cancer is the leading site of cancer in males in Rhode Island and the second leading cause of male cancer deaths for the state.

Prostate cancer disproportionately affects African American men; the mortality rate for African American males is 63.5/100,000 compared to 29.8 for whites and 12.2 for Hispanic men (although Hispanic ethnicity rates are likely to be inaccurate due to underreporting of Hispanic ethnicity).<sup>63</sup> Given that prostate cancer is such a significant cause of morbidity (disease) and mortality (deaths), a screening test that accurately detects a life-threatening tumor has the potential to prevent many early deaths.

Prostate cancer is unique among cancers, however, in its course of progression and is

***“Because a decision of whether to be screened for prostate cancer is a personal decision, it’s important that each man talk with his doctor about whether prostate cancer screening is right for him.”***

not easily amenable to early detection by screening. There is currently no scientific consensus of how to accurately screen for prostate cancer in order to

reduce mortality. Randomized, controlled clinical trials are currently under way that could clarify the efficacy of various screening methods and bring consensus around an appropriate screening protocol.

### SCREENING FOR SKIN CANCER

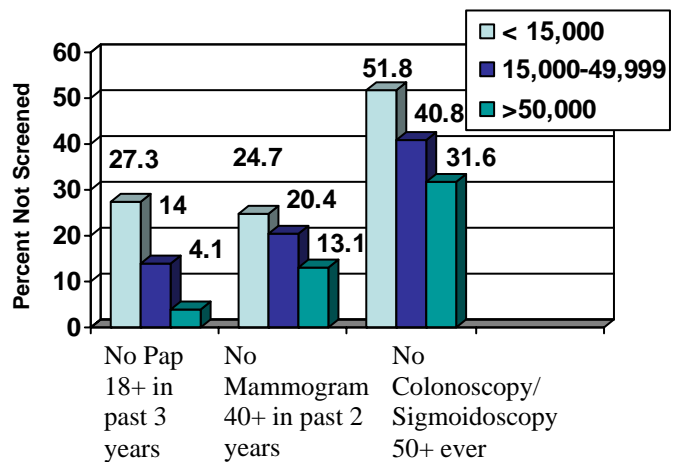
The efficacy of routine skin self-examination for reducing melanoma mortality has also not been proven. Some studies, however, have suggested there is a benefit in doing skin self-examination. One case-control study suggested a 63% reduction in melanoma mortality associated with monthly skin self-examinations.<sup>64</sup> The importance of finding these lesions early in their evolution is critical as the prognosis depends on the depth of the primary lesion. Melanoma can be detected by screening for early detection as it is visible on the skin by a primary care provider, a partner, or oneself. In Rhode Island, one random digit dial survey shows that only 9% of adults in Rhode Island perform thorough skin self-examination at least once every few months, and 75% reported that their healthcare provider never brought it up. Only 7% reported that their physician examined all areas of their skin likely to have a lesion during physical exam.<sup>65</sup> Evidence suggests that thorough

skin self exam would lead to earlier detection of and reduced mortality due to melanoma, particularly for fair skinned individuals who are at greatest risk. Primary care providers are in the best position to encourage this as a protective health habit.

### SCREENING DISPARITIES

The data show that mammogram screening rates for Hispanics are similar to that of white, non-Hispanics. Pap test data in RI indicates that the cervical cancer screening rate for black women 18 and older is 91% compared to 88% for white, non-Hispanic women 18 years or older and 94% for Hispanic women in the same age range.<sup>66</sup> The data also show that despite the success of screening programs targeting at-risk populations, those with the lowest income are the least likely to be screened.

Figure 15. Screening Rates by Income



Center for Disease Control & Prevention, BRFSS data, 2004.

**Goal: Increase proven, science-based cancer screening rates among all segments of the population in Rhode Island.**

**OBJECTIVE A:**

- **Increase access to primary care for the medically underserved.**

**STRATEGIES:**

1. Improve ongoing data collection and dissemination to assess gaps in screening.
2. Support adherence to both mandated and recommended Federal Culturally and Linguistically Appropriate Services (CLAS) standards, especially in primary care.<sup>67</sup>
3. Support efforts to ensure healthcare coverage and a medical home for all residents of Rhode Island.

**COLORECTAL CANCER**

**OBJECTIVE B:**

- **Increase rates of endoscopic screening for colorectal cancer among Rhode Island adults ages 50 and older by at least 10% before 2012.**

**STRATEGIES:**

1. Ensure standards or incentives for insurers to increase screening rates.
2. Increase awareness and compliance among primary care providers of the American College of Gastroenterology colorectal cancer screening recommendations.
3. Provide multi-lingual, culturally competent patient education materials such as posters and brochures on colorectal cancer screening to primary care providers in Rhode Island.
4. Encourage all insurers to drastically reduce or eliminate co-pays for colonoscopy screening.
5. Increase the use of patient navigators and medical interpreters, when appropriate.
6. Increase the use of electronic medical records for prompts, reminders, and

organization of data for primary care practices.

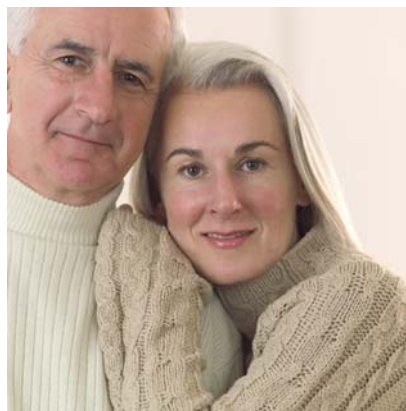
7. Facilitate communication between community-based organizations and providers around the importance of colorectal cancer screening.

**OBJECTIVE C:**

- **Increase public awareness of the screening recommendations and importance of compliance with colorectal cancer screening.**

**STRATEGIES:**

1. Develop a culturally appropriate social marketing campaign to increase awareness of colorectal screening, recognizing March as Colorectal Cancer Screening month.
2. Challenge each health insurer and hospital to come up with a plan to increase screening awareness and acceptance rates.



**OBJECTIVE D:**

- **Improve access to colorectal cancer screening among un/underinsured persons using the Women's Cancer Screening model.**

**STRATEGIES:**

1. Seek additional sources of funding for a colorectal cancer screening program.



2. Educate policy makers about the importance of and barriers to colorectal cancer screening for the un/underinsured.
3. Identify key stakeholders on a federal and state level to build support for a Colorectal Cancer Screening program.
4. Recognizing that colonoscopy is the preferred method of screening, increase the use of sigmoidoscopy in combination with fecal occult blood testing (FOBT) when colonoscopy is not possible.

**OBJECTIVE E:**

- **Create a data collection mechanism that differentiates between sigmoidoscopy and colonoscopy.**

**STRATEGIES:**

1. Recommend a distinction be made in the BRFSS between screening modalities of sigmoidoscopy and colonoscopy.
2. Develop a state-wide solution utilizing community hospitals to increase screening for colorectal cancer.

**BREAST CANCER**

**OBJECTIVE F:**

- **Increase percentage of women aged 40+ who have had a mammogram in the past two years from 86% to 90% by 2012.**<sup>68</sup>

**STRATEGIES:**

1. Perform assessment to identify and screen those who do not currently qualify for and are not screened by the current programs.
2. Support ongoing efforts by the Women’s Cancer Screening Program to identify and address gaps among those served within their target audience; with particular attention to identifying possible racial or ethnic disparities.
3. Expand and increase support for the Women’s Cancer Screening Program,

including outreach and publicity for the program.

4. Search for funding opportunities to provide mammograms for women aged 40-50 who do not have coverage.
5. Increase awareness of recommendations among all populations – the insured *and* the uninsured.
6. Reduce wait-times for mammograms and specialty care.
7. Increase awareness of MRI breast imaging guidelines among providers for high risk individuals.



**CERVICAL CANCER**

**OBJECTIVE G:**

- **Increase the proportion of women, ages 18 and older, who have received a pap test in the past 3 years from 89% to 95% by 2012.**<sup>69</sup>

**STRATEGIES:**

1. Determine and address who is not being served by the current program.
2. Increase and maintain funding and support for the proven programs for cervical cancer screening such as the Women’s Cancer Screening Program, Title X and RItE Care.
3. Look for funding/support to continue efforts by the program to target the underserved.

4. Increase knowledge of publicly funded cervical cancer screening programs in underserved communities.
5. Educate public about implications of the new HPV vaccine; and reinforce the importance of screening even after having the HPV vaccine.
6. Decrease wait-times for treatment of pre-cancerous lesions regardless of income.

## PROSTATE CANCER

### *OBJECTIVE H:*

- **Increase the number of Rhode Island men who have knowledge about the benefits and risks of prostate cancer screening and detection.**

### *STRATEGIES:*

1. Increase awareness of the most up-to-date information in making decisions about prostate cancer screening and detection.
2. Monitor on-going prostate cancer screening clinical trials for new data.
3. Recommend new objectives and strategies based on increased evidence.
4. Disseminate information to all health professionals, key stakeholders, and the general public in culturally appropriate ways.

### *OBJECTIVE I:*

- **Increase access to prostate cancer screening when desired, as supported by scientific evidence.**

### *STRATEGIES:*

1. Increase access to prostate cancer community-education programs that give priority to the medically underserved (these programs may or may not include screening).
2. Sustain community-based outreach efforts to increase awareness of prostate cancer screening.

3. Generate educational materials utilizing culturally and linguistically appropriate methods and materials.
4. Promote dissemination of patient education materials that describe the benefits and risks of prostate cancer screening and detection, particularly for high risk groups.



## SKIN CANCER

### *OBJECTIVE J:*

- **By 2010, Increase percentage of Rhode Islanders who perform thorough skin self exams from 9% to 25%.<sup>70</sup>**

### *STRATEGIES:*

1. Assess baseline for self-exams, provider exams, and set goals for improvement.
2. Monitor evidence on skin screening and self exams as it evolves.
3. Encourage healthcare providers to perform skin screenings or to recommend self-screening during annual physicals.
4. Promote skin self-exams as a health habit for all people.
5. Increase educational programs for providers and the public on the importance of skin screening and self-exams. Disseminate existing educational materials.
6. Ensure that educational materials discuss the differing risks and sites of possible skin cancer by skin color and encourage people to monitor their skin accordingly.

# Treatment

A cancer diagnosis is not something anyone expects to have happen, but it will be a reality for an estimated 6,360 Rhode Islanders this year alone.<sup>71</sup> Every Rhode Island resident should have ready access to compassionate, state-of-the-art cancer treatment should they face this challenge.

As the smallest state “in the union,” Rhode Island has a unique treatment landscape. Rhode Island has the will and the ability to provide high quality care. Even though Rhode Island has a lower reimbursement

**“Rhode Island has the will and the ability to provide high quality care.”**

rate when compared to the surrounding states, the state has been able to attract high quality medical providers and researchers. This is

possible because of Rhode Island’s small size, attractive geography, and close knit communities. Rhode Island has many qualified specialists in a consolidated area and is home to nationally recognized institutions, including Brown University Medical School, and a number of high quality acute care medical centers.

*The National Cancer Institute’s Cancer Control Objectives for the Nation: 1985-2000* makes a convincing case for the widespread adoption of state-of-the-art cancer therapy, arguing that doing so would reduce the overall cancer mortality rate in the U.S. by 26%. One of the two primary strategies that they suggest are the adoption of the American College of Surgeons’ (ACoS) approved cancer programs and the other is increased enrollment of eligible

patients in approved clinical trials. The state already has American College of Surgeons (ACoS) approval for 10 out of the 12 acute care hospitals, and is aiming for 100% certification in the next 2 years. ACoS approved cancer programs are required to achieve high standards of cancer care and treatment, including accurate tumor staging with American Joint Committee on Cancer (AJCC) staging methodology. ACoS approved cancer programs have active quality assurance mechanisms designed to ensure optimal, multidisciplinary care of the patient with cancer.

Rhode Island does not, however, have an NCI-designated Comprehensive Cancer Center. This limits access to novel treatments, clinical trials, and sub-specialization that may be required for rare or complicated conditions. Consequently, there is no central focal point for referrals.

Over the years, the trend has been for more and more cancers to be treated exclusively outside of the hospital. This change in treatment pattern poses new challenges for data collection and surveillance, and needs to be closely monitored to respond to the new challenges that arise.



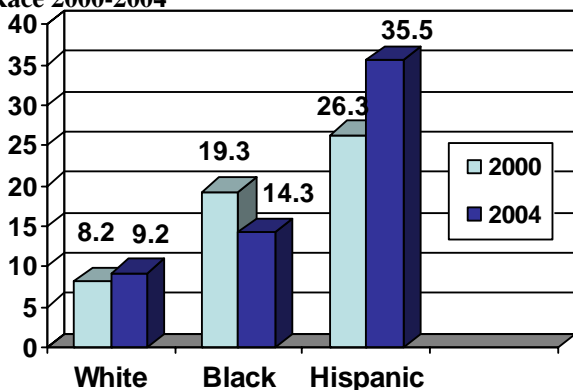
Although disparities in treatment may take many different forms, lack of proper healthcare coverage has an impact on the level of care in many important ways. Without adequate healthcare coverage an individual is less likely to have a primary care provider, to receive preventive health screenings, to be diagnosed with a cancer at an early stage and to be referred promptly.<sup>72</sup> Rhode Island used to have one of the highest rates of insurance in the nation, but today,

**“Fewer Rhode Islanders have health insurance than at any time in the last fifteen years”**

fewer Rhode Islanders have health insurance than at any time in the last 15 years. According to the CDC in 2005, 14%

of RI adults age 18 to 64 reported not having any health care coverage. Health insurance rates vary widely among different populations. While 7.9% of Whites report having no healthcare coverage, 17.1% of Blacks and 36.7% of Hispanics report not having any source of health care coverage.<sup>73</sup> Wide differentials in healthcare coverage also exist along lines of socio-economic status, educational level, age, and immigration status.

Figure 16. RI Uninsured Rates of Adults 18-64 by Race 2000-2004



Center for Disease Control, BRFSS, 2004.

## PEDIATRIC CANCER

Pediatric cancer care requires specialized treatment and a unique approach. Treatment



of childhood cancer, even when cured, is extremely traumatic both for the children and their families. Thus childhood cancer should be treated as a family disease. Every effort needs to be made to bring

support systems not only into the treatment regimen but also into the child's recovery. Quality of life and long-term supportive or palliative care may still be needed. Long term survivors of childhood malignancies are also at high risk for second malignancies and other side effects of their disease and treatment.<sup>74</sup>

**Goal #1: Ensure access to cancer care for all residents of Rhode Island.**

### OBJECTIVE A:

- **Increase equitable access to treatment and minimize disparities in cancer care.**

### STRATEGIES:

1. Support efforts to establish universal healthcare coverage in Rhode Island.
2. Establish benchmarks for acceptable wait-times from diagnosis to initiation of treatment.
3. Increase support for cancer treatment provided under the Women's Cancer Screening program for medically underserved women and support efforts to ensure treatment for medically underserved men.



4. Reduce financial burden by accelerating the process of acceptance to Medicaid for cancer patients to a maximum of 30 days.



**OBJECTIVE B:**

- **Assure access to comprehensive, multidisciplinary cancer care at a pediatric cancer center for children and adolescents with cancer.**

**STRATEGIES:**

1. Support, recruit, train, mentor and retain skilled pediatric oncology professionals.
2. Assess the effects of childhood cancer on family function and quality of life.
3. Develop appropriate culturally sensitive interventions for positive outcomes.
4. Educate survivors, their families, and their primary care providers about screening and treatment for the late effects of childhood cancer.
5. Maintain high level of participation of children and adolescents in approved clinical trials.

**Goal #2: Improve the quality of cancer treatment provided in Rhode Island.**

**OBJECTIVE C**

- **By 2012, providers in Rhode Island will follow NCCN treatment guidelines for all cancer patients.**

**STRATEGIES:**

1. Adopt guidelines set forth by the National Comprehensive Cancer Network (NCCN) statewide and identify gaps in utilization and implementation.
2. Support professional organizations in efforts to establish best practices through increased awareness and education about the NCCN guidelines.

**OBJECTIVE D:**

- **By 2010, all hospitals in RI treating cancer patients will be ACoS approved.**

**STRATEGIES:**

1. Provide public recognition for any hospital gaining ACoS approval
2. Assist non-ACoS approved hospitals with the approval process.

**OBJECTIVE E:**

- **Improve quality of treatment data maintained by the RI Cancer Registry.**

**STRATEGIES:**

1. Ensure consistent collection of and reporting of the data elements such as race, ethnicity, and country of origin in compliance with state and federal guidelines.
2. Promote completeness in reporting, especially in private clinics and outpatient services through compliance with the National Program of Cancer Registries (NPCR) standards.



**Goal #3: Enhance the treatment experience for cancer patients.**

**OBJECTIVE F:**

- **Increase patient satisfaction with their treatment experience as evidenced by an increase in patient satisfaction survey scores of at least 5% over the current baseline by 2012.**

**STRATEGIES:**

1. Increase use of patient navigation tools and programs that ensure a seamless transition for patients and their families between services and agencies.
2. Increase access to complimentary care therapies.
3. Ensure ready access to options in social/emotional support for patients and their social networks.
4. Compile and maintain a state-wide support resource guide.

**OBJECTIVE G:**

- **By 2012 all cancer treatment providers will be in compliance with Culturally and Linguistically Appropriate Services (CLAS) standards.**

**STRATEGIES:**

1. Identify and reduce gaps in interpreter services.
2. Assess need and provide training and technical assistance to professionals, assuring provision of culturally competent care.
3. Identify and reduce gaps in the diversity of the workforce at all levels.

**OBJECTIVE H:**

- **Increase patient transportation options for cancer treatment in Rhode Island.**

**STRATEGIES:**

1. Identify transportation resources within all RI communities.
2. Identify gaps in transportation services for patients seeking care.
3. Increase funding as needed for transportation assistance.

**OBJECTIVE I:**

- **By 2012, all 12 hospitals will have a resource room with access to cancer treatment education and information resources in RI.**

**STRATEGIES:**

1. Establish a resource center in every ACoS approved hospital that includes internet access and a phone.
2. Ensure the presence of high-quality and web-based educational materials that are culturally and linguistically appropriate in ACoS certified hospital resource rooms.
3. Encourage the use of cancer information hotlines such as American Cancer Society and National Cancer Institute hotlines.



## Workforce Issues

In order to carry out the prevention, detection, treatment, and support efforts outlined in this plan, Rhode Island needs an adequate supply of qualified, skilled personnel. As the population is aging and cancer appears disproportionately among older populations, the shortage of qualified personnel in the health care industry will have particular significance to cancer control services. Age-specific cancer incidence rates show that deaths from cancer increase dramatically with age. Over 70% of invasive cancer cases occur in the over-60 population.<sup>75</sup> Although at this time there is thought to be an adequate supply of physicians, the number of nurses for the state does not meet the growing demand.

### ADEQUATE SUPPLY OF WORKERS

Rhode Island faces particular challenges with a nursing shortage. Due to the aging of the baby boom generation and increased life expectancy, demand for nurses is expected to continue to increase while the supply dwindles. Today, the supply of nurses in Rhode Island is 8% less than the demand.

***“By 2010 the nursing shortage will rise to 25% and will rise to 55% by 2020 if current trends continue.”***

by 2020 if current trends continue.<sup>76</sup> The nursing shortage is projected to be more severe in Rhode Island than in the nation as a whole and more than in neighboring states such as Massachusetts. This means that Rhode Island is competing with both other jobs and other states for the same nurses.

Projections for the future indicate that by 2010 the nursing shortage will rise to 25% and will rise to 55%

Addressing the nursing shortage means increasing the training and development of new nurses, and also improving the retention of trained nurses in the field. Recruitment and retention strategies that encourage a diverse and qualified workforce to join the nursing profession and to stay in it will require improved working conditions, increased respect and autonomy, and improved financial incentives for both nurses and nursing faculty. Specially trained nurses are required in many of the sub-specialties essential to cancer care, including oncology nursing, visiting nurse services, hospice nurses, and surgical nurses. Addressing the nursing shortage plays a vital role in cancer control.



### WORKFORCE COMPOSITION

Given the increasing diversity of the population of Rhode Island, it is important to increase the minority representation among healthcare workers to reflect the demographics of Rhode Island residents. Minority representation, especially in leadership positions, will increase cultural competency and improve patient care outcomes.

Cultural sensitivity training and an understanding of diverse cultures by all members of the healthcare profession can serve to increase the effectiveness and acceptability of their recommendations.

Communication across cultures and languages can pose a particular challenge. Especially relevant are Medical Interpreters who are specially trained to broker misunderstandings that can arise from differences in language and culture in a healthcare encounter. Medical Interpretation is an evolving profession whose increased use would both enhance the diversity of the workforce and add an element of cultural and linguistic appropriateness.



## **QUALITY OF WORKFORCE**

The workforce needs to have access to high quality education around cancer control in nursing, medical, and pharmacy schools.

Cancer control education should prepare individuals with current knowledge around prevention, detection, treatment, palliative care, and quality of life for survivors and their families.



Continuing education opportunities for health professionals must exist in this area. It is increasingly important to provide easily accessible continuing education opportunities. Online, teleconference, or interactive educational software should supplement other opportunities that some may find hard to attend.

***“Healthcare professionals are often the primary source of information about cancer risks and screening. They must be well-trained active participants in the cancer control plan for it to be effectively carried out.”***

Healthcare professionals are often the primary source of information about cancer risks and screening. They must be well-trained active participants in the cancer control plan for it to be effectively carried out. Physicians, nurses, nurse practitioners, mental health providers, social workers, cancer registrars, dentists, dieticians and health educators and others require continuing education for their knowledge to stay current.

**Goal: Reduce workforce gaps and ensure an adequate supply of diverse and highly trained professionals in all aspects of cancer care and control.**



**OBJECTIVE A:**

- **Ensure an adequate supply of workers, with particular attention to increasing the number of nurses by at least 25% by 2012.**

**STRATEGIES:**

1. Increase recruitment of new nurses through increased training opportunities.
2. Encourage retention of currently practicing nurses by addressing issues of job satisfaction, work hours, adequate pay, career ladders, educational opportunities, respect and autonomy.
3. Support strategies to increase and maintain the number of cancer registrars in RI.

**OBJECTIVE B:**

- **Decrease disparities in care by ensuring a diverse and culturally competent workforce reflecting the racial and the ethnic make-up of the state.**

**STRATEGIES:**

1. Ensure compliance with National Standards on Culturally and Linguistically Appropriate Services (CLAS)<sup>77</sup>.
2. Implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the state.
3. Ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.
4. Provide cultural competency training for immigrant populations seeking employment in Rhode Island healthcare settings.

5. Increase language access provision and promote the use of Medical Interpreters in the healthcare setting.
6. Facilitate training of personnel responsible for collecting patient information at intake to ensure compliance with the Office of Management and Budget's (OMB) Statistical Policy Directive No. 15 concerning Race and Ethnic Standards for Federal Statistics and Administrative Reporting.<sup>78</sup>

**OBJECTIVE C:**

- **Support efforts to increase the number of Oncology-Certified Nurses from 108 to at least 150, especially in underserved areas.**<sup>79</sup>

**STRATEGIES:**

1. Provide increased oncology-certification opportunities in Rhode Island.
2. Support continuing education opportunities related to cancer prevention, detection, and care for all levels of professionals.
3. Attain enhanced workforce knowledge, skills and practices in cancer control through continuing education opportunities related to cancer.



## Clinical Trials

Clinical trials have led to advances in all aspects of cancer care and are a critical part of the research process. Today's most effective cancer treatment, prevention, screening and early detection approaches are based on clinical trial results.<sup>80</sup>

Unfortunately, only 3 percent of U.S. adults diagnosed with cancer actually participate in cancer clinical treatment trials<sup>81</sup>. Increased participation in clinical trials is an essential component of ensuring high-quality, up-to-date cancer prevention, detection, and treatment. According to the Harris poll survey<sup>82</sup> of cancer patients conducted in 2000, most patients (85%) were either unaware or unsure whether participation in clinical trials was an option for their treatment. Most (75%) actually indicated that they would have been willing to participate in a study had they known it was available. In this same survey, those who received treatment through a clinical trial found it to be a positive experience. 97% said that they were treated with dignity and respect and that the quality of care they received was excellent or good. 86% said their treatment was covered by insurance.

Rhode Island specific data is insufficient to describe the numbers of people enrolled in clinical trials at this time and a comprehensive assessment is recommended to address this lack. Some barriers to participation, however, appear to be universal in their presence and impact. What we know about enrollment in clinical trials in RI is that there are 104 cancer clinical trials listed on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) in 2007.<sup>83</sup> Rhode Island does have legislation supporting healthcare coverage for clinical

trials. Since 1994, health insurance carriers in Rhode Island have been required to cover experimental cancer treatment as part of phase III and phase IV trials and many experimental treatment and investigational drugs in phase II trials. At the time, this was the only state in the nation with such legislation.



There are significant barriers which must be overcome to encourage greater awareness and participation in cancer clinical trials throughout Rhode Island. Lack of awareness

among healthcare providers is one of the most common reasons physicians fail to refer patients to trials<sup>4</sup>. Physicians might feel genuine concern about losing control of their patients' care to a study investigator and facility. Other providers may not have the time or the infrastructure and support within their institutions that would allow them to broach the topic with patients. Lack of awareness among the general public also contributes to low rates of participation. Even if patients know about clinical trials they may be reluctant to participate. Patients may harbor feelings of fear, distrust, and suspicion about the clinical research process. They fear being a "guinea pig." There are also practical barriers such as lack of access, financial issues, language differences and home/family considerations.

Populations that are underrepresented in clinical trials include low income, elderly and racial/ethnic minorities, who unfortunately also bear a disproportionate burden of cancer morbidity and mortality.<sup>84</sup> These and other impediments to participation have been heightened further for minority groups and traditionally medically underserved audiences, some of whose cultural and historical legacies include serious abuse within the framework of clinical research. Racial and ethnic minority groups are underrepresented in clinical trials nationally; less than 10% of participants in clinical trials testing cancer drugs during 1995-1999 represented African American, Asian/Pacific Islanders, Hispanics, and Native Americans, collectively<sup>85</sup>.



Without representation from all segments of the population, researchers cannot learn how their findings affect different groups and the ability to generalize

findings is limited.<sup>86</sup> Broad participation in clinical trials increases access to state-of-the-art cancer care both today and tomorrow.

**Goal: Increase awareness, access, and participation in cancer clinical trials by Rhode Island residents.**

**OBJECTIVE A:**

- **Establish a baseline for clinical trial participation in 2008 and increase that number by at least 10% by 2012.**

**STRATEGIES:**

1. Perform an assessment of capacity for delivery of cancer clinical trials in RI.
2. Perform an assessment of barriers to awareness, access and participation among cancer patients in cancer clinical trials in Rhode Island.
3. Pending the assessment results, develop a train-the-trainer program for educating healthcare professionals about cancer clinical trials and communicating about them to patients and families.
4. Deliver appropriately tailored trainings and programs to key health professional organizations, patient groups, and community based organizations, with emphasis on those reaching ethnic minority and medically underserved audiences.
5. Ensure that facilities providing cancer clinical trials have mechanisms in place to address specific barriers to participation, especially financial concerns and issues.
6. Promote use of an existing and accessible repository listing of all cancer clinical trials available in Rhode Island, such as the NCI's Physician Data Query (PDQ) database.
7. Support the existing telephone and on-line resources for cancer patients and their families regarding state-specific information on available clinical trials in RI from organizations such as the ACS and NCI.
8. Support the Rhode Island Cancer Registry and other appropriate organizations to expand their capacity to collect and report data on participation in cancer clinical trials at RI facilities.
9. Develop and establish an NCI-affiliated Rhode Island Community Cancer Oncology Program (CCOP) by 2015.

## Palliative Care

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families. Palliative care prevents or treats the symptoms of the disease, side effects caused by treatment, and psychological, social and spiritual problems related to the disease and its treatment. Palliative care does not alter the course of the disease but can improve the quality of a patient's life. The care strives to meet physical needs through pain relief and to emphasize the patient's and family's rights to participate in an informed discussion about their choices. Hospice, an approach to palliation, provides care to terminally ill patients who are in the final stage of their illness. Unfortunately, many terminally ill cancer patients still do not receive adequate palliative care. As a result, many experience very poor quality of life at the end of life. Many live and die in pain.



Second only to heart disease as a leading cause of death in Rhode Island, cancer is one of the most common ways for a resident of Rhode Island to die. While at least 70% of Americans would prefer to die at home, only about 16.7% of Rhode Islanders die at home, which is less than ever before and less than in the U.S. as a whole.<sup>87, 88</sup>



Nursing homes are becoming a more common site of death for patients at the end of life. In 1989, 19.5% of all non-traumatic deaths occurred in nursing homes, but by 2001 the number had more than doubled to 44.1%.<sup>89</sup> Nursing homes in Rhode Island are often unable to provide the specialized palliative care and support that patients and

**“Many Americans don’t know about these options for good end-of-life care and thus don’t ask for them.”**

families desire.

Although patients generally reported less pain in Rhode Island Nursing homes than in the general U.S., they rated persistent severe pain among

patients with cancer as slightly higher than the national average. About 46% of nursing home patients with cancer in Rhode Island reported severe pain.<sup>90</sup> Palliative care may be provided in nursing homes, at private homes, or in hospitals. The most common site of death is the hospital, and despite their best efforts some patients report having unmet needs for symptom amelioration, physician communication, emotional support, and treatment with respect.<sup>91</sup>





Hospice and palliative care are currently underutilized in Rhode Island. Only one out of the 16 RI hospitals has a formal palliative care program leaving the majority of hospitalized patients without access to palliative care services.<sup>92</sup> While most hospitals are able to access hospice consultation and services for their terminally ill patients, cancer patients who are not terminally ill do not have access to a palliative care team. Cancer patients are often not aware of palliative care as an option and when they are referred it is often in the last few weeks of life after expensive, unwanted treatment and uncontrolled pain. In fact, only about 40% of terminally ill cancer patients receive hospice care, and Rhode Island has the shortest length of stay on hospice in the country with an average of just 13.7 days.<sup>93</sup>

Hospice represents a proven, systematic approach to the provision of palliative care which has been successful in both improving the quality of life and reducing healthcare costs at the same time. Research shows that there is a clear reduction in healthcare costs associated with palliative care at the end of life.<sup>94</sup> There is a documented decrease in both routine and ICU hospital stays, decreases in emergency room visits, and physician fees.<sup>95</sup> Through the reduction of misdirected and painful curative technologies at the end of life, palliative care

has the potential to provide patients with what they want, and also provide significant savings in healthcare costs.<sup>96</sup>

Hospice Care is also not utilized equally across different populations in Rhode Island. Although cancer mortality rates are highest among African Americans, they are underrepresented among palliative care

***“Many Americans fear spending their final days in intensive care ‘connected to machines.’”***

patients. One national study found that more than 50% of African American patients who were nearing the end of life, were not informed about

hospice as an option for end of life care. Of those who were informed, 77% chose to enroll.<sup>97</sup> Researchers have documented differences in treatment patterns, pain management, and the use of hospice care exists between African American breast cancer patients and women in other ethnic groups.<sup>98</sup> Studies have shown that African American and Hispanic patients report increased rates of pain, pain-related distress, and more pain related interference with function than white patients and that they are often under-treated for cancer pain.<sup>99,100</sup> A high priority for the Rhode Island Palliative Care work group is to increase access of palliative and end of life care to members of minority groups diagnosed with cancer.



**Goal: Improve access to palliative care for all patients seeking end-of-life care due to cancer in Rhode Island.**

**OBJECTIVE A:**

- **All acute care Rhode Island Hospitals will have inpatient palliative care teams by 2012.**

**STRATEGIES:**

1. Advocate for the formation of palliative care teams in RI hospitals that include physicians, nurses, social workers, and spiritual care practitioners.
2. Educate hospital discharge planners, emergency room staff, hospital clinic directors about hospice eligibility guidelines and program components.
3. Collect data to assess quality, cost and access to end-of-life care in a variety of settings; disseminate information to key decision-makers.
4. Encourage requirements for continuing medical and nursing education about end-of-life care.



**OBJECTIVE B:**

- **By 2012, improve pain management quality measures in nursing homes by 20%.**

**STRATEGIES:**

1. Perform assessment to determine extent to which quality end-of-life care improves in nursing homes that collaborate with hospice and palliative care.
2. Improve access to information for Oncologists and Primary Care Providers regarding hospice and palliative care services for nursing home residents with cancer.
3. Update the available Hospice and Palliative Care Services information available for residents in Long Term Care in RI.
4. Identify and inventory pain clinics available in RI.
5. Identify an agent in the nursing home industry that can keep palliative care resources current and available to the community.

**OBJECTIVE C:**

- **Increase access to palliative care and hospice care for nursing home residents living with cancer from 35% to 50% by 2012.<sup>101</sup>**

**STRATEGIES:**

1. Encourage nursing home physicians to offer palliative care consultation services to all nursing home residents with cancer.
2. Develop and make available to RI Nursing Homes a comprehensive list of hospice and palliative care services available in RI.
3. Include hospice education and eligibility guidelines in the training of Nursing Home Surveyors.

**OBJECTIVE D:**

- **Require all licensed health insurance companies, HMOs, and non-profit medical and hospital service corporations to provide cancer patients with palliative care treatment as a benefit by 2010.**

**STRATEGIES:**

1. Inform key decision makers about importance of healthcare coverage for palliative care to improve client satisfaction and cost savings in healthcare.
2. Identify and eliminate financial obstacles that impede access to palliative care for cancer patients.
3. Encourage contributions to charitable entities for the benefit of patients in need of palliative care.
4. Encourage licensed health care providers to participate in free or and low cost prescription drug programs for the benefit of patients in need of palliative care.
5. Encourage alternative and complementary treatment provider to offer services at reduced costs or free for palliative care cancer patients.



**OBJECTIVE E:**

- **Provide quality palliative and end-of-life care to cancer patients of all races and ethnicities by 2012.**

**STRATEGIES:**

1. Gather data about hospice admission rates and palliative care consultation rates for cancer patients of underrepresented minority groups.
2. Develop and support community outreach/educational programs that increase awareness of hospice and palliative care for cancer patients in minority communities.
3. Create and disseminate culturally relevant information about hospice and palliative care programs.
4. Support efforts to increase cultural sensitivity in delivery of care to cancer patients from all racial and ethnic groups in need of palliative or end-of-life care according to the CLAS standards.
5. Hospice agencies will ensure that all employees receive training in cultural competency/sensitivity.
6. Hospice and palliative care agencies and providers will intensify recruitment of minority health care providers and employees.



# Survivorship

Cancer patients and their families need to be empowered to make effective choices not only during active treatment but also after it has been completed. With the passage of time, the needs and problems of people who have had cancer change. Some require few services while others find it difficult to continue without support and many resources to help them.

Rhode Island has the highest overall cancer incidence rate among the 50 states.

Estimated new cancer cases for 2007 in

***“RI has the highest overall cancer incidence rate among the 50 states.”***

Rhode Island indicate an increase of 460 (7%)

new cases compared to the previous year for an estimated 6,360 new cases in 2007 (see Figure 16).<sup>102</sup> Currently, approximately 62% of cancer survivors are expected to live at least 5 years after diagnosis.<sup>74</sup> Survival rates have been increasing, reflecting progress in diagnosing certain cancers at an earlier stage and improvements in treatment. The National Cancer Institute (NCI) estimates that approximately 10.5 million Americans with a history of cancer were alive in January 2003.<sup>103</sup> Some were cancer-free, while others

still had evidence of cancer and may have been undergoing treatment. The NCI estimate does not include

***“Survival rates have been increasing, reflecting progress in diagnosing certain cancers at an earlier stage and improvements in treatment.”***

others affected by a cancer diagnosis, such as family members, caregivers, and friends.

**Figure 17. Rhode Island Cancer Rates**  
(age adjusted per 100,000)

	RI	U.S.
<b>Annual Incidence Rate</b>	627.2	562.1
<b>Annual Death Rate</b>	248.1	243.7
<b>Estimated New Cancer Cases, 2007</b>	6,360	1,4449.20

American Cancer Society Facts and Figures, 2007

Public health programs address the prevention and control of health problems affecting large groups of people. Although many public health initiatives address early detection, prevention, and control of cancer, the Rhode Island Cancer Control Program is new to the cancer survivorship area.





### ***Redefining Cancer Survivorship***

When cancer was considered incurable, the term “survivor” was used to describe family members who survived the loss of a loved one to cancer. As knowledge and success in understanding cancer increased, physicians

***“Survivorship is more than beating the odds. It’s about living life to the fullest.”***

began to use a 5-year time frame to define survivorship.

If cancer did not recur in the 5 years following either diagnosis or treatment, patients were considered to have become “survivors.” Recently, strong advocacy efforts led by national organizations helped to redefine “cancer survivor.” Throughout this section, the term “cancer survivors” refers to those people who have been diagnosed with cancer and the people in their lives affected by the diagnosis, including family members, friends, and caregivers.



Further definition of cancer survivorship by Mullan in 1985 in “Seasons of Survival: Reflections of a Physician with Cancer,” was the first to discuss the experience of cancer in terms of a progression of events or stages. He proposes a model of survival that includes three stages: “acute,” “extended,” and “permanent.” The **acute stage** begins with diagnosis and spans the time of further diagnostic and treatment efforts. The stage

is defined not only by the experience of the person diagnosed with cancer but also by those of the family members affected by the diagnosis. The **extended stage** begins when the survivor goes into remission or has completed treatment. A time of watchful waiting, wondering if symptoms may recur. The **permanent stage** is defined as a time when the “activity of the disease or likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested.”<sup>104</sup>

Recent cancer survivor data from the Lance Armstrong LiveSTRONG 2006 Summit identified the following unmet needs at the national level. The list included patient navigation support, standards for communication between survivors and healthcare, flexibility and responsibility of the insurance system, and empowerment of survivors and families to advocate on their behalf.<sup>105,106</sup>

**Goal: Promote the well being and quality of life of Rhode Islanders who are living with, through, and beyond cancer.**

#### ***OBJECTIVE A:***

- **Complete an initial assessment of the survivorship needs in Rhode Island by 2008.**

#### ***STRATEGIES:***

1. Examine the existing state and national data.
2. Identify health disparities affecting cancer survivors.
3. Stratify the existing state and national data.
4. Develop assessment tool to further define the specific needs of Rhode Island survivors.

**OBJECTIVE B:**

- **Identify the currently existing resources for Rhode Island survivors by June 2008.**

**STRATEGIES:**

1. Research all available resources for survivors.
2. Investigate specific resources available to health disparate populations.
3. Compile a database of all the available resources.
4. Prepare information on the opportunities that exist comparing the alignment between needs and resources.



**OBJECTIVE C:**

- **Begin community education initiative addressing the needs of Rhode Island survivors and the available resources by January 2009.**

**STRATEGIES:**

1. Educate health care providers on the needs of Rhode Island survivors and on existing evidence based practice models such as the Health Disparities Chronic Care Model and Model for Improvement.

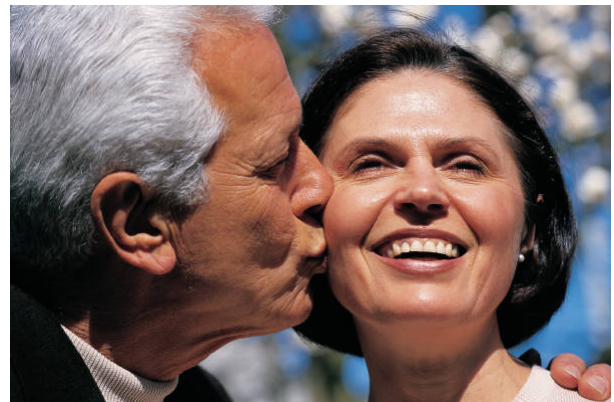
2. Educate the community regarding the needs and disparities of RI survivors and available resources.
3. Educate the broader community on resources available to Rhode Island survivors.

**OBJECTIVE D:**

- **Develop an implementation strategy by January 2010, to identify and meet the needs of cancer survivors.**

**STRATEGIES:**

1. Assess data gathered in RI to develop effective intervention using the LAF 2006 Summit information.
2. Stratify strategic interventions to address specific needs of individuals throughout the lifecycle: Pediatrics, Young Adults, Adults and Seniors.
3. Develop a statewide clearinghouse. Research and compile all available survivor resources into one statewide database.
4. Use a 1-800 number to direct survivors to all available cancer survivorship resources.
5. Create a statewide website with links to all available cancer survivorship resources.



# Surveillance and Evaluation

Quantitative surveillance of “cancer burden” -- the *determinants, incidence, and consequences* of cancer -- and its distribution across diverse population groups -- is essential to the planning and management of a comprehensive cancer control program. Surveillance for cancer control:

- defines existing cancer control challenges and issues,
- monitors cancer burden and disparities in burden over time,
- suggests priorities for the reduction of cancer burden,
- monitors the implementation of cancer control activities and
- evaluates the effectiveness of cancer control interventions.

## DEFINING PRINCIPLES

1. The use of surveillance data should be integral to the planning and management of cancer control policies and programs.
2. Surveillance data should be readily and flexibly available to cancer control programs, academic researchers, government at all levels, and the general public.
3. Surveillance and evaluation of cancer control programs should be conducted in accordance with the highest standards of data collection, management, and analysis.
4. Surveillance and evaluation efforts should anticipate the needs of all those who seek to understand, control, and reduce cancer burden.

## OVERSIGHT AND MANAGEMENT

Beginning in January, 2007, the Rhode Island Cancer Control Program shall establish and maintain a Cancer Surveillance and Evaluation Committee, (CSE) charged with the following mission:

*The essential goals of the Cancer Surveillance and Evaluation Committee (CSE) of the Rhode Island Cancer Control Program (CCP) are to reduce the cancer burden in the Rhode Island population and eliminate disparities across diverse populations. The group will work to assure the use of timely, complete, accurate, and informative data in the planning, monitoring and evaluation of cancer control policies and public initiatives. The Committee’s work will be evidence-based, will address the needs of organizations charged with the planning and implementation of cancer programs, academic and research activities, of cancer patients, caregivers and the general public, and will work expeditiously to respond to their future surveillance, monitoring, evaluation and management needs.*





## MEMBERSHIP AND ORGANIZATION

The CSE will have from six to eight core members with surveillance and evaluation experience, representing public health, academia, and community based organizations. The CSE will be led by a Chair and Vice-Chair invited to serve by the Program Manager of the Rhode Island Comprehensive Control Program. As the need arises to distribute oversight tasks, the CSE may form sub-committees.

## ADVISORS

The CSE may invite advisors on an ad hoc basis to supplement the expertise of its core members. Advisors will be invited from a variety of diverse settings, including representatives from the cancer surveillance programs, cancer control intervention programs, and research institutions.

## CORE SYSTEMS

Several data collection, management, and analysis systems form the core of basic cancer surveillance in Rhode Island, and as such, are necessary to assure the integrity and continuity of cancer surveillance data in the state. They include:

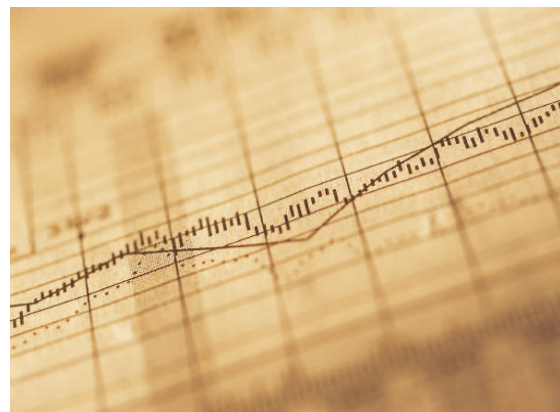
- Rhode Island Cancer Registry
- Rhode Island Behavioral Risk Factor Surveillance System
- Rhode Island Youth Risk Behavior Survey
- Rhode Island Vital Records System
- Hospital Discharge Data

As well, estimates of Rhode Island-specific cancer burden produced annually by the American Cancer Society (*Cancer Facts and Figures*, etc.) are carefully prepared, are widely disseminated and used, and should be considered a “core system.”

## RELATED SYSTEMS

Several data collection, management, and analysis systems designed to monitor various public health needs in Rhode Island, not normally considered “cancer control” surveillance systems, are nonetheless informative for the management of cancer control programs, and should be evaluated for their utility in doing so. For example:

- Rhode Island Sexually Transmitted Diseases Surveillance Program
- Rhode Island Title X Family Planning Management Program







**Goal: Assure the use of timely, complete, and accurate cancer surveillance data in the planning, management and evaluation of cancer control programs.**

**OBJECTIVE A:**

- **Assure the integrity and continuity of Core Surveillance Systems of the Cancer Control Program.**

**STRATEGIES:**

1. Convene the Cancer Surveillance and Evaluation Committee periodically to evaluate surveillance and evaluation needs related to core surveillance of cancer control.
2. Assess whether data collection, data management and reporting are meeting the needs of cancer control activities on a quarterly basis.
3. Recommend changes to data collection and management as necessary.

**OBJECTIVE B:**

- **By January 1, 2008, develop recommendations for the specific uses of cancer surveillance data in the planning, development, and management of existing and projected cancer control programs.**

**STRATEGIES:**

1. Evaluate core and related state surveillance systems for their usefulness in addressing cancer control issues, and recommend modifications as necessary to enhance their use as cancer control surveillance systems.
2. By March 1, 2008, assess and report on the evaluation needs of the Rhode Island Cancer Control Program for each of the implementation work groups.
3. By July 1, 2008, collate the reports produced and write a summary report on the evaluation needs of the Rhode Island Cancer Control program.
4. Provide advice and guidance to evaluators in the development of plans for the Cancer Control Programs.

The Cancer Surveillance and Evaluation Committee will write an annual report each July summarizing for the past year:

- Achievements in surveillance and evaluation.
- Barriers to surveillance and evaluation.
- Lessons learned.
- Recommendations for the coming year.





## Committee Members & Contributors

**Cheryl Albright**

American Cancer Society

**Susan M. Allen, PhD**

Brown University

**Barbara Baldwin**

The Partnership to Reduce Cancer in RI

**Betty Bernal**

American Cancer Society

**Beth Bock, PhD**

The Miriam Hospital/Brown University Medical School

**Lisette Boehm**

Rhode Island Department of Health

**Carrie Bridges, MPH**

Rhode Island Department of Health

**Alfred Cabral**

Rhode Island Department of Health

**Melissa Campbell**

American Cancer Society

**Carolyn Campos**

Center for Hispanic Policy and Advocacy

**Amy Chandler**

Rhode Island Cancer Council

**Kathleen Cullinen, PhD, RD**

(Co-Chair, Prevention Committee)  
Rhode Island Department of Health

**Suzette Defond, RN**

Leukemia and Lymphoma Society

**Brian Denton**

Pfizer Oncology

**Kris Diana**

National Cancer Institute's Cancer Information Service

**Christy Dibble, MD**

Women and Infants Hospital/Brown University Medical School

**Don S. Dizon, MD, FACP**

Women & Infants Hospital/Brown University Medical School

**Joyce J. Dolbec, MA**

YMCA Women's Health Programs

**Erin Dugan, MPH, CLC**

Rhode Island Department of Health

**Linda Dziobek, RN**

Rhode Island Health Center Association

**Nancy Farrell, MPH, CHES**

Centers for Behavioral and Preventative Medicine

**Alexandra Fiore**

American Cancer Society

**John Fulton, PhD**

(Chair, Surveillance and Evaluation Committee)  
Rhode Island Department of Health

**Maureen G. Glynn**

Rhode Island Department of the Attorney General

**Celia Gomes-McGillivray**

(Co-Chair, Detection and Screening Committee)  
Rhode Island Health Center Association

**Josie Halpern-Finnerty**

John Snow, Inc. (JSI)

**Jana Hesser, PhD**

Rhode Island Department of Health

**Laura Hilderley**

American Cancer Society

**Brian Hitsman, PhD**

The Miriam Hospital/Brown University Medical School

**Jennifer Kawatu, RN, MPH**

John Snow, Inc. (JSI)

**Marty Kerzer, DO**

Brown University Medical School

**Bill Koconis**

Leukemia and Lymphoma Society

**Robert Legare, MD**

Women and Infants Hospital/Brown University Medical School

**Donna Levesque**

Rhode Island Department of Health

**Nancy Libby Fisher, MMHS**

Rhode Island Department of Health

**Gilda S. Medeiros**

Memorial Hospital

**Kathy Marceau**

Rhode Island Department of Health

**Edward W Martin MD**

(Chair, Palliative Care)

Home & Hospice Care of Rhode Island

**Lori Martone-Roberts, RN, BSN, OCN**

Landmark Medical Center

**Patricia Mitchell, RN**

Kent Hospital

**John B. Murphy, MD**

Brown University Medical School

**Deborah Pearlman, PhD**

Rhode Island Department of Health/Brown University

**Carolyn Rabin, PhD**

(Co-Chair, Prevention Committee)

The Miriam Hospital/Brown University Medical School

**Ramona Rhodes, MD, MPH**

Division of Geriatrics/Brown University Medical School

**Therese Rochon, RNP, MSN, MA**

Home & Hospice Care of Rhode Island

**David Rousseau**

(Co-Chair, Surveillance and Evaluation Committee) Rhode Island Cancer Registry, Hospital Association of Rhode Island

**Cara Sammartino**

Health and Wellness Institute, Blue Cross/Blue Shield

**Barbara Schepps, MD**

Rhode Island Hospital/Brown University Medical School

**Cindy L. Schwartz, MD**

Hasbro Children's Hospital/Brown University Medical School

**LaReesa Seastrunk**

Rhode Island Hospital

**Samir Shah, MD**

Brown University Medical School

**Deborah Smith**

American Cancer Society

**David Stoll, MD**

Private Oncology Practice

**Christopher Tanguay, MPA**

Central Rhode Island Area Health Education Center

**Alvaro Tinajero, MD, MPH, ScM**

Rhode Island Department of Health/Brown University/Latino Cancer Control Task Force

**Linda Tisch, MBA**

Rhode Island Cancer Council

**Robert Vanderslice**

Rhode Island Department of Health

**John Veazey, RN, MSW**

Rhode Island Department of Health

**Michael P. Vezeridis, MD**

(Chair, Treatment Committee)

American College of Surgeons/Brown

University Medical School

**Heidi Wallace**

Rhode Island Department of Health

**Melanie Wasserman, PhD**

Brown University

**Martin Weinstock, MD, PhD**

(Chair, Detection and Screening Committee)

VA Medical Center/Brown University Medical

School

**Jessica Whiteley, Ph.D.**

The Miriam Hospital/Brown University Medical

School

**Michael Williams**

American Cancer Society

**Jim Willsey**

(Chair, Survivorship Committee)

Roger Williams Medical Center

---

**Cancer Burden Section Citations**

<sup>1</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

<sup>4</sup> State Cancer Profiles. Available at: [www.statecancerprofiles.cancer.gov](http://www.statecancerprofiles.cancer.gov). Accessed February 2007.

<sup>5</sup> Cancer Health Disparities. Available at: [www.cancer.gov/cancertopics/factsheet/cancerhealthdisparities](http://www.cancer.gov/cancertopics/factsheet/cancerhealthdisparities). Accessed February 2007.

<sup>6</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.

<sup>7</sup> Fulton J. RI Cancer Registry Data; 2007.

---

<sup>8</sup> State Cancer Profiles. Available at: [www.statecancerprofiles.cancer.gov](http://www.statecancerprofiles.cancer.gov). Accessed February 2007.

<sup>9</sup> Revisions to Federal Reporting Regulations. Available at: [www.whitehouse.gov/omb/fedreg/1997standards.html](http://www.whitehouse.gov/omb/fedreg/1997standards.html). Accessed May 3, 2007.

<sup>10</sup> Davis, K and Rowland D. Uninsured and Underserved: Inequities in Health Care in the United States. *Milbank Memorial Fund Quarterly*. 1983; 612:149-175.

<sup>11</sup> Franks, PL, Clancy CM and Gold MR. Health Insurance and Mortality. *JAMA*. 1993; 270:737-741.

<sup>12</sup> American Cancer Society. *Cancer Facts and Figures 2006*. ACS; 2006.

**Prevention Section Citations**

<sup>13</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.

<sup>14</sup> Ibid.

<sup>15</sup> Thun, M.J. & Jemal, A. How much of the decrease in cancer death rates in the United States is attributable to reductions in tobacco smoking? *Tobacco Control*, 2006; 15, 345–347.

<sup>16</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004.

<sup>17</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.

<sup>18</sup> Ibid.

<sup>19</sup> Thun, M.J. & Jemal, A. (2006). How much of the decrease in cancer death rates in the United States is attributable to reductions in tobacco smoking?

<sup>20</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004.

<sup>21</sup> French SA, Story M, Jeffrey RW. Environmental influences on eating and physical activity. *Annual Review of Public Health*. 2001; 22:309-335

<sup>22</sup> HIS Survey 2004. Available at: [www.cdc.gov/nchs/nhis.html](http://www.cdc.gov/nchs/nhis.html). Accessed January, 2007.

<sup>23</sup> Guthrie JF, Morton JF. Food sources of added sweeteners in the diets of Americans. *JAMA Diet Association*. 2000; 100:43-51.

<sup>24</sup> RI Department of Health. Prevalence of WIC Children's Overweight and Obesity, Children 24-60 Months of Age. Rhode Island; 2004.

<sup>25</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.

---

<sup>26</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004.

<sup>27</sup> RI Department of Health, *Rhode Island Plan for Healthy Eating and Active Living*. Rhode Island; July 2006.

<sup>28</sup> U.S. Department of Health and Human Services. *Physical Activity and Health: A Report of the Surgeon General*. Atlanta: Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Promotion. U.S. Government Printing Office; 1996.

<sup>29</sup> American College of Sports Medicine. American College of Sports Medicine Position Stand: The recommended quantity and quality of exercise for developing and maintaining cardiorespiratory and muscular fitness in healthy adults. *Medicine and Science in Sports and Exercise*. 1990; 22 (2): 265 – 274.

<sup>30</sup> Collaborative Group on Hormonal Factors in Breast Cancer. Breast cancer and breastfeeding: Collaborative reanalysis of individual data from 47 epidemiological studies in 30 countries, including 50,302 women with breast cancer and 96,973 women without the disease. *The Lancet*. 2002; 360:187 – 195.

<sup>31</sup> Rhode Island Department of Health (n.d.). *Breastfeeding for Breast Health*.

<sup>32</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.

<sup>33</sup> Rhode Island Department of Health (n.d.). Breastfeeding: Rhode Island Breastfeeding Data. Available at: [www.health.ri.gov/family/breastfeeding/data/php](http://www.health.ri.gov/family/breastfeeding/data/php). Accessed January 2007.

<sup>34</sup> Centers for Disease Control and Prevention, CDC. *HPV and HPV Vaccine: Information for Health Care Providers*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2006.

<sup>35</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.

<sup>36</sup> French SA, Story M, Jeffrey RW. Environmental influences on eating and physical activity. *Annual Review of Public Health*. 2001; 22:309-335.

<sup>37</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.

<sup>38</sup> Ibid.

<sup>39</sup> RI Department of Health Radon Data. Available at: <http://www.health.state.ri.us/environment/occupation/radon/index.php>. Accessed March 8, 2007.

---

<sup>40</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2006.

<sup>41</sup> Healthy RI 2010 Mid-Course Review. Available at: [http://www.health.ri.gov/hri2010/hriplan\\_midcourse.pdf](http://www.health.ri.gov/hri2010/hriplan_midcourse.pdf). Accessed May, 2007.

<sup>42</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004.

<sup>43</sup> RI Department of Health, *Rhode Island Plan for Healthy Eating and Active Living*. Rhode Island; July 2006.

<sup>44</sup> Healthy RI 2010 Mid-Course Review. Available at: [http://www.health.ri.gov/hri2010/hriplan\\_midcourse.pdf](http://www.health.ri.gov/hri2010/hriplan_midcourse.pdf). Accessed May, 2007.

<sup>45</sup> RI Department of Health, *Rhode Island Plan for Healthy Eating and Active Living*. Rhode Island; July 2006.

<sup>46</sup> RI Department of Health, *Rhode Island Plan for Healthy Eating and Active Living*. Rhode Island; July 2006.

<sup>47</sup> RI Health Interview Survey. Available at: [www.health.state.ri.us/chic/statistics/his2000.pdf](http://www.health.state.ri.us/chic/statistics/his2000.pdf). Accessed March 13, 2007.

<sup>48</sup> Healthy RI 2010 Mid-Course Review. Available at: [http://www.health.ri.gov/hri2010/hriplan\\_midcourse.pdf](http://www.health.ri.gov/hri2010/hriplan_midcourse.pdf). Accessed May, 2007.

## Detection and Screening Section Citations

<sup>49</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004.

<sup>50</sup> Ibid.

<sup>51</sup> RI Health Center Association. *Toward a Healthier RI: The Vital Role of Community Health Centers in Improving Public Health*. Rhode Island; 2004.

<sup>52</sup> RI Free Clinics. Available at: [www.rifreeclinic.org](http://www.rifreeclinic.org). Accessed February 2007.

<sup>53</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004.

<sup>54</sup> USPSTF Recommendations. Available at: [www.ahrq.gov](http://www.ahrq.gov). Accessed December 2006.

<sup>55</sup> [www.acg.gi.org/media/releases/march212005](http://www.acg.gi.org/media/releases/march212005). Accessed January, 2007.

- <sup>56</sup> RICAN. Current status and challenges: colorectal cancer screening in RI. Rhode Island: RICAN; 2005.
- <sup>57</sup> Coburn NG, et al. Decreased breast cancer tumor size, stage, and mortality in Rhode Island: an example of a well-screened population. *Cancer Control*. 2004; 11(4):222-230.
- <sup>58</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004.
- <sup>59</sup> American Cancer Society. *Facts and Figures, 2007*. Atlanta: American Cancer Society; 2007.
- <sup>60</sup> USPSTF Recommendations. Available at: [www.ahrq.gov](http://www.ahrq.gov). Accessed December 2006.
- <sup>61</sup> Ibid.
- <sup>62</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004.
- <sup>63</sup> Rhode Island Department of Health. Rhode Island Cancer Registry Data. RI; 2007.
- <sup>64</sup> Berwick M, et al. Screening for cutaneous melanoma by skin self-examination. *National Cancer Institute*. 1996; 88:17-23.
- <sup>65</sup> Weinstock MA, et al. Thorough skin examination for the early detection of melanoma. Rhode Island.
- <sup>66</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2006.
- <sup>67</sup> Office of Minority Health. CLAS Standards. Available at: <http://www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=15>. Accessed May, 2007.
- <sup>68</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2006.
- <sup>69</sup> Ibid.
- <sup>70</sup> Weinstock MA, et al. Thorough skin examination for the early detection of melanoma. Rhode Island.

## Treatment Section Citations

- <sup>71</sup> American Cancer Society. *Cancer Facts and Figures 2007*. Atlanta: ACS; 2007.
- <sup>72</sup> Fine M, Liscord E. Improving Health Care Access for Uninsured Rhode Islanders. *Medicine and Health*. Rhode Island. 2006; (89)8:287.
- <sup>73</sup> Centers for Disease Control and Prevention, CDC. *Behavioral Risk Factor Surveillance System Survey*

*Data*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2006.

- <sup>74</sup> Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, D.C.: National Academies Press; 2002.

## Workforce Section Citations

- <sup>75</sup> National Cancer Institute DevCan. Available at: <http://srab.cancer.gov/devcan>. Accessed February, 2007.
- <sup>76</sup> *Help Wanted: The Growing Crisis in Rhode Island's Nursing Workforce*. A Report of the Rhode Island Shape Foundation. Rhode Island: Shape Foundation; 2004.
- <sup>77</sup> Office of Minority Health. Available at: <http://www.omhrc.gov>. Accessed February, 2007.
- <sup>78</sup> Revisions to Federal Reporting Regulations. Available at: [www.whitehouse.gov/omb/fedreg/1997standards.html](http://www.whitehouse.gov/omb/fedreg/1997standards.html). Accessed May, 2007.
- <sup>79</sup> Wozny M. Personal Correspondence with Certification Operations Manager at the Oncology Nursing Certification Corporation. January 2007.

## Clinical Trials Section Citations

- <sup>80</sup> National Cancer Institute Cancer Clinical Trials: The Basic Workbook. Available at: <http://www.cancer.gov/clinicaltrials/resources/basicworkbook/>. Accessed February 2007.
- <sup>81</sup> Harris Interactive 2001. *Health Care News*. 2001: 1(3). [Poll]
- <sup>82</sup> Ibid.
- <sup>83</sup> Available at: [www.clinicaltrials.gov](http://www.clinicaltrials.gov). Accessed February 28, 2007.
- <sup>84</sup> Intercultural Cancer Council. Available at: <http://iccnetwork.org/cancerfacts>. Accessed February, 2007.
- <sup>85</sup> Evelyn B, et al. Participation of racial/ethnic groups in clinical trials and race-related labeling: a review of new molecular entities approved 1995-1999. *Journal of the National Medical Association*. 2001; 93(12 Supplement):18s-24s.
- <sup>86</sup> Swanson GM, Balar JC. Selection and description of cancer in clinical trials: science or happenstance? *Cancer*. 2002; 95(5):950-959.



---

## Palliative Care Section Citations

- <sup>87</sup> SUPPORT. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA*. 1995; 274:1591-1598.
- <sup>88</sup> Brown University Center for Gerontology and Health Care Research. Facts on Dying. Available at: [www.chcr.brown.edu](http://www.chcr.brown.edu). Accessed March 8, 2007.
- <sup>89</sup> Ibid.
- <sup>90</sup> Ibid.
- <sup>91</sup> Teno JM, Clarridge B, Casey V, Welch L et al. Family Perspectives on End-of-Life Care at the Last Place of Care. *JAMA*. 2004; 291 (1): 88-93.
- <sup>92</sup> *Last Acts: A Means to a Better End: A Report on Dying in America Today*. Washington, DC; Last Acts National Program; 2002.
- <sup>93</sup> Ibid.
- <sup>94</sup> Ibid.
- <sup>95</sup> Ibid.
- <sup>96</sup> Smith TJ, Coyne P, Cassel B, et al. A High-Volume Specialist Palliative Care Unit and Team May Reduce In-Hospital End-of-Life Care Costs. *Journal of Palliative Medicine*. 2003; 6(5).
- <sup>97</sup> Rhodes RL, Teno JM, Welch LC. Access to hospice for African Americans: Are they informed about the option of hospice? *Journal of Palliative Medicine*. 2006; 9:268-272.
- <sup>98</sup> Payne R, Medina E, Hampton JW. Quality of life concerns in patients with breast cancer: evidence for disparity of outcomes and experiences in pain management and palliative care among African-American women. *Cancer*. 2003; 97(1 Suppl.):311-317.
- <sup>99</sup> Vallerand AH, Hasenau S, Templin T, et al. Disparities between black and white patients with cancer pain: the effect of perception of control over pain. *Pain Medicine*. 2005; 6:242-250.
- <sup>100</sup> Eversley R, Estrin D, Dibble S et al. Post-treatment symptoms among ethnic minority breast cancer survivors. *Oncology Nursing Forum*. 2005; 32:250-256.
- <sup>101</sup> Facts on Dying. Available at: <http://www.chcr.brown.edu/dying/factsondying.htm>. Accessed March, 2007.

## Survivorship Section Citations

- <sup>102</sup> American Cancer Society. *Cancer Facts & Figures 2007*. Atlanta: ACS; 2007.
- <sup>103</sup> RI Department of Health. *Cancer in Rhode Island*. Providence, RI: HEALTH; February, 2004.
- <sup>104</sup> Mullan. Seasons of Survival: Reflections of a Physician with Cancer, *New England Journal of Medicine*. 1985; 313:270-273.

---

<sup>105</sup> *LiveSTRONG Summit*. Lance Armstrong Foundation. Austin, Texas: October 27, 2006.

<sup>106</sup> *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*. Centers for Disease Control and the Lance Armstrong Foundation. April, 2004.