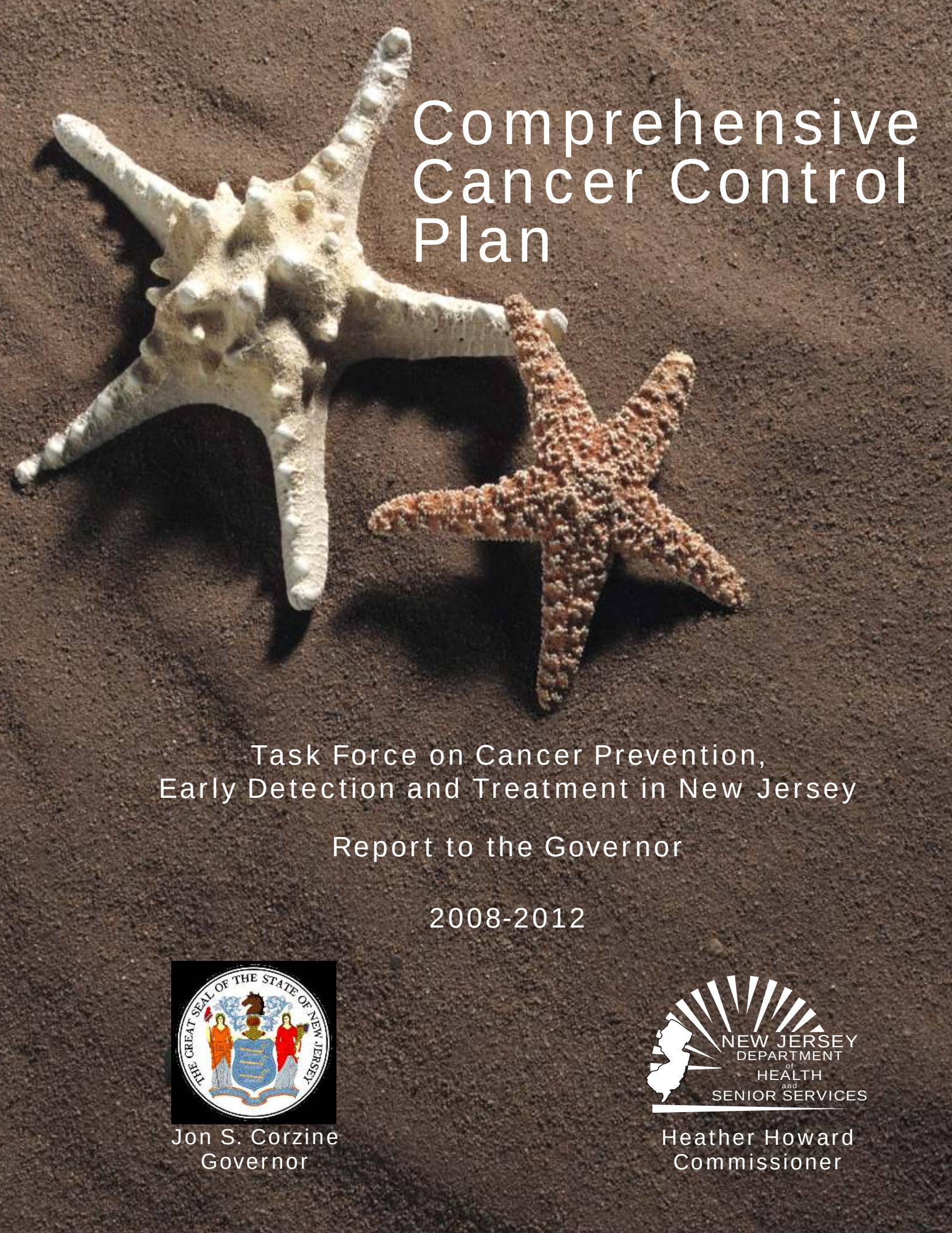

Comprehensive Cancer Control Plan

Task Force on Cancer Prevention,
Early Detection and Treatment in New Jersey

Report to the Governor

2008-2012

Jon S. Corzine
Governor

NEW JERSEY DEPARTMENT of HEALTH and SENIOR SERVICES

Heather Howard
Commissioner

www.njcancer.gov

The Starfish Story

There was a young man walking down a deserted beach just before dawn. In the distance he saw a frail old man. As he approached the old man, he saw him picking up stranded starfish and throwing them back into the sea. The young man gazed in wonder as the old man again and again threw the small starfish from the sand to the water. He asked, “Old man, why do you spend so much energy doing what seems to be a waste of time.” The old man explained that the stranded starfish would die if left in the morning sun. “But there must be thousands of beaches and millions of starfish!” exclaimed the young man. “How can you make any difference?”

The old man looked at the small starfish in his hand and as he threw it to the safety of the sea, he said, “It makes a difference to this one!”

- Author unknown

This Plan is dedicated to those with cancer and their loved ones and acknowledges their courage. It salutes all those providing care and finding cures. And it memorializes all those who have gone, especially Erica DelCore, whose zest for life was reflected by her accomplishments in addressing childhood cancer. To all, thank you for making a difference and helping to tell New Jersey’s story.

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The work of the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey is supported by the New Jersey Department of Health and Senior Services, Office of Cancer Control and Prevention. The Task Force has been recognized for its efforts and has been memorialized through the enactment of Public Law 2005, Chapter 280 as of January 6, 2006.

The ***New Jersey Comprehensive Cancer Control Plan*** *would not have been possible without the extraordinary generosity and vision of the many key stakeholders, consultants, and expert reviewers who have assisted in its development. The process that propelled development of this document has brought together individuals and organizations whose passion is reflected in, and whose names appear with, each respective chapter of the* ***Plan****. We especially acknowledge the rich resources available within the Departmental programs that have provided invaluable assistance.*

We also acknowledge various organizations that offered hospitality for the many Task Force Standing Committee and Workgroup sessions.

In addition, we value the expertise and best practices of sister state agencies, especially Arkansas, Maine, and North Carolina, who have provided history, data, and ongoing support to the Task Force and to this monumental planning initiative.

Finally, we wish to thank the staff of the Centers for Disease Control and Prevention, who guided us with their technical assistance and wealth of resource materials.

EXECUTIVE SUMMARY

A leading cancer journal recently reported that the United States had experienced the most significant drop in cancer deaths in more than 70 years, pointing to cancer prevention, early detection, and treatment as the likely explanation. The researchers warned, however, that the fight against cancer is far from over.[1] Cancer control efforts must continue to work toward reducing the burden of cancer for all Americans. Thus, the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (the Task Force), established by Executive Order 114 and memorialized by Public Law 2005, Chapter 280, continues its mission of developing and implementing the *New Jersey Comprehensive Cancer Control Plan* (the *Plan*).

THE FIRST FIVE YEARS

New Jersey's comprehensive cancer control program grew from a charge in 2000 by former Governor Whitman, who established the Task Force and the Office of Cancer Control and Prevention (OCCP). Under the auspices of the Office of the State Epidemiologist, New Jersey Department of Health and Senior Services, OCCP coordinates all statewide cancer control efforts, which include the Task Force, its standing committees, workgroups, and the 21 county cancer coalitions (Coalitions)—a volunteer cadre of over 2,000 individuals and organizations.

Utilizing guidelines developed by the Centers for Disease Control and Prevention (CDC),[2] the Task Force told New Jersey's story of cancer incidence and mortality as a spur to reducing the burden of the disease among its citizens. Supported through state appropriations, the Task Force conducted the first-ever statewide capacity and needs assessment in each of New Jersey's 21 counties, both to benchmark the current status of the cancer burden in each county and to develop an extensive inventory of the state's cancer-related activities and resources.

The Task Force and its work have been recognized nationally by the CDC for its local implementation model; and internationally by Canada as it began to develop its own nationwide cancer plan. Among the highlights of the first five years of implementation, as reported in the *2006 Status Report to the Governor and Legislature*,[3] are the following:

- The majority of all strategies (82%) found in New Jersey's first *Plan* released in 2003 are either completed or ongoing. The remaining strategies have encountered barriers, primarily insufficient funding or a shortage of volunteers to spearhead the strategy.
- One of the greatest successes of New Jersey's program thus far is the establishment of a cancer Coalition in each county. Many Coalitions have been extremely successful in bringing together various stakeholders, including those from competing organizations, to implement cancer prevention and control activities.
- Results of the statewide initiative of the county-based cancer capacity and needs assessments have been disseminated to the public and are continually utilized by county cancer Coalitions and other groups to prioritize local cancer initiatives.
- In 2004, the OCCP was selected to join the National Comprehensive Cancer Control Program of the CDC through a cooperative agreement award. The CDC has praised the

nature and extent of evaluation efforts in New Jersey. Prominent among these was an assessment of stakeholders that revealed overall satisfaction among the Task Force members and its volunteer base with respect to membership, communication, implementation, process, and collaboration. Further analysis demonstrated representation of the key types of organizations suggested by the CDC both organizationally and geographically among its stakeholders.

THE BLUEPRINT FOR 2008–2012

The Task Force began development of the second edition of the *Plan u*tilizing best practices and the internal monitoring system developed by the Battelle Centers for Public Health Research and Evaluation in conjunction with the University of Medicine and Dentistry of New Jersey, New Jersey Medical School. The *Plan*'s evidence-based chapters are grounded in data provided by the New Jersey State Cancer Registry and trends gleaned from peer-reviewed publications. Highlights from the second edition of the *Plan*, developed by the Task Force and its workgroups and standing committees, are presented below. Please note that legislative initiatives, clinical trials, and the application of current technologic research and resource data are integrated as recurrent themes throughout each chapter.

Advocacy. The primary focus of this Task Force standing committee is continuation of the internal structure and funding for cancer awareness, education, and early detection programs. Committee members will continue to advocate for increased access to cancer care and for reducing cancer-related health disparities among minorities and the medically underserved.

Nutrition and physical activity. The Nutrition/Physical Activity Workgroup plans to promote long-term healthy eating patterns, healthy weight, and physical activity with an overall goal of reducing cancer incidence in New Jersey by improving diet and increasing physical activity among the state's residents. Additionally, workgroup members aim to improve survival and quality of life among cancer patients and survivors by assuring proper nutritional care.

Palliation. An overall goal to increase awareness of and access to palliative care services, defined as beginning with the diagnosis of cancer, has this workgroup planning to integrate the knowledge of palliation into professional, public health, and legislative systems. Workgroup members will also be addressing the benefits and risks of the utilization of complementary and alternative medicine in palliative care.

Breast. The key elements of this chapter continue to be awareness and education for those at higher than expected risk of developing breast cancer. This workgroup will also be focusing on improving patient awareness and education relating not only to screening, but also to rescreening and follow-up visits to maximize optimal outcomes.

Childhood. The overall goal of this workgroup is enhancing the quality of life of the child, adolescent, and/or young adult cancer patient from diagnosis through treatment to survivorship across the life span. Workgroup members will continue to stress the importance of awareness of late effects, neurocognitive and psychosocial deficits, as well as advocacy issues related to long-term survivorship, e.g., education, employment, and insurance coverage.

Colorectal. Raising awareness of colorectal cancer with respect to effective measures available for prevention, detection, and treatment remain a goal for this chapter. Workgroup members will also address measures to increase colorectal cancer screening rates in an effort to reduce this third leading cause of cancer among New Jersey residents.

Gynecologic. Renamed to acknowledge inclusion of ovarian cancer, the former Cervical Cancer Workgroup will strive to increase public, patient, and professional awareness and education regarding cervical and, now, ovarian cancers. The workgroup will also be addressing utilization of the human papillomavirus vaccine in indicated populations, the fostering of clinical research, and increased participation in clinical trials.

Lung. This workgroup continues its tradition of support for the New Jersey Comprehensive Tobacco Control Program and also aims to increase the proportion of providers who will implement the Public Health Service guidelines regarding tobacco-dependency treatment. Workgroup members will further address heightening public awareness and knowledge of lung cancer, its risk factors, symptoms, treatment, and the potential for early detection.

Melanoma. The Melanoma Workgroup intends to increase the practice of preventive behaviors among New Jersey's youth, promote worksite education by employers to employees, and educate the community on melanoma and other skin cancers based on experience gleaned through its collaboration on a K–12 sun safety program. The workgroup will also address measures to decrease the exposure of New Jersey residents to ultraviolet radiation from the use of tanning beds and booths.

Oral and oropharyngeal. New Jersey has the distinction of being the first state with a chapter of its plan dedicated to oral cancer. Moving forward with this model, the Oral Cancer Workgroup will continue its goal of heightening public awareness of oral and oropharyngeal cancers and the need for access to screening for all segments of the population. Workgroup members will also continue to collaborate with their colleagues—dentists, hygienists, specialty physicians—to increase the current level of education and training among healthcare providers.

Prostate. Promoting a public health message regarding screening, the benefits and risks of early detection, and the follow-up necessary for normal and abnormal screening and treatment continues to be the major focus of this chapter. Workgroup members will also continue to address increasing access to prostate cancer services for all New Jersey men through education, screening, treatment, and palliative care.

MOVING FORWARD

Implementation of the second *New Jersey Comprehensive Cancer Control Plan* (2008–2012) will herald an invigorated campaign to address the issues facing New Jersey cancer patients and their families. Addressing survivorship and diversity, *Plan* implementation will continue with unwavering support from the New Jersey Department of Health and Senior Services and the coordinated efforts of its relevant programs—the OCCP, the New Jersey State Cancer Registry, the Division of Family Health Services, the New Jersey Commission on Cancer Research, and the Comprehensive Tobacco Control Program.

Implementation of the second *Plan* will require continuing intensive collaboration among the Task Force and its public and private partners. An impressive collaborative effort has already produced this document. Yet, New Jersey's comprehensive cancer control initiative can only continue to grow by expanding the efforts of the volunteers who have already invested their time, energy, and expertise to make this *Plan* happen. Partnerships can and should be optimized with a focus on mutual benefits and a coordinated approach to planning as a means to achieve the "higher good" of reducing cancer's burden in the state.

The cornerstone of implementation will be periodic updating of the statewide capacity and needs assessment, through which the most current and accurate information is made available to the public via the OCCP website—www.njcancer.gov. This information will also be invaluable to the Task Force, its standing committees, workgroups, and county cancer Coalitions as they prioritize implementation based on the most current evidence. The New Jersey State Cancer Registry will play a pivotal role as a data resource able to document the differential cancer burden in various geographic locations and segments of the population, thus guiding delivery of effective and appropriate interventions to those in greatest need.

No discussion of *Plan* implementation would be complete without addressing the critical importance of funding. The state of New Jersey has clearly demonstrated its support through annual appropriations, and with New Jersey's recognition as a comprehensive cancer control state, cooperative agreements and grant monies have been awarded by the CDC. Foundations and not-for-profit organizations have also provided not only financial but also in-kind support for this "organization of organizations". Yet, as CDC points out in its *Guidance for Comprehensive Cancer Control Planning*, the ongoing activity of mobilizing support extends beyond merely securing funding. It requires a broad campaign that increases visibility, develops political will, and enhances awareness of community leaders, who become advocates for both funding and implementing portions of the *Plan*.[2] This has been the vision of the Task Force since its inception and will continue to inspire the actions of its members as they engage current and new partners in comprehensive cancer control, not for their expertise alone, but because they are key decision-makers who can advocate persuasively for and deliver on commitments to *Plan* implementation.

Successful implementation will continue through the demonstrated effectiveness of the OCCP in facilitating consensus-building and coordination among a diverse mix of partners and activities. Further, an enhanced emphasis on communication—through establishment of a Task Force Standing Committee charged to develop a communications plan—can only improve the dialogue among collaborators. Impact will be measured under the guidance of the Evaluation Committee, with an emphasis on context, implementation, and outcome logic models in development of an annual evaluation plan and status report assessing progress by the Task Force.

The value of the *Comprehensive Cancer Control Plan* lies in improved integration and coordination of cancer control activities among relevant New Jersey agencies, organizations, and individual stakeholders. This collaborative effort will reduce duplication and enhance delivery of programs at the state and community levels, to the ultimate benefit of all New Jerseyans. Together we can make a difference.

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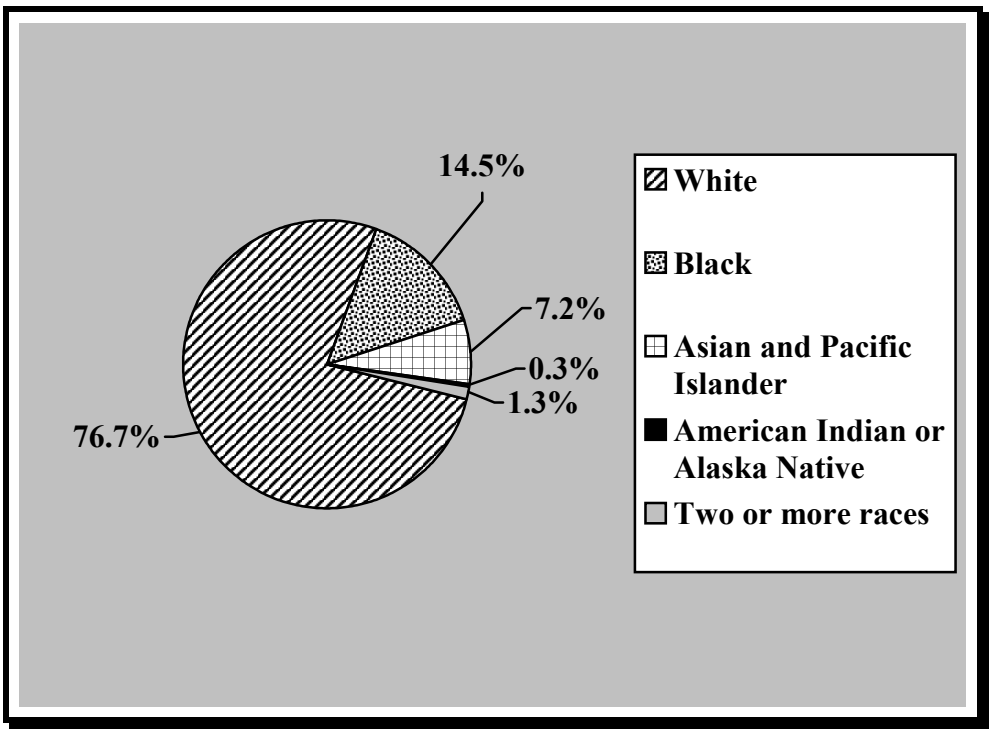
THE BURDEN OF CANCER IN NEW JERSEY

A DEMOGRAPHIC PICTURE OF NEW JERSEY

New Jersey is a geographically small but heavily populated state. The state's population in 2006 was estimated to be over 8.7 million, making it the 11th highest in the nation.[1] According to 2006 population estimates, New Jersey is the most densely populated state, with 1,184 persons per square mile.[2]

Figure 1 demonstrates the racial composition of New Jersey. According to 2005 U.S. Census Bureau estimates, populations of all races are increasing in New Jersey. Approximately 15.2% of the population was Hispanic of any race, which accounts for 69% of New Jersey's total population growth from 2000 to 2005.[1]

Figure 1. Breakdown of New Jersey Population by Race, Based on 2005 U.S. Census Bureau Estimates[1]



Estimates based on the 2005 American Community Survey reveal that New Jersey's population is also older than the national average, with a median age of 38 years as compared to 36.4 years for the nation.[2] In 2005, the percentage of the population aged 65 and older was estimated to be 13.0% in New Jersey and 12.4% in the nation as a whole.[3] Similar to the national trend, the oldest age group (85 years and over) is growing at the fastest rate, increasing by 24% in New Jersey and 19% in the nation from 2000 to 2005.[4,5]

Estimates from the 2005 American Community Survey demonstrate that New Jersey ranks first in the nation for median household income ($61,672). It follows, then, that the percentage of New Jersey's population living in poverty is much lower than in the nation as a whole. According to the 2005 American Community Survey, 8.7% of New Jerseyans had incomes below the poverty level, compared to 13.3% nationally.[6]

Additionally, adult New Jerseyans exceed national estimates of average educational attainment. In 2005, 86.3% of state residents aged 25 and over had completed high school, compared to 84.2% nationally; 34.2% had completed a bachelor's degree, compared to 27.2% nationally; and 12.5% had completed an advanced degree, compared to 10.0% nationally.[6]

CANCER INCIDENCE IN NEW JERSEY

In 2004*, the data reported to the New Jersey State Cancer Registry (NJSCR) indicate that 45,001 cases of invasive cancer were diagnosed among New Jersey residents. Males (all races combined) had a rate of 567.1 per 100,000** compared to females (all races combined), who had a rate of 439.3 per 100,000** (Figure 2). The American Cancer Society predicts that in 2007, the number of new cancer cases among New Jersey residents will increase to 49,370.[7] In 2004, approximately 51% of cancers were diagnosed in the early stages (in situ and local); this is about the same percentage as in 2000 (Figure 3). Patterns from the NJSCR statistics for age, race, and gender are highlighted in the paragraphs below. Additional incidence data can be viewed on the New Jersey Department of Health and Senior Services (NJDHSS) website, http://www.state.nj.us/health, and can also be found in previously issued NJSCR cancer incidence reports.

Males. Data from the NJSCR demonstrate that the overall cancer incidence rate for New Jersey males has declined from 630.2 per 100,000 in 1995 to 567.1 per 100,000 in 2004. While white males mirrored the overall trend for New Jersey males, black males have seen a decline since 1995. Lung cancer incidence rates (all races combined) were stable from 1995 through 1998, and then a decrease was seen from 1999 to 2004*. The same trend is seen in black and white males diagnosed with lung cancer, although the incidence rates are higher among black males in New Jersey. Overall, New Jersey prostate cancer rates (all races combined) were 188.4 per 100,000** in 1995 compared to 157.7 per 100,000 in 2004*. Malignant melanoma of the skin increased from 16.6 per 100,000** in 1995 to 27.2 per 100,000** in 2004*.

Cancer incidence increases with age. According to 1999–2004 data, men in the 80–84 age group have the highest incidence rate of cancer. White males mimic this trend, while black males have the highest cancer incidence rate in the 75–79 age group.

In 2004*, 54% of the new cancer cases in New Jersey males were diagnosed in the early stages (in situ and local), an increase from 42% in 1995. Cancers are being diagnosed earlier among white men in New Jersey than among black men.

* Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
** Rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) standard.

Females. Data from the NJSCR demonstrate that during the years 1995 through 2004*, the overall cancer incidence rate for New Jersey females increased gradually through 1998 and then generally declined through 2004. The incidence rates for both white and black females in New Jersey mimic the trends seen in overall cancer incidence rates. Incidence rates for lung cancer appear stable during the years 1995 to 2004* for all races combined. Declines continued to be seen for invasive cervical cancer, especially among black women. Invasive breast cancer incidence rates rose slightly through 1997, and then began decreasing. Incidence rates for malignant melanoma of the skin increased from 10.5 per 100,000** in 1995 to 15.9 per 100,000** in 2004*.

Similar to the rates for New Jersey males, the incidence rates for New Jersey females increase with age. Women in the 80–84 age group have the highest incidence rate of cancer.

In 2004*, 50.4% of the new cancer cases in New Jersey females were diagnosed in the early stages (in situ and local), an increase from 44% in 1995. Cancers are being diagnosed earlier in white women in New Jersey than in black women.

NEW JERSEY COMPARED TO THE NATION, 1995–2004

Historically, New Jersey rates have been representative of the Northeast region, which tends to have higher cancer incidence rates than the U.S. as a whole (Figure 2).

For males all races combined, total cancer incidence rates were higher in New Jersey than in the U.S. during the period 1995 to 2004. During the same time period, the incidence rates for colorectal and prostate cancers were higher for New Jersey men than for U.S. men. Melanoma incidence rates for the U.S. and New Jersey were similar until 2001–2004, when the New Jersey incidence rate rose above the U.S. rate. Since 1995 the total cancer incidence rates for both white and black males in New Jersey have been higher than the national incidence rates.

For females, New Jersey had higher incidence rates than did the U.S. during the period 1995 through 2004 for total cancers and colorectal cancer. In New Jersey, females had higher breast cancer rates than in the U.S., although the rates in 1998–1999 were more similar. Melanoma incidence rates for New Jersey females were lower than for U.S. females until 2000–2003, when the rates were similar. Total cancer incidence rates among white females in New Jersey have consistently been higher than the U.S. incidence rates for white females. Black women in New Jersey also generally have higher incidence rates when compared to black women in the U.S.

* Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
** Rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) standard.

CANCER AMONG OLDER ADULTS IN NEW JERSEY

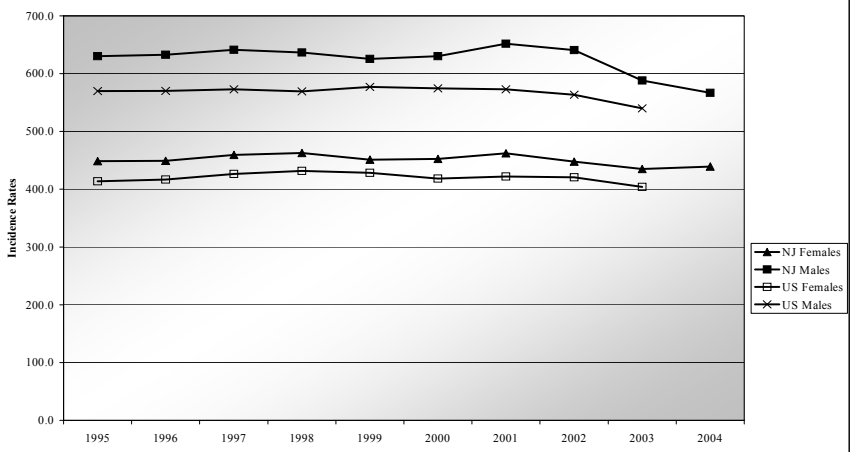
According to the 2005 American Community Survey, about 13.0% or 1.1 million people in New Jersey are aged 65 and older.[2] In New Jersey and nationally, over one-half of all newly diagnosed cancers occur in adults aged 65 and older. In New Jersey alone, 58.5% of those who are newly diagnosed with cancer are aged 65 and older and, therefore, this age group bears the greatest burden of cancer.[8]

In New Jersey, both incidence and mortality rates for total cancer have been higher for each successive age group. In recent years, incidence rates in the oldest old (age 85 and older) have converged toward the older old (age 75 to 84 years) for both men and women. Incidence and mortality rates vary greatly by gender among older adults. Incidence rates for older men are higher than rates for older women, especially for men aged 75 and older. Mortality rates for older men are also higher than rates for older women and share a similar pattern over time.[9]

Among older adults in New Jersey, favorable patterns for stage at diagnosis are seen for female breast cancer, prostate cancer, and melanoma of the skin, which may be the result of effective screening. Less favorable patterns for stage at diagnosis are seen for cervical, colorectal, and oral and oropharyngeal cancers. Better screening efforts among older adults and their physicians may increase the detection of these cancers at an earlier stage.[9]

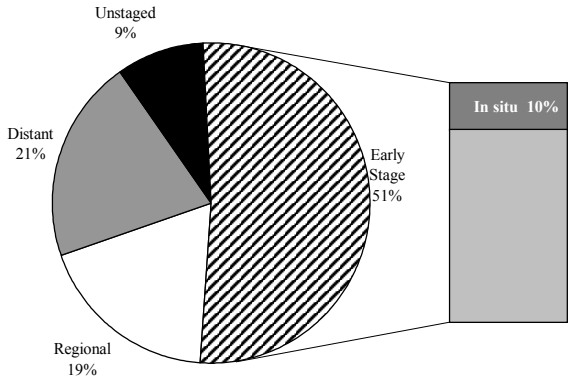
With the rising number and proportion of older adults with cancer in New Jersey over the coming decades, attention should be paid to interventions that will decrease the burden of cancer among adults aged 65 and older. There are many opportunities for research to understand the issues of early diagnosis, treatment, and support of older adults with cancer. It appears that chronological age by itself is less a factor in determining patient outcomes than other related factors, such as functional status, co-morbidities, and overall health status. Because of the heterogeneity in health and economic status of our aging population, comprehensive assessments and individualized management may be of significant value in improving survival of and quality of life in older adults with cancer.[9]

Figure 2. U.S. and New Jersey Age-Adjusted Incidence Rates by Gender, All Cancer Sites, 1995–2004*



Source: New Jersey State Cancer Registry (NJSCR) and SEER; rates are per 100,000 and age-adjusted to the 2000 U.S. standard.
*Incidence rates for the year 2004 data from the NJSCR are preliminary; 2004 data are not available from SEER.

Figure 3. Stage of Diagnosis for New Cancer Cases in New Jersey Males and Females, 2004*



Source: NJSCR; *incidence rates for the year 2004 data from the NJSCR are preliminary.

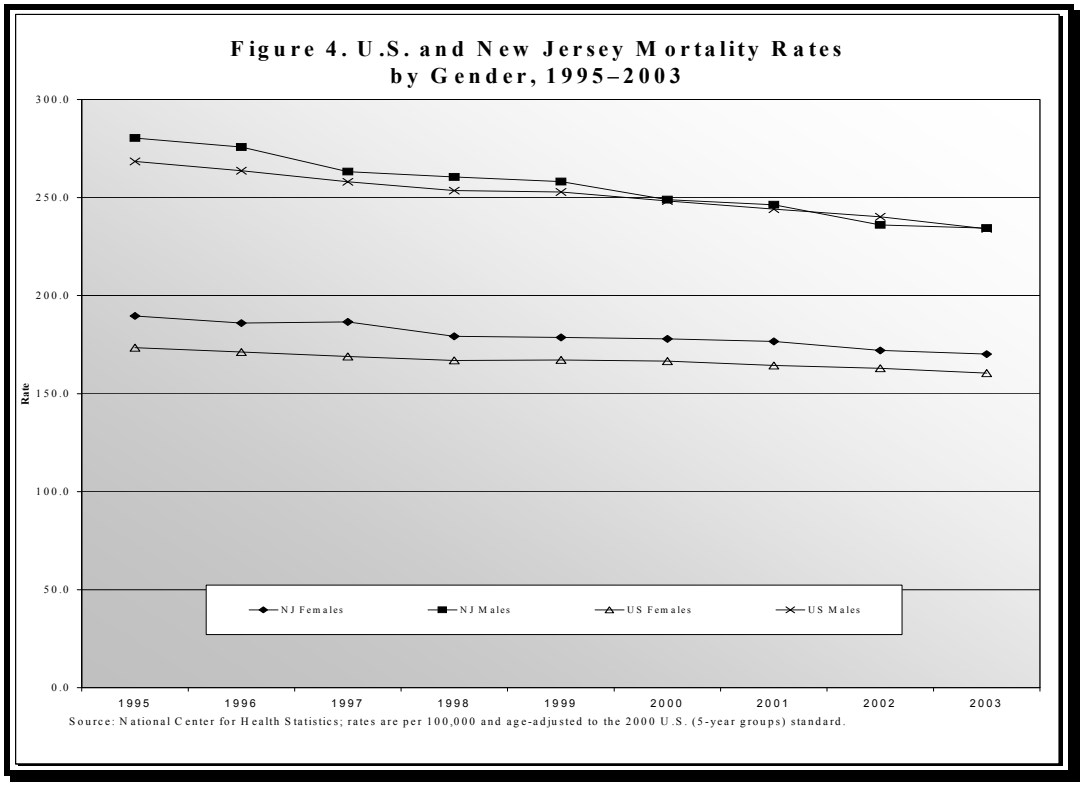
CANCER MORTALITY IN NEW JERSEY

Cancer is the second leading cause of death in New Jersey.[10] According to data from the National Center for Health Statistics, cancer mortality rates in New Jersey have been declining since 1991, and the decline has been more rapid since 1995. There were 17,957 deaths in 2003 for which cancer was designated on the death certificates as the underlying cause. The mortality rate for New Jersey was 234.4 per 100,000** for males (all races combined) and 170.2 per 100,000** for females (all races combined) in 2003.[11]

In New Jersey, from 1995–2003, cancer mortality rates for males (all races combined) were generally higher than the rates for the U.S. (Figure 4). The mortality rates for white males were higher in New Jersey than in the U.S. from 1995–1999, but then fell lower than the U.S. rate from 2000–2003; the mortality rates for black males in New Jersey were generally lower than the U.S. rates for black males from 1995–2003. For the same time period, New Jersey cancer mortality rates for females (all races combined) and white females were higher than the mortality rates for the U.S. Although mortality rates for black females in New Jersey were higher than the U.S. rates, in recent years the rates have become similar.[11,12]

Although life expectancy in the United States has been increasing, blacks live shorter lives than whites. This earlier mortality tends to hold across gender, age, and disease subgroups.[13] Potential explanations for this disparity fall into two broad categories: environmental/societal/behavioral (which are potentially subject to intervention) and biological/genetic. The latter factors, some of which may vary among different ethnic/racial groups, were long considered immutable. However, given evolving genetic knowledge, the genome holds the promise that, if used ethically, it may facilitate improved screening, earlier diagnosis and intervention, and the tailoring of specific therapies to improve prognosis.

**Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.



SURVIVAL AFTER CANCER IS DIAGNOSED

In general, the New Jersey five-year relative cancer survival rates were similar to the U.S. rates for the diagnosis years 1994–1997. For all cancers combined, the New Jersey five-year relative survival rate was 61%, while the U.S. rate was higher at 64%. The New Jersey survival rates were very high for specific cancers such as prostate cancer (98%), thyroid cancer (94%), female breast cancer (85%), and Hodgkin's lymphoma (85%). Similar to the U.S. rates, the five-year survival rates in New Jersey were very low for pancreatic cancer (6%), liver cancer (7%), esophageal cancer (13%), and lung cancer (14.5%).

Disparities in survival rates exist by gender and race. White men in New Jersey had substantially higher five-year relative survival rates for all cancers combined compared to black men (63% versus 54%, respectively); as did white women compared to black women (60% versus 51%, respectively). Black men had lower survival rates than did white men for each specific cancer type except myeloma and brain. Black women had lower survival rates than did white women for each specific cancer type except myeloma, brain, stomach, liver, and pancreas.

For the six most common cancers diagnosed among New Jersey residents in 1994–1997 (female breast, cervical, colorectal, lung, melanoma of the skin, and prostate), the five-year relative survival rates were much higher for local-stage cancers than for regional- or distant-stage cancers. The survival rates for these cancers were between 80% and 100% for local-stage cancers (except for lung cancer) and under 30% for distant-stage cancers. Over the past 20 years, the five-year relative survival rates have

improved, especially for cancers diagnosed at the local and regional stages. However, disparities continue to exist between blacks and whites and, to a lesser extent, between men and women.[14]

It has been estimated that on January 1, 2003, there were nearly 334,000 people living in New Jersey who had been diagnosed with cancer; about 149,000 men and over 185,000 women. They represent 3.9% of the total population. About 87% of the 334,000 people were white, and about 8.5% were black. The types of cancer that contributed most to the cancer prevalence among men were prostate (61,483), colorectal (18,468), bladder (13,499), melanoma of the skin (7,546), and non-Hodgkin's lymphoma (5,868). Among women, the types of cancer that contributed most to cancer prevalence were breast (72,595), colorectal (20,041), endometrial (17,395), cervical (9,184), and melanoma of the skin (7,940).[15]

More than 10 million cancer survivors live in the United States today—three times the number who were alive 30 years ago. Many survivors and their families experience long-term physical, emotional, and practical needs resulting from cancer that affect their quality of life. Advances in treatment options and early detection have played roles in allowing those with cancer to lead full lives during and after treatment. The cancer "survivorship" concept includes the physical, emotional, and practical issues that arise during and after a cancer diagnosis.[16] Strategies to improve survivorship have been incorporated across the *Plan*.

Reducing the Cancer Burden

The goal of cancer control and of this *Plan* is to reduce the burden of cancer for all New Jersey residents. Many types or forms of cancer can be prevented. It is critically important to provide New Jerseyans with the information they need to avoid risky behaviors that increase their chances of developing cancer. Other cancers can be detected early and ameliorated, controlled, or cured. Data about these kinds of cancer and the potential to survive them once detected must be disseminated broadly. Access to high-quality cancer screening and state-of-the-art treatment must be available. Finally, even for cancers for which a cure has not been found, there are certain life-prolonging, life-enhancing, and palliative care measures, including pain control, to which New Jersey's residents deserve access. These are the aims of this *Plan* and will, once achieved, reduce the burden of cancer in New Jersey.

Strategies addressing specific basic research are not addressed in the *Plan*. However, the respective chapters propose ways to nurture and increase support for these efforts. New Jersey is rich in resources for basic research through the biopharmaceutical industry, academic centers of excellence, innovative research institutes, and the work of the New Jersey Commission on Cancer Research. Through the efforts of these dedicated scientists in our state, new approaches and therapies are realized that pave the way to understanding how cells and organisms function normally and what goes wrong in the development of cancer.

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Section I
Overarching Issues

Chapter 1. Advocacy
Chapter 2. Nutrition and Physical Activity
Chapter 3. Palliation

CHAPTER 1. Advocacy

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ADVOCACY

Cancer is a personal, tangible, and powerful issue for millions of Americans and thousands of New Jerseyans. The disease has political, as well as medical, social, psychological, and economic facets. Every day legislators make decisions that impact the lives of current and future cancer patients, survivors, and their families.[1] To influence those decisions constructively, the *Comprehensive Cancer Control Plan for New Jersey* will continue to incorporate advocacy as a major strategy to promote beneficial policies, laws, and regulations for those affected by cancer.

Advocacy is the pursuit of influencing outcomes—including public policy and resource allocation decisions within political, economic, and social systems and institutions that directly affect people's lives.[2] The goal of advocacy for this *Plan* is to promote public policies at all levels of government that support cancer prevention and detection programs, provide access to care, and enhance quality of life for those affected by cancer.

While cancer issues are increasingly attracting attention on the legislative front, additional advocacy work remains to be done by the Task Force and its workgroups, subcommittees, and county-level Coalitions.[3] Through the implementation of the first five-year *Plan*, the Advocacy Ad Hoc Committee of the Task Force was instrumental in the passage of 35 bills pertaining to cancer in 2005. Legislative priorities in the cancer arena have and will continue to focus on advancing the *Plan* and ensuring that all residents have access to cancer education, screening, and quality cancer care. Specific advocacy goals, objectives, and strategies are also cited within each site-specific chapter of the *Plan*. However, the following overarching advocacy goals, objectives, and strategies reflect the most urgent and comprehensive actions needed to implement and sustain this ambitious state plan.

GOALS, OBJECTIVES, AND STRATEGIES

The recommendations of the Advocacy Ad Hoc Committee are summarized below:

- Develop *internal structure and funding* for cancer awareness, education, and early detection programs and access to care.
- Advocate for increased *access* to cancer care, prevention, early detection, and awareness programs.
- Advocate for reduced cancer-related *health disparities* among minorities and the medically underserved.

OVERALL GOAL	Promote public awareness of cancer prevention, early detection, and treatment in New Jersey.

INTERNAL STRUCTURE AND FUNDING FOR CANCER ADVOCACY

Our nation has made remarkable progress since the war against cancer began three decades ago. Some cancers have been cured, while others are being detected earlier and treated more effectively. The National Cancer Institute estimates that approximately 10.5 million Americans with a history of cancer were alive in January 2003.[4] In addition, the overall cancer death rate has been declining since 1992.[5] Yet there is a crisis of confidence in the capacity of our medical system to treat those with chronic and life-threatening illnesses such as cancer. Efforts to define quality care must underscore the fact that 41 million Americans are uninsured and many millions more are underinsured.[6]

To build and support the advocacy component of the *Plan* as outlined, the Advocacy Ad Hoc Committee recommends building an infrastructure to foster its successful implementation.

GOAL AD-1	To advocate for funding of and support for the *New Jersey Comprehensive Cancer Control Plan*, including cancer awareness, education, and early detection programs, as well as access to care.

Objective AD-1.1

To identify, engage, and involve interested public and private parties, institutions, and agencies to garner ongoing support of the *Plan*.

Strategies

AD-1.1.1 Build cancer advocacy capacity through recruitment of identified interested parties. Parties initially identified include, but are not limited to, media, legislators, insurers, pharmaceutical companies, healthcare professionals, corporations, state agencies, and other key decision-makers.

AD-1.1.2 Identify champion(s), e.g., patients and patients' families, to advocate on behalf of the *Plan*.

Objective AD-1.2

To educate legislative members and staff about the importance of funding cancer prevention and control programs.

Strategies

AD-1.2.1 Charge the Task Force on Cancer Prevention, Early Detection and Treatment to maintain an Advocacy Ad Hoc Committee, comprised of a representative from each of the Task Force workgroups, to address the legislative initiatives cited within each respective chapter of the *Plan*.

AD-1.2.2 Work with partner organizations and coalitions to build and continue support for cancer education, early detection, and access to care.

Advocacy for Access to Cancer Care

In 1999, in accordance with its charge, the President's Cancer Panel reviewed the evolution of the National Cancer Program and considered how the nation should move forward to reduce the burden of the disease more rapidly. It was decided that the equal importance of the research and delivery components of the National Plan on Cancer be recognized; that the current barriers preventing quality cancer care from reaching people in all neighborhoods of the nation be removed; and that the unequal burden of cancer carried by the poor, ethnic minorities, and the underserved be relieved.[7] The complex issue of healthcare access encompasses many barriers, including inadequate health insurance coverage, insufficient cost reimbursement, inconvenient health center hours and locations, and a lack of efficient and affordable transportation for screening and treatment services.

For many in New Jersey and the U.S., lack of adequate health insurance is a significant impediment to access to healthcare, including both traditional and cutting-edge treatments, and to prevention or early detection tools that have long been accepted by the medical community. The percentage of New Jersey residents without health insurance has been increasing steadily over the last decade. In 2005, an estimated 1.3 million New Jersey residents lacked any kind of healthcare coverage, and many more

reported having inadequate health insurance.[8,9] As a result, the Advocacy Ad Hoc Committee has adopted a position of support for universal healthcare for all New Jersey residents and recommends adopting universal standards of care.

Access to needed services can also be adversely affected by unrealistic provider reimbursement practices.[10] Providers are often inadequately reimbursed for the cost of providing preventive services, such as counseling patients on tobacco cessation. Ensuring that providers are reimbursed at acceptable rates for cancer prevention, early detection, and treatment services would create incentives for providing these services.

Although a lack of insurance and prohibitive costs are the primary reasons cited for low cancer screening rates, transportation has been identified as another significant barrier. According to a report by the New Jersey Department of Health and Senior Services, healthcare services may not be located in places that are easily accessible, particularly to those who lack private transportation.[11] In a study of access to primary care in New Jersey, it was found that "transportation options are often limited for people living in rural settings, seniors, and those with disabilities and diseases. Some options provide only one-way transportation, and cab fare is viewed as prohibitively expensive."[12] In metropolitan areas, which offer more extensive public transportation systems, schedules and route maps can be confusing to consumers with limited knowledge of such systems. Furthermore, schedules and route maps may not be widely available to the general public. In less urban areas, lack of centralized, efficient public transportation forces vulnerable populations to rely on community resources to meet transportation needs. However, the private sector is often overwhelmed and unable to keep pace with demand.[12]

While there are organizations throughout the state that provide free transportation services to patients undergoing cancer treatment, these programs are not without their limitations. Transportation programs are often operated at the local or county level and are unable to transport patients outside the service area. In many cases, the demand for transportation exceeds the capacity of a program to provide adequate services.

GOAL AD-2	To advocate for increased access to quality cancer care, prevention, early detection, and awareness programs.

Objective AD-2.1

To advocate for providing to all New Jerseyans adequate health insurance coverage relating to cancer prevention and control.

Strategies

AD-2.1.1 Assess current New Jersey insurance coverage for cancer prevention, detection, and treatment to identify gaps.

AD-2.1.2 Educate legislators and insurance companies on identified gaps in cancer coverage.

AD-2.1.3 Monitor emerging issues related to adequate health insurance for cancer care and identify those issues for possible position development, e.g., undocumented citizen healthcare.

Objective AD-2.2

To ensure that cancer patients have access to quality prevention and cancer care, including both current therapies and treatments provided through high-quality, peer-review clinical trials.

Strategies

AD-2.2.1 Assess and/or review current and pending cancer-related legislation.

AD-2.2.2 Advise legislative members and staff of identified cancer-related needs.

AD-2.2.3 Continue to make policy-makers aware of data on cancer-related issues such as reimbursement.

AD-2.2.4 Advocate for improved transportation in order to increase access to cancer care and screening in New Jersey.

Objective AD-2.3

To create a state-level service that would provide a centralized resource for cancer information.

Strategies

AD-2.3.1 Evaluate current cancer resource information systems.

AD-2.3.2 Support and cooperate with the appropriate governmental body to develop a state-level cancer resource information system service.

AD-2.3.3 Advocate for funding of a centralized cancer resource information system in New Jersey.

ADVOCACY TO REDUCE DISPARITIES—THE UNEQUAL BURDEN OF CANCER

In order for a comprehensive health agenda to be truly effective in reducing cancer incidence and mortality, it must address all populations. We cannot address the differences in the burden of cancer for minority, poor, and medically underserved populations without creative interventions to overcome the barriers to care that threaten our ability to effectively reach and serve these populations.

Cancer among Minorities

Overall, black men in New Jersey and the U.S. are more likely to develop and die from cancer than persons of any other racial and ethnic group. (See Burden of Cancer in New Jersey chapter for additional information.) For the years 1998 through 2003, the U.S. incidence rates for all cancer sites were highest among blacks, followed by whites, Hispanics, Asian/Pacific Islanders, and American Indians/Alaska Natives. U.S. mortality rates during 1998 through 2003 were also highest among blacks, followed by whites, Hispanics, American Indians/Alaska Natives, and Asian/Pacific Islanders.[5] Despite the high rates of incidence from all cancers combined from 1992–1998, rates among blacks, Hispanics, and whites decreased, while remaining relatively stable among American Indians/Alaska Natives and Asian/Pacific Islanders. Similarly, mortality rates for all cancer sites decreased annually among blacks, Asian/Pacific Islanders, whites, and Hispanics, while leveling off among American Indians/Alaska Natives.[4,5] Many disparities among cancer sites also exist and are detailed in the site-specific chapters of the *Plan*.

These disparities must be addressed as part of any comprehensive cancer control plan.

Population Demographics Adding to the Cancer Burden

Cancer can strike at any age, but approximately 77% of all cancers are diagnosed at ages 55 and older.[4] The American population is graying, with a growing percentage of people now in their 60s and older. With the oncoming retirement of the Baby Boomers, the number of Americans over age 65 will double in the next 30 years. At current rates, the number of new cancer cases will rise dramatically, causing cancer to surpass heart disease as the nation's leading killer.[10] A higher percentage of retirement-age New Jerseyans have cancer and die of it than in the nation as a whole. Among those aged 65 and older, the cancer rate is 13% higher among men, 12% higher among women, as compared to the national average.[13]

GOAL AD-3	To reduce cancer-related health disparities among racial and ethnic minority populations, seniors, and the medically underserved.

Objective AD-3.1

To advocate for a healthcare system that provides cancer services that address the psychosocial, economic, physical, and educational needs of the patient in a culturally sensitive and linguistically appropriate manner.

Strategies

AD-3.1.1 Advocate for required quality improvement standards for cancer screening, diagnostic tests, treatment, rehabilitation, and palliation services and therapies that would be available and cost effective for all underserved and seniors.

AD-3.1.2 Advocate for organized healthcare systems that reduce fragmentation of available cancer services.

AD-3.1.3 Advocate for funding toward increased numbers of knowledgeable and competent navigators for cancer patients and families to help access and navigate the healthcare system.

AD-3.1.4 Collaborate with other interested stakeholders to integrate existing initiatives addressing health disparities.

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NUTRITION AND PHYSICAL ACTIVITY

IMPORTANCE OF NUTRITION AND PHYSICAL ACTIVITY FOR CANCER PREVENTION AND CONTROL

While the important role of cigarette smoking in cancer etiology and prevention cannot be underestimated, for the great majority of Americans who do not smoke cigarettes, dietary and physical activity behaviors are the most important modifiable determinants of cancer risk.[1,2] Former smokers, a group at high risk of developing cancer, can also benefit from a healthy diet and a physically active lifestyle. According to the World Health Organization (WHO), dietary factors are second only to tobacco as the most important known preventable cause of cancer.[1] There is also increasing evidence that physical activity may be inversely related to some cancers.[3] The role of diet in cancer etiology and prevention is well established. A panel of experts commissioned by the World Cancer Research Fund (WCRF) and the American Institute for Cancer Research (AICR) concluded that approximately 30% of all cancers are preventable by dietary means, physical activity, and maintenance of appropriate body weight.[4] Overweight and obesity have been associated with 14–20% of all deaths from all cancers.[5] Maintaining healthy eating patterns throughout the life course can play a major role in cancer prevention, mainly because this is a potentially modifiable behavior. Therefore, the introduction of healthy eating patterns and physical activity at any time will promote overall health and greatly reduce the risk of cancer.

Evidence-based national dietary guidelines for cancer prevention have been issued by various organizations. Overall, recommendations include maintenance of a healthy weight and an active lifestyle, eating a healthy diet—emphasizing a variety of fruits and vegetables and whole grain products—and drinking alcohol only in moderation or not at all.[1,2]

Less well known is the role played by diet and physical activity during the various phases of cancer survivorship—active treatment phase, recovery phase, health maintenance phase and, for some, a phase of living with advanced cancer. After a cancer diagnosis, many survivors look actively for information on dietary choices, alternative therapies, including supplements, and physical activity to help them gain some measure of control over their condition and improve their symptoms. Survivors have evolving needs and challenges regarding nutrition and physical activity throughout the phases of survivorship. The current scientific evidence on nutrition and physical activity was recently reviewed by a panel of experts organized by the American Cancer Society.[2] In general, the panel concluded that adequate dietary intake can improve nutritional status in virtually all cancer survivors and recommended that survivors follow the basic national dietary guidelines described above for a healthy diet. Yet, clearly, further research in this area is imperative.[6]

NUTRITION AND PHYSICAL ACTIVITY IN NEW JERSEY

As noted in the introductory section to this *Plan* on "Cancer Burden in New Jersey," the incidence and mortality rates for certain cancer types in New Jersey are higher than the national average. The *Healthy New Jersey 2010 Report*[7] and *Healthy New Jersey 2010: Update 2005*[8] focus on the following goals for nutrition and health:

Objective 1. To increase the percentage of persons aged 18 and over eating at least five daily servings of fruits and vegetables (including legumes) to 35.0%.

Objective 2. To reduce the percentage of persons aged 18 and over who are overweight but not obese to 27.6% for all adults.

Objective 3. To reduce the percentage of persons aged 18 and over who are *obese* to 12.0% of all adults.

Objective 4. To reduce the percentage of persons aged 18 or older who do not engage regularly in moderate physical activity for at least 30 minutes per day to 57.5% of all adults.

Consumption of fruits and vegetables. As shown in Table 1, according to Behavioral Risk Factor Surveillance System (BRFSS) data, only 25.9% of New Jersey adults reported consuming fruits and vegetables at least five times a day in the year 2005. Although, the proportion of New Jersey residents eating 5 servings of fruits and vegetables a day is higher than the national average for the total population and for each race, gender, and age subgroup (Table 1), we are still far from the Healthy New Jersey 2010 target of 35%. BRFSS trend data also indicate that the proportion of people eating the recommended five servings of fruits and vegetables has remained essentially stable during the past decade. These data underscore the need for more effective nutrition interventions to help New Jersey residents achieve this goal. Males, Hispanics, and New Jersey residents aged 25 to 44 years may derive the most benefit from these interventions (Table 1).[9]

Table 1. Proportion of New Jersey residents 18 years and older who reported consuming fruits and vegetables at least five times a day in the year 2005* and specified target % in Healthy New Jersey 2010**

	New Jersey (2005)	Nationwide (2005)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	25.9	23.2	35	50
By Race and Ethnicity				
White	26.2	23.7	35	50
Black	28.3	21.8	35	50
Hispanic	22.0	20.4	35	50
Other	30.6	26.0	35	50
By Gender				
Male	22.0	18.6	***	***
Female	29.5	28.1		
By Age				
18–24	24.4	21.0	***	***
25–34	23.2	21.7		
35–44	23.3	20.1		
45–54	26.5	22.4		
55–64	26.7	24.8		
65+	31.3	31.0		
By Education				
< High School	23.0	18.7	***	***
HS or GED	22.9	19.0		
Some post-HS	25.9	23.6		
College graduate	29.0	29.2		

* Behavioral Risk Factor Surveillance System data, Centers for Disease Control and Prevention, 2006.
** *Healthy New Jersey 2010*, New Jersey Department of Health and Senior Services, 2001.
*** Target and preferred endpoint not set by gender, age, or education.

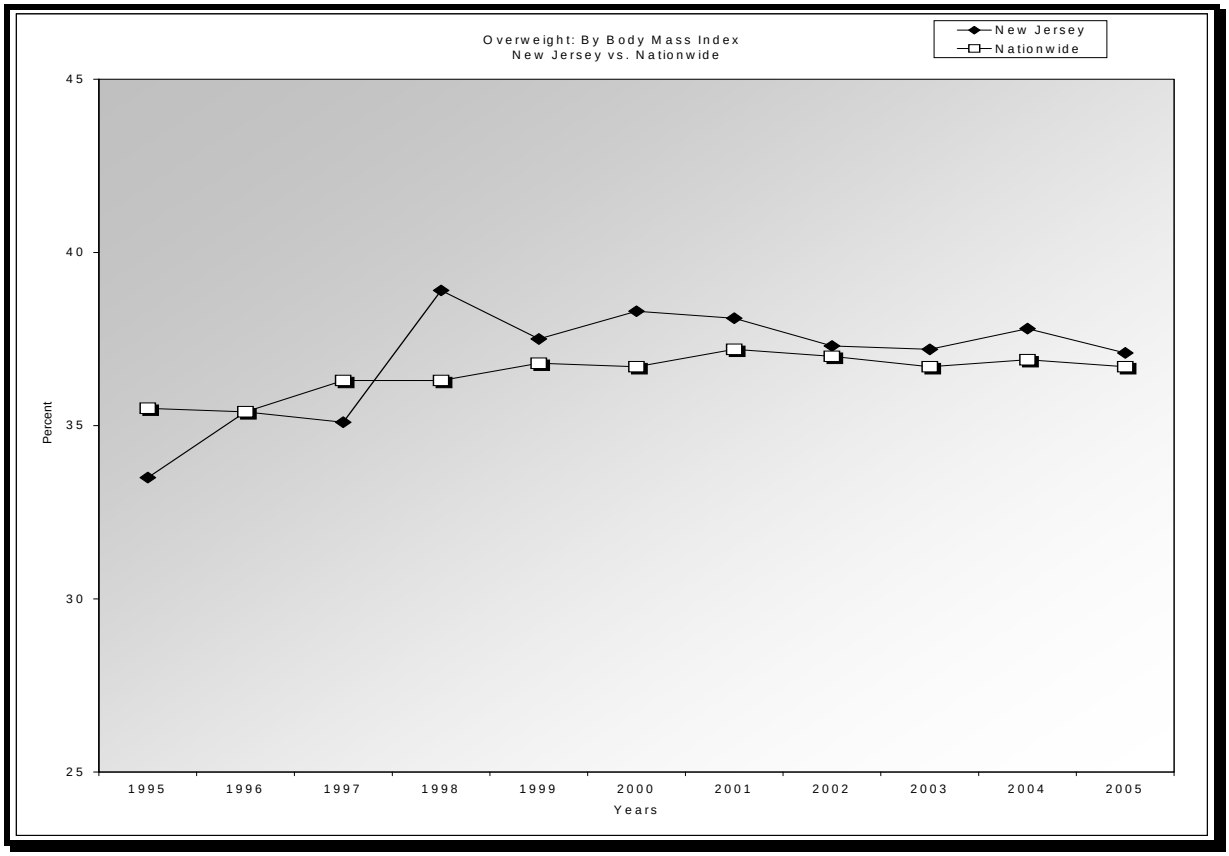
Overweight. As Table 2 shows, the proportion of overweight subjects in 2005 was slightly higher in New Jersey than the national average (37.1% and 36.7%, respectively). This is also illustrated in Figure 1, where the prevalence of overweight subjects seems to have been slightly increasing over the last decade. The percentage of overweight males was considerably higher than that of females in the year 2005 (Table 2). The data also reveal differences by race and ethnicity, with the highest prevalence of overweight being reported by Hispanics (42.1%), followed by blacks (38.7%), and whites (36.5%) (Table 2). Although male and Hispanic populations appear to have the greatest need for the intervention and research programs, all groups are far from the Healthy New Jersey 2010 target of 27.6% and could benefit from health promotion activities aimed at achieving long-term healthy body weight.[7,9]

Table 2. Percentage of New Jersey residents 18 years and older who are overweight (defined as BMI* between 25 and 29.9) in 2005 and specified target % in Healthy New Jersey 2010*****

	New Jersey (2005)	Nationwide (2005)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	37.1	36.7	27.6	25
By Race and Ethnicity				
White	36.5	36.8	28.1	25
Black	38.7	36.1	28.4	25
Hispanic	42.1	37.8	32.4	25
By Gender	43.2	43.8	36.6	25
Male	31.2	29.3	25.1	25
Female				
By Age				
18–24	26.4	26.5	****	****
25–34	34.9	35.0		
35–44	38.0	37.6		
45–54	37.9	38.5		
55–64	41.3	39.8		
65+	40.4	40.5		

* BMI (Body Mass Index) is defined as weight in kilograms divided by height in meters squared (w/h^2).
** Behavioral Risk Factor Surveillance System data, Centers for Disease Control and Prevention, 2005.
*** *Healthy New Jersey 2010*, New Jersey Department of Health and Senior Services, 2001.
**** Target and preferred endpoint not set by age.

Figure 1. Trends in percentages of New Jersey residents who are overweight* versus nationwide, Behavioral Risk Factor Surveillance System, 1995–2005



* All respondents 18 and older who report that their Body Mass Index is between 25.0 and 29.9. BMI is defined as weight in kilograms divided by height in meters squared (w/h^2). Denominator includes all survey respondents except those with missing, don't know, and refused answers.

Obesity. Although New Jersey is closer to the Healthy New Jersey 2010 objective than the national average (Table 3), considerable efforts must still be expended to bring the current obesity prevalence of 22.1% to the Healthy New Jersey 2010 target of 12%. The obesity prevalence is particularly high among blacks (32.5%). Figure 2 illustrates the alarming trend in increasing obesity over the past decade and highlights the need for immediate effective intervention and research to reverse this trend.

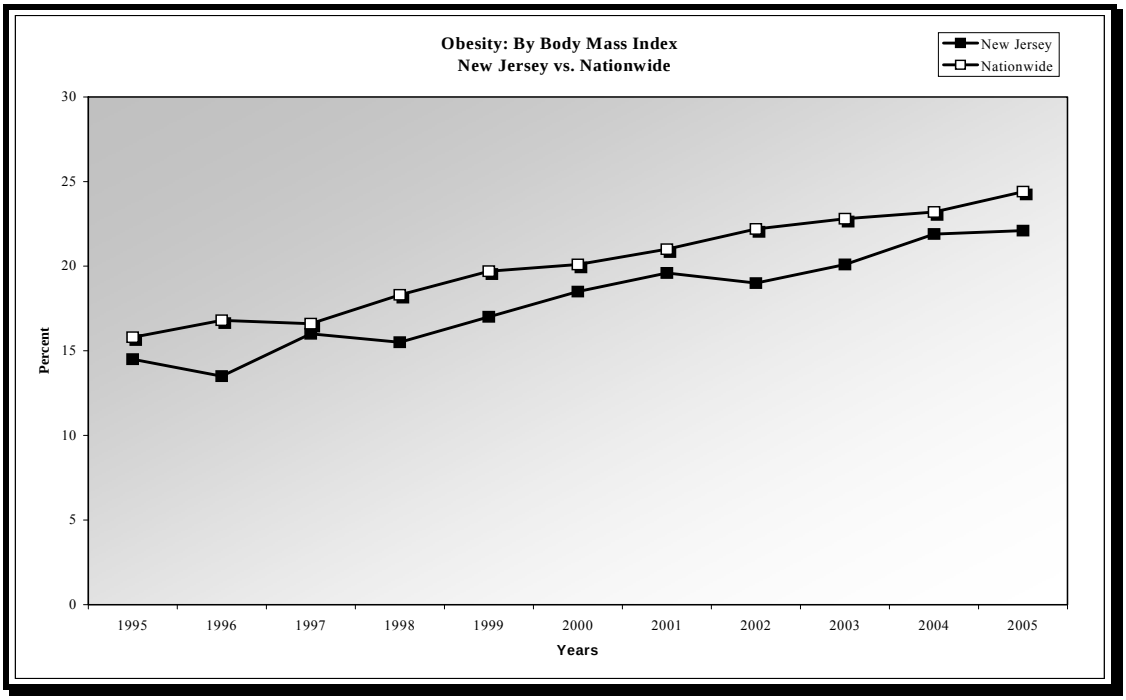
Physical activity. Obesity results from an imbalance between energy intake and energy expenditure. The obesity epidemic in the U.S. and in New Jersey is the result of unhealthy diets and a sedentary lifestyle. As shown in Table 4, in 2005, 51.3% of U.S. and 54.1% of New Jersey adults did not meet the recommendations in *Healthy New Jersey 2010* for moderate physical activity (see Table 4 for definition of "moderate"). Activity levels vary by race, gender, age, education, and income. For example, males and Hispanics tended to be less likely to meet the recommendations. For both New Jersey and the U.S., the level of physical activity is directly related to education and income. Although the Healthy New Jersey 2010 target of reducing the percentage of adults who do not engage regularly in moderate physical activity to 57.5% has been reached for some populations such as whites, younger adults, the more educated, and the more affluent, reaching the target for blacks, Hispanics, older adults, the less affluent, and the less educated still appears to be a challenge.[7,9]

Table 3. Percentage of New Jersey residents 18 years and older who are obese (defined as BMI* of 30.0 or greater) in 2005 and specified target % in Healthy New Jersey 2010*****

	New Jersey (2005)	Nationwide (2005)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	22.1	24.4	12.0	12.0
By Race and Ethnicity				
White	21.6	23.5	12.0	12.0
Black	32.5	34.7	15.0	12.0
Hispanic	22.2	24.6	12.0	12.0
By Gender				
Male	23.7	24.6	14.0	12.0
Female	20.5	24.0	12.0	12.0
By Age				
18–24	14.6	16.2	****	****
25–34	18.5	23.1		
35–44	21.3	26.3		
45–54	26.3	29.1		
55–64	28.7	30.5		
65+	21.0	21.0		

* BMI (Body Mass Index) is defined as weight in kilograms divided by height in meters squared (w/h^2).
** Behavioral Risk Factor Surveillance System data, Centers for Disease Control and Prevention, 2005.
*** *Healthy New Jersey 2010*, New Jersey Department of Health and Senior Services, 2001.
**** Target and preferred endpoint not set by age.

Figure 2. Obesity trends in New Jersey versus nationwide, Behavioral Risk Factor Surveillance System, 1995–2005



* All respondents 18 and older who report that their Body Mass Index is 30.0 or more. BMI is defined as weight in kilograms divided by height in meters squared (w/h^2). Denominator includes all survey respondents except those with missing, don't know, and refused answers.

Table 4. Percentage of adults at risk for not meeting the moderate physical activity recommendation* and specified target % in Healthy New Jersey 2010**

	New Jersey (2005)	Nationwide (2005)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total group	54.1	51.3	57.5	50.0
By gender				
Males	52.4	49.5	57.5	50.0
Females	55.6	52.3	57.5	50.0
By race and ethnicity				
White	50.0	48.8	57.5	50.0
Black	58.3	58.2	57.5	50.0
Hispanic	62.8	56.2	57.5	50.0
By age				
18–24	47.5	40.6	***	***
25–34	53.2	48.3		
35–44	50.0	49.7		
45–54	54.9	51.5		
55–64	55.1	55.3		
65+	62.8	61.0	57.5	50.0
By education				
< High school	71.3	62.2	***	***
High school graduate	55.8	54.1		
Some college	51.8	50.4		
College graduate	49.8	46.9		
By income				
<15,000	64.5	61.3	***	***
15,000–24,999	62.7	57.1		
25,000–34,999	61.3	52.1		
35,000–49,999	53.9	50.4		
≥50,000	47.3	46.2		

Source: Behavioral Risk Factor Surveillance System data, Centers for Disease Control and Prevention, 2005.

* 30+ minutes of moderate physical activity five or more days per week or vigorous physical activity for 20+ minutes 3 or more days per week.

** *Healthy New Jersey 2010: Update 2005*, New Jersey Department of Health and Senior Services, 2005.

*** Target and preferred endpoint not set by age group (other than 65+), education, and income.

GOALS, OBJECTIVES, AND STRATEGIES

The recommendations of the Nutrition and Physical Activity Workgroup are summarized below for the following focal areas:

- Cancer prevention
- Cancer survivorship

OVERALL GOAL	To reduce cancer incidence in the State of New Jersey by improving the diet and increasing physical activity among its residents; and to improve survival and quality of life among cancer patients and survivors.

CANCER PREVENTION AND NUTRITION/PHYSICAL ACTIVITY

In this section we discuss the role of nutrition and physical activity in cancer prevention, as well as current efforts to promote sound nutrition and increased physical activity among New Jersey residents.

The Role of Nutrition and Physical Activity for Cancer Prevention

The role of diet and nutrition in cancer prevention is well established.[1,2,4] It has been estimated that approximately one-third of all cancers occurring in the U.S. are attributable to dietary factors.[1,4,10] The precise biological impact for any single dietary factor is difficult to determine, given the endless number of compounds present in diet and the interactions among them. However, we do know that the foods we eat contain agents with both carcinogenic (cancer-causing) and anticarcinogenic (cancer-preventing) potential.

At the present time many aspects of the relationship between diet and cancer are not fully understood. For example, the role of dietary fat as a key factor in cancer development has been recently challenged.[11,12] The type of dietary fat consumed, rather than total fat, seems to be a more important factor in determining cancer risk.[13,14] Nevertheless, there is fairly consistent evidence supporting a role for fruits and vegetables, whole grains, and physical activity in preventing some cancers, whereas obesity, alcohol, certain food preparation methods (such as barbequing at high temperatures) may increase cancer risk.[6,15]

The body of literature showing that diets high in fruits and vegetables are associated with a reduced risk of cancer is large and fairly consistent, particularly for cancer of the gastrointestinal and respiratory tracts.[16] The WCRF/AICR report concluded that increasing the consumption of fruits and vegetables may prevent at least 20% of all cancers worldwide.[4]

A growing body of evidence suggests that obesity increases the risk of prostate cancer for males and of post-menopausal breast cancer, endometrial, ovarian, gall bladder, and cervical cancer for females; and of colon, kidney, and adenocarcinoma of the esophagus for both males and females.[13,15] Hormonal mechanisms have been proposed to explain the relationship between body size and cancers of the breast,

endometrium, and colon, in particular through increases in estrogens and insulin and insulin-like growth factors. These hormonal factors have been implicated in the etiology of breast, endometrial, and colon cancer.[13,15]

Evidence for a role of physical activity in reducing cancer risk is also accumulating.[3,5] A recent systematic review of the epidemiologic literature concluded that the evidence for a protective role of physical activity for colon and breast cancer is convincing, for prostate cancer is probable, for lung and endometrial cancer is possible, whereas for testicular and ovarian cancers evidence is insufficient.[17] Several mechanisms have been proposed to explain the beneficial effects of regular physical activity, including modification of endogenous sex and metabolic hormonal levels and growth factors, decreased body fat content, and possibly enhanced immune function.[17]

A decrease in physical activity most likely has contributed to the increased proportion of individuals nationwide who are overweight or obese. Labor-saving devices at home and work, fewer safe areas for pedestrians and cyclists, and less emphasis on physical education in schools are just a few examples of factors that have caused a decrease in physical activity. At the same time, while physical activity continues to decrease, there is growing popularity and availability of fast foods and snack foods, which are increasing caloric intake and resulting in energy imbalance and, subsequently, overweight/obesity.

A study found that physically active individuals had lower annual direct medical costs than did inactive people. The cost difference was $330 per person, based on 1987 dollars. The potential savings if all inactive American adults became physically active could be $29.2 billion in 1987 dollars, or $76.6 billion in 2000 dollars.[18]

According to the report of the Surgeon General, physical activity also appears to improve health-related quality of life by enhancing psychological well-being and by improving physical functioning in persons compromised by poor health.[19]

Several reports have been published that provide suggestions to improve healthy eating habits and increase physical activity to decrease the risks of cancer. The Surgeon General suggests that consistent influences on physical activity patterns among adults and young people include confidence in one's ability to engage in regular physical activity (i.e., self-efficacy), enjoyment of physical activity, support from others, positive beliefs concerning the benefits of physical activity, and lack of perceived barriers to being physically active. Interventions targeting physical education in elementary school can substantially increase the amount of time pupils spend being physically active in physical education class. For adults, some interventions have been successful in increasing physical activity in communities, worksites, healthcare settings, and at home.[19]

The *Harvard Report on Cancer Prevention* provides steps for prevention of cancer at the individual, community, and government levels. Researchers recommend that individuals foster better dietary habits, exercise moderately, avoid heavy alcohol intake (i.e., more than 2 drinks per day for men and more than 1 drink for women), and speak with their doctors about lifestyle decisions that reduce cancer risk. At the community level, nutrition and physical activity in school curricula are recommended, as well as mass media campaigns and accessibility for physical activity and nutrition education programs. Communities are advised to support physical and health education for all grades and to monitor food supplement programs for a nutritional balance.[2]

The WHO recommends establishing *enabling environments* in schools, workplaces, and communities, supported by transport and urban design policies; access to the resources necessary for a healthy diet; and legislative, regulatory, and fiscal policies. An enabling environment is one that encourages, supports, and protects healthy living.[1] In order to accomplish this, the WHO has published the following strategic actions for promoting healthy diets and physical activity:

- Surveillance of people's diets, physical activity, and related disease burden.
- Enabling people to make informed choices and take effective action.
- Making the best use of standards and legislation.
- Ensuring that "healthy diet" components are available to all.
- Achieving success through intersectoral initiatives.
- Making the best of health services and the professionals who provide them.

Current Efforts in New Jersey

The New Jersey Department of Health and Senior Services (NJDHSS) has created a new Office of Nutrition and Fitness to help lead New Jersey's fight against obesity. The office will oversee more than $2 million in nutrition and fitness programs and will work to implement the Governor's appointed New Jersey Obesity Prevention Task Force's recommendations outlined in its 2006 report, *The New Jersey Obesity Prevention Action Plan.*[20] The recommendations include: improved nutrition, increased fruit and vegetable consumption, increased physical activity, exclusive breastfeeding of infants, and decreased time spent on television, computers, and video games.

The NJDHSS serves as the state health authority of the National Fruit and Vegetable Program. In 2007 the public health initiative Fruits and Veggies – More Matters™ was introduced to replace the program formerly known as the 5 A Day for Better Health Program when it is phased out by the end of 2008. The lead national program partners are the Centers for Disease Control and Prevention and the Produce for Better Health Foundation. The program is a national effort to achieve the Healthy People 2010 objective to increase the per capita consumption of fruits and vegetables to five or more servings daily. In 1995, a group known as the New Jersey 5 A Day Coalition was created to work collaboratively to increase consumption of fruits and vegetables. Approximately 30 organizations participate in the coalition. The group currently operates under its 2001 mission statement: "The New Jersey 5 A Day Coalition is a diverse group of stakeholders advocating the consumption of 5 or more servings of fruits and vegetables a day, for the purpose of promoting health and improving the quality of life for all New Jerseyans."

The Nutrition and Physical Activity Workgroup is collaborating with the 5 A Day Coalition to secure funding for New Jersey to participate in the USDA Fruit and Vegetable Snack Program (FFVP). The FFVP grants designate funds for states to provide school children with fresh fruits and vegetables. In a pilot study of the program, it was observed that FFVP lessened the risk of obesity, encouraged children to eat healthier food, increased children's awareness of a variety of fruits and vegetables, and helped children, who would otherwise be hungry, obtain more food. School staff and parents of children enrolled in the program noticed that children requested more fruits and vegetables and consumed fewer unhealthy foods throughout the day.[21]

As mentioned above, all activities and events coordinated by the New Jersey 5 A Day Coalition are directed toward achieving the Healthy New Jersey 2010 objective to: "Increase the percentage of

persons (aged 18 years and over) eating at least 5 daily servings of fruits and vegetables (including legumes) from 27.0% to 35.0%."[7]

It is widely recognized that nutrition plays a significant role in health promotion and disease prevention. It is also clear that consumers are not only listening, but also attempting to apply the information available to them. The availability of accurate nutrition information and use of well-researched nutrition education tools continues to be important. Tools appropriate to age and literacy level, as well as culturally appropriate tools are needed.

The New Jersey Core Curriculum Content Standards, with which local school districts' curricula must be aligned, were most recently reviewed in 2004. The Standards were expanded to address in additional depth and clarity the many health issues that face school-aged children. There was a specific effort to increase the number of progress indicators in the Standards in grades Kindergarten through 12 that address healthy eating, increasing physical activity, and disease prevention strategies. The next revision of the Standards will occur in 2009.

To enhance existing nutrition and physical activity programs/services, the Nutrition and Physical Activity Workgroup advises that New Jersey residents continue to be educated about healthy eating patterns and exercise through such programs as the Mayor's Wellness Campaign. Various nationwide research has shown successful community education[22,23] and worksite education programs[24–26] focusing on the importance of healthy eating patterns and moderate physical activity for cancer prevention. Additionally, school-based curricula[27] have a positive impact on the eating patterns of students. Therefore, the Nutrition and Physical Activity Workgroup proposes that New Jersey residents be educated about the importance of dietary factors and physical activity to decrease the risk of cancer through academic, worksite, and community education. Improving access[2] and services provided can enhance existing public health programs. Additionally, high-risk groups—such as certain ethnic groups,[25] those with lower incomes, and those at lower educational levels—should be targeted for education about cancer-risk reduction.[1,2]

GOAL NP-1	To promote long-term healthy eating patterns, healthy weight, and physical activity for cancer prevention among New Jersey residents.

Objective NP-1.1

To increase the proportion of healthy foods, especially fruits and vegetables, that New Jersey residents consume each day.

Strategies

NP-1.1.1 Review the New Jersey Core Curriculum Content Standards for education about diet and nutrition, including healthy eating patterns, physical activity, and the prevention of

cancer. Make recommendations for improvements if and where needed in time for the 2009 revisions.

NP-1.1.2 Recommend an evaluation of food services in educational institutions, daycare facilities, and workplaces in order to implement improvements in these services in line with federal guidelines.

NP-1.1.3 Increase access to healthy foods, especially for high-risk groups, by supporting state-level nutrition programs, such as WIC, Fruits and Veggies – More Matters™, and Team Nutrition.

NP-1.1.4 Assess needs and develop nutrition education programs for cancer prevention among college students.

NP-1.1.5 Assess needs and develop nutrition education programs for cancer prevention among Head Start parents and other low-income groups.

NP-1.1.6 Create a mass media campaign to promote statewide nutrition programs that encourage consumption of a diet consistent with dietary guidelines.

Objective NP-1.2

Enhance, or support where necessary, statewide nutrition programs to help New Jersey residents reduce the risk of developing cancer.

Strategies

NP-1.2.1 Support an infrastructure within state government to coordinate and collaborate on activities among existing nutrition programs.

NP-1.2.2 Coordinate and support comprehensive nutrition education programs in allied fields by sponsoring collaboration.

NP-1.2.3 Encourage and support the incorporation of an evaluation component in nutrition education programs to evaluate effectiveness in persuading people to eat healthier diets, thereby modifying behaviors that affect cancer risk.

Objective NP-1.3

To increase frequent, leisure-time physical activity, as consistent with Healthy New Jersey 2010 goals.

Strategies

NP-1.3.1 Educate the public about ways to increase physical activity using existing programs and information sources.

NP-1.3.2 Increase the availability and accessibility of affordable opportunities for physical activity within communities.

NP-1.3.3 Support an infrastructure within state government to coordinate and collaborate on activities among existing physical activity programs.

NP-1.3.4 Coordinate and support comprehensive physical activity education programs in allied fields by sponsoring collaboration.

NP-1.3.5 Encourage and support the incorporation of an evaluation component in physical activity education programs to evaluate effectiveness in persuading New Jersey residents to increase their physical activity.

Objective NP-1.4

Advocate for policy and environmental changes to increase support for proper nutrition and physical activity at the state and local level.

Strategy

NP-1.4.1 Increase advocacy efforts and public support for initiatives, policy, and legislation that promote healthy eating and physical activity.

Cancer Survivorship and Nutrition/Physical Activity

Currently every year nearly 1.4 million people are diagnosed with cancer in the U.S., and approximately 10.5 million cancer survivors are living today.[28] Proper nutrition and appropriate levels of physical activity have been demonstrated as important for the optimal efficacy of cancer treatment regimens and may reduce the chances of disease recurrence.[29]

Cancer survivors are intensely interested in nutrition and complementary and alternative treatment regimens. Studies clearly demonstrate that they practice these treatments, often without the knowledge of their physicians and often without sufficient information to support their usefulness or safety.[30] This practice can have detrimental effects, as some products—such as certain dietary supplements—have been shown to have negative interactions with some conventional cancer treatments. It is important that patients and physicians discuss nutritional and lifestyle choices before, during, and after cancer treatment.[25]

As advances in modern oncologic medical care become increasingly successful at extending the lives of those diagnosed with cancer, and in many cases curing the disease altogether, the number of people living with a history of cancer will continue to grow. As the number of cancer survivors increases, so does the need to address the specific health requirements and quality of life of this population. To date there has been limited study of the role of nutrition and physical activity in cancer survivorship.[6] However, several ongoing studies are currently addressing precisely this topic, and the Nutrition and Physical Activity Workgroup plans to closely monitor study findings.

It is necessary for cancer survivors in all stages of treatment, recovery, living after recovery and, in some cases, living with advanced cancer to have ready access to solid evidenced-based information on dietary habits and physical activity that will permit them to make decisions to optimize their health and well-being. Cancer survivors should be able to obtain this information easily and to avail themselves of appropriate professional advice and services. Access should be equivalent regardless of socioeconomic status or education level. Finally, it is the responsibility of the healthcare community to generate this information through further research into the impact of dietary habits, nutrition, and physical activity on cancer survivorship.[6,14]

GOAL NP-2 To assure proper nutritional care for cancer patients.

Objective NP-2.1

Encourage healthcare professionals to use nutrition guidelines for cancer patients/survivors during and after cancer treatment.

Strategy

NP-2.1.1 Promote national practice guidelines targeted to healthcare professionals relating to nutritional care for cancer patients.

Objective NP-2.2

Provide cancer patients/survivors with information about proper nutrition and physical activity during and after treatment.

Strategies

NP-2.2.1 Advocate for reimbursement coverage for Medical Nutrition Therapy.

NP-2.2.2 Provide support to those New Jersey residents who are receiving/or have received cancer treatment and are currently battling a nutritional problem.

Objective NP-2.3

To provide ongoing information regarding nutrition and physical activity guidelines to cancer survivors for the prevention of recurrence and of other cancers and chronic diseases.

Strategies

NP-2.3.1 Assess current needs and develop educational programs for cancer survivors.

NP-2.3.2 Provide primary care physicians with educational materials to facilitate long-term care for cancer survivors for the prevention of recurrence and of other cancers and chronic diseases.

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CHAPTER 3. Palliation

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PALLIATION

DEFINING PALLIATION IN NEW JERSEY

The initial challenge facing the Palliation Workgroup under the first edition of the *Plan* was to develop a definition of palliative care that was operational, yet inclusive of a variety of perspectives. Workgroup members noted a lack of consensus in the healthcare world on the meaning of the term *palliative* care. One widely accepted definition—an early definition developed by the World Health Organization (WHO)—begins, "Palliative care is the active total care of patients whose disease is not responsive to curative treatment ..." A major drawback with this definition, in the workgroup's view, was the limitation of access to palliative care to those at the end of life, when others with chronic rather than terminal illness may also benefit. Subsequently, in 1990, WHO suggested a more global approach by stating, "… control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment."[1] It is this latter, broader definition that the Palliation Workgroup chose as a model for its own definition.

Another issue considered by the workgroup was the relationship of palliative care to hospice care and a tendency among professionals in the two fields to view their efforts as mutually exclusive. The impact of reimbursement issues on palliative care was a third issue considered. Other challenges in palliative care arise from cultural, ethnic, racial, and religious differences. In developing a definition that was sufficiently inclusive professionally that the interdisciplinary approach would not become lost in the more familiar medical model hierarchy, workgroup members strove to be sensitive to these issues and to the resultant political implications.

Acknowledging that those with cancer are increasingly *living with it* rather than (quickly) *dying from it,* the workgroup concurred that palliative care was certainly indicated for patients whose cancers were responsive to curative treatment, as well as for those in need of end-of-life care. For patients with cancer at any stage, the benefits of care that recognizes psychological distress and spiritual needs as well as physical symptoms are readily apparent. In recognition of these deliberations, the workgroup proposes the current 2006 definition, slightly revised from the 2001 definition that appeared in the first edition of the *Plan*.

> *"Palliative care is a coordinated, inter-disciplinary approach to healthcare that enhances the quality of life of people with cancer and other illnesses. It targets the physical and psychological symptoms and spiritual needs of survivors from the time of diagnosis to end-of-life care in all settings."*
>
> (Palliation Workgroup, 2006)

Note that through the phrase "from time of diagnosis to end-of-life care in all settings" workgroup members intend to include those with both chronic and terminal illness as appropriate recipients of palliative care.

IMPORTANCE OF PALLIATION IN CANCER CARE

Palliation is frequently described as managing the physical, emotional, and spiritual needs of both patient and family. This comprehensive approach requires a multi-disciplinary team for care, including nursing, pharmacy, social work, volunteer services, pastoral care, nutrition, arts, physical therapy, and medicine.[2,3]

The first hospice opened in New Haven, Connecticut, in 1974, inaugurating the hospice movement in the United States. The mission of a hospice was to allow patients to live as long as possible and then to die with the basic elements of a good death: care, communication, continuity, control, calmness, and closure.[2] Although it evolved out of hospice, palliative care has grown to encompass all stages along the continuum of care, including improving and maintaining a patient's comfort, dignity, and quality of life, whether in an inpatient or outpatient setting. (See Chapter 5 Childhood Cancer for additional information about palliation.)

Cancer patients are increasingly seeking complementary and alternative medicine (CAM) to aid in disease- and treatment-related symptom management. CAM includes alternative medical systems, mind-body interventions, biological-based therapies, manipulative and body-based methods, and energy therapies.[4] Both patients and physicians must be aware of the risks and benefits associated with CAM use in palliative care.

Although it evolved out of hospice, palliative care is quickly becoming a more common practice in mainstream U.S. healthcare[5] and is a key issue in cancer control. The potential number of cancer patients needing palliative care services in New Jersey is very high. As noted earlier in this *Plan*, the American Cancer Society estimates that 43,370 new cancer cases will be identified and 17,140 cancer deaths will occur in New Jersey in 2007.[6]

However, despite advances in palliative care in the past three decades, many cancer patients continue to suffer from unmanageable symptoms, including an unacceptable 70% to 90% experiencing acute pain.[7] While approximately one-half of all terminal cancer patients receive hospice care at the end of life, most could benefit from comprehensive palliative care earlier in the disease continuum.[8] Cancer patients receiving palliative care reported prevalence of lack of energy, pain, dry mouth, shortness of breath, and difficulty sleeping.[9] Pain includes physical and mental as well as spiritual manifestations (feelings of abandonment, anger, betrayal, despair, fear, guilt, sense of meaninglessness, regret, self-pity, and sorrow/ remorse).[2] Barriers to seeking effective pain management include a patient's reluctance to report pain, fear that pain signifies advancing disease, and the desire to be a "good" patient and not bother the physician with complaints of pain.[2]

Every year the number of New Jersey residents who die with cancer in an inpatient setting is decreasing. In 1989, approximately 63% of New Jerseyans who died from cancer were inpatients, compared to 42% in 1998.[10] As an increasing number of people are living with and dying of cancer in their homes rather than in medical facilities, so too expands the need to provide quality, comprehensive, and multi-disciplinary outpatient palliative care throughout the continuum of disease.

However, the cost of palliative care is also increasing. Medicare hospice expenditures climbed from $205 million in FY1989 to $2.1 billion in FY1998.[11] Medicaid hospice expenditures rose from $1.5 million in FY1987 to $197.2 million in FY1999. New Jersey was the 35th state to offer hospice under Medicaid in 1992.[11] Expenditures for palliative care will continue to rise due to an aging population,

increasing interest and concern about palliative care and end-of-life issues in conjunction with rising healthcare costs. Yet research shows that palliative care programs can also lower "costs per day" during a hospital stay. Factors contributing to lower costs per day include transfers out of the ICU and reduction in ancillary services and pharmacy costs.[12]

In the next decade, barriers to effective palliative care at all levels must be overcome. The Palliation Workgroup determined that addressing lack of awareness among healthcare professionals and the public about palliative care is a priority in New Jersey. Secondly, access to palliative care must be increased. Both these issues are described in further detail in the remainder of this chapter, and recommendations for improvement are outlined.

GOALS, OBJECTIVES, AND STRATEGIES

The recommendations of the Palliation Workgroup are summarized below for the following focal areas:

- Education
- Access
- Complementary and alternative medicine

OVERALL GOAL To increase awareness of and access to palliative care.

EDUCATION ON PALLIATIVE CARE

In order to influence quality of life in a positive manner, there must be clarity regarding the goals of care. To achieve clarity, the clinician must be knowledgeable about options that exist in the domain of palliative care along with the primary therapies. Just as important, the patient must also be aware of available options.

The challenges facing patients and their families at the time of diagnosis, during treatment stages, and continuing into survivorship years, are significant not only physically, but also psychosocially and spiritually. Therefore, effective, responsible care requires the integration of counseling into the treatment plan, whereas medical professionals may not regard this as a core component of care. Another problem impeding broader access to palliative care is the fact that patients and their surrogates may not be aware of the care options that exist.[13]

Despite the many societal and professional barriers to effective pain management, the Palliation Workgroup has identified addressing physician knowledge gaps, as well as misconceptions about pain management and symptom control, as the top priority to improve palliative care in New Jersey. In recent years, several medical and nursing programs have added education regarding palliative care concepts to their curricula. Many require that a hospice rotation be included in the clinical experience, since the focus of hospice is on pure palliative care. Palliative care should also be integrated into continuing professional education. The number of professionals certified in palliative care may be expected to increase, as educational opportunities in the field become available.

Although small steps have been made toward improving healthcare professionals' understanding of palliative care, the need for better care that promotes quality of life continues to grow. However, the transition from a medical model of care to a holistic one requires a paradigm shift in healthcare philosophy. Healthcare professionals and the public need support in understanding dying not as a failure of medicine, but as a natural part of life. People are living longer with chronic illnesses, and many are dying more slowly. Healthcare professionals need to respond to the challenge of supporting quality of life in addition to length of life.

Education is the first step in understanding suffering. With knowledge comes the power to truly affect quality of life along the entire continuum of care and, most intensively and poignantly, at the end of life. Therefore, the Palliation Workgroup proposes the following educational goal, objective, and strategies as next steps in improving palliative care in New Jersey through provider education.

GOAL PA-1	To integrate knowledge of palliative care into professional, public health, and legislative systems.

Objective PA-1.1

To educate and mobilize legislators, healthcare professionals, and the general public regarding the right to access palliative care and the benefits of comprehensive palliative care in all settings.

Strategies

PA-1.1.1 Integrate training on palliative care into primary and continuing education for practicing professionals.

PA-1.1.2 Develop a public education plan on palliative care for targeted populations based on capacity and needs assessments.

ACCESS TO PALLIATIVE CARE

Members of the Palliation Workgroup hold that every patient in New Jersey is entitled to access to palliative care services, regardless of the chronic illness from which they are suffering and regardless of the setting in which they may be found—whether in their own homes; a long-term care facility (such as nursing home, mental institution, center for the mentally and physically challenged); a hospital; an assisted-living facility; a boarding home; a state veterans' hospital; or a prison. Many of these patients will have family members and/or significant others (hereafter referred to as the family) who are entitled to the supportive care services offered by palliative care.

Due to conflicting regulations, especially within institutional settings, patients may have difficulty receiving appropriate palliative care services, even when the patient and family desire such services. Healthcare providers, as well, often become frustrated with the system, as they cannot provide appropriate care for the patient and family. On the other hand, even when the focus on curative care is no longer the avenue of choice, some healthcare providers may find it difficult to offer palliative care. Other times, the distinction between curative and palliative care may not be clear-cut, necessitating the addressing of a patient's needs on an individual basis.

While Medicare and a number of insurance and managed care plans cover hospice, palliative care services are often covered only indirectly under another aspect of care, if at all. In reality, palliative care services and hospice should be part of a continuum of care, in which patients and families can make choices they are comfortable making and ready to make, with support and guidance from healthcare professionals. Patients and families need to be empowered to participate in healthcare decisions.

Further dialogue needs to take place with insurance companies and managed care plans as to the benefits of palliative care services for those in need and the long-term savings to payment sources. Government

agencies and institutions also need to be educated as to the importance of palliative care, the long-term savings, and their obligations for reasonable reimbursement and/or provision of these services.

In addition to institutional and financial barriers to access, numerous patient and family barriers have been identified.[14] Socioeconomic backgrounds, cultural backgrounds and practices, personal values and beliefs, and religious or spiritual belief systems can influence perception of palliative care services.[15] For widespread acceptance of palliative care to occur, a multi-pronged effort is needed to engage healthcare providers, voluntary community-based organizations, faith-based groups, and other identified entities that are in a position not only to stimulate establishment of palliative care in healthcare settings in their communities,[5] but also to provide information to and support for patients, their families, and the community at large.

There are also legal barriers to providing quality end-of-life care. One example among several relates to adequate pain management. Many effective pain management drugs have been classified by the U.S. Drug Enforcement Agency (DEA) as Schedule II controlled substances and are therefore subject to state and federal regulations. Patients and their families are often hesitant to take these controlled substances, while physicians may be fearful of prescribing them due to intense legal scrutiny. Legislators can help to remove these barriers, which would benefit every constituent in their districts.[16,17]

Research has been done on cost savings and quality-of-life outcomes for patients and families that need and receive palliative care services. Comfort from pain, relief of symptoms, emotional and spiritual supports are only a few of the benefits for patients. For example, it is important to recognize pain as the fifth vital sign, along with blood pressure, temperature, pulse, and respiration. Prevention and/or reduction of physical, emotional, and financial problems, as well as prevention of long-term psychosocial problems, are but a few of the benefits for families. Social workers and pastoral counselors within healthcare settings can be helpful in obtaining resources to assist patients and families in obtaining needed palliative care services.

Existing data have been compiled for this *Plan*. Future surveys or research projects can focus on gaps in the existing data. Foundations, grants, insurance companies, government agencies, universities, and healthcare centers may be avenues for future funding. Commissions or task forces, such as that charged with producing this *Plan*, may be another avenue of study and recommendations for appropriate funding.

GOAL PA-2	To ensure that palliative care services are accessible to cancer patients and others with chronic illnesses.

Objective PA-2.1

To ensure reimbursement for palliative care services.

Strategy

PA-2.1.1 Investigate palliative care reimbursement initiatives and engage insurance companies in further discussion of reimbursement for palliative care services, including psychosocial and bereavement counseling for the patient and the patient's family.

Objective PA-2.2

To develop standards for palliative care.

Strategy

PA-2.2.1 Link with national organizations that can help frame the palliative care issue on a national scale.

Objective PA-2.3

To identify, prioritize, and reduce the system barriers to palliative care service availability.

Strategies

PA-2.3.1 Develop strategies to address the gaps in palliative care services.

PA-2.3.2 Educate state legislators who can serve as advocates in supporting palliative care policies.

Objective PA-2.4

To identify, prioritize, and reduce personal barriers to palliative care services.

Strategy

PA-2.4.1 Partner with interdisciplinary and grassroots organizations to alleviate personal barriers to palliative care.

Complementary and Alternative Medicine (CAM) in Palliative Care

Complementary and alternative medicine cannot be overlooked by conventional medicine. CAM is being used by a significant proportion of the U.S. population for therapy as well as for health promotion and disease prevention. CAM has become increasingly prevalent over the past few decades among cancer patients in particular, who often experience pain, anxiety, and fatigue as a result of their disease and treatment.[4] An estimated 94% of cancer patients experience disease-related symptoms that are not addressed by conventional medicine.[18]

The National Center for Complementary and Alternative Medicine (NCCAM) defines CAM as "a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine."[19] Complementary medicine is generally used in conjunction with conventional medicine, while alternative therapies are used in place of the conventional.[19] However, the delineation between conventional medicine and CAM is becoming increasingly blurred as some forms of CAM are now taught in medical and nursing schools, and hospitals and health maintenance organizations now offer it.[20] In fact, laws in some states require that health plans cover it.[21] CAM is identified with the following types of therapies: acupuncture, biofeedback, chiropractic, commercial weight-loss programs, energy healing (including magnets), folk remedies, music therapy, herbal medicine (including teas), homeopathy, hypnosis, imagery, lifestyle diets (e.g., macrobiotics), massage, mega-vitamins, relaxation techniques (including meditation), self-help groups, and spiritual healing.[4,18,19] It is estimated that as many as 84% of cancer patients in the U.S. have utilized CAM for its potential to boost their immune systems, relieve pain, and control the side-effects of disease and treatment.[4,18]

The funds expended for CAM have also increased and are significant. The estimated expenditures for alternative medicine professional services in the U.S. increased over 45% between 1990 and 1997 and were conservatively estimated at $21.2 billion in 1997, with at least $12.2 billion paid out of pocket. Total 1997 out-of-pocket expenditures relating to alternative therapies were conservatively estimated at $27 billion, which is comparable with the projected 1997 out-of-pocket expenditures for all U.S. physician services. Further, this increase was attributable primarily to an increase in the proportion of the population seeking alternative therapies, rather than increased number of visits per patient.[18]

The reasons people with cancer choose CAM are multiple. Many cancer patients are likely to do so when conventional therapies no longer offer the possibility of cure or remission. Others seek CAM out

of fear of chemotherapy, surgery, and radiation, the most common conventional therapies. For some tumor systems, no conventional therapy exists or there are only experimental clinical trials whose outcome is unknown. It has been suggested that cancer patients may feel a loss of control that leads them to use CAM as a way to regain or exercise some control over their care; through CAM they achieve a sense of contributing to the care of their malignancy.[18,22–24]

Studies have shown that those using CAM tend to have a higher education level, higher income, and hold a philosophical orientation toward health that can generally be characterized as holistic, e.g., they believe in the importance of body, mind, and spirit in health.[18,23] Users of alternative healthcare are also more likely to report poorer health status than nonusers. However, users of CAM are reported to be no more dissatisfied with or distrustful of conventional care than nonusers.[23]

While the benefits of CAM are becoming increasingly accepted, the use of such non-traditional therapies can be detrimental to the cancer patient's health. In a study of CAM users, close to 90% of respondents who saw a provider of unconventional therapy did so without the recommendation of their medical doctor. More than 70% of CAM users did not inform their medical doctor of this use.[25,26]

This lack of disclosure can have serious consequences for cancer patients and others. Because vitamins and herbs are considered to be nutritional supplements, they are unregulated by the U.S. Food and Drug Administration (FDA). This permits a lack of quality control in the products, and misleading labeling can persuade patients they are taking an appropriate amount, when in fact they are receiving excessive amounts of potent or harmful substances.[24] Additionally, CAM may interact with commonly prescribed drugs and other conventional therapies in unpredictable and potentially adverse ways.[18,23,27] Patients should discuss with their physician any use of CAM before, during, or after treatment.

It is because CAM, for the most part, lacks scientific evidence for safety and efficacy, as required by the FDA for the approval of drugs and by peer-reviewed medical journals for the publication of research reports, that medical authorities set it apart.[28] Although most CAM therapies are relatively low risk, any therapy that results in a delay of a proven therapy indirectly causes harm. Particularly troublesome to conventional providers are the alternative therapies that espouse a simple etiology to explain all cancers. It is generally agreed that there is inconclusive evidence about the safety, efficacy, mechanism of action, and cost-effectiveness of individual alternative treatments.[23,27] Exceptions to this premise include the use of spinal manipulation for acute low-back pain, acupuncture for nausea, and behavioral and relaxation techniques for chronic pain and insomnia.[29–31]

It is expected that as the public's interest in CAM increases, the number of conventional schools offering courses in CAM will continue to grow. Centers in medical schools and schools of public health to study CAM have also been established. The Office of Alternative Medicine, renamed the National Center for Complementary and Alternative Medicine, under the auspices of the National Institutes of Health, was established in 1992. This Center is making headway in funding studies that evaluate unproven treatments for cancer.

The public is increasingly exposed to information about CAM and conventional treatments through direct-to-consumer (DTC) advertising in the media and on the web. Although the reliability of the public information received through these sources is not always known, an argument put forth by the pharmaceutical industry is that DTC advertising encourages patients to take more questions to their doctors, and this may be a benefit rather than a disadvantage. Another argument for receiving

information through the lay media or advertising is that it encourages patients to become partners in their own healthcare.[32]

As the public becomes aware of both conventional and CAM modalities, healthcare providers should ask their patients about their use of CAM. In order to safeguard a patient's health, these questions should be asked during the initial history-taking and should be repeated at regular intervals. For cancer patients, this information can be critically important as it can reveal that the patient is taking herbs or other substances that may interfere with conventional therapy or alter laboratory values. The conventional provider may also be a source of information on CAMs that are not harmful and can offer the cancer patient a level of comfort not achieved by conventional therapy alone.

GOAL PA-3	To increase awareness of the benefits and risks of CAM use in palliative care.

Objective PA-3.1

To increase awareness among healthcare professionals of the benefits and risks of CAM use in palliative care.

Strategy

PA-3.1.1 Integrate training on CAM in palliative care into primary and continuing education for practicing professionals.

Objective PA-3.2

To increase awareness among the public of the benefits and risks of CAM use in palliative care.

Strategy

PA-3.2.1 Develop a public education plan on CAM in palliative care for targeted populations based on capacity and needs assessments.

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Section II
Site-Specific Cancers

Chapter 4. Breast
Chapter 5. Childhood
Chapter 6. Colorectal
Chapter 7. Gynecologic
Chapter 8. Lung
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CHAPTER 4. Breast Cancer

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BREAST CANCER

IMPORTANCE OF BREAST CANCER FOR CANCER PREVENTION AND CONTROL

Nationally, female breast cancer is the most common cancer among women, comprising an estimated 26% of new cancer cases and causing 15% of cancer deaths in U.S. females for 2007.[1] (Information about breast cancer in males can be found by contacting http://www.nci.nih.gov.) The greatest impact on reducing the number of years lost to cancer will come from progress against common cancers such as breast cancer.[2] From 1992 to 2002, breast cancer incidence rates increased for Asian/Pacific Islander women, decreased among American Indian/Alaska Native women, and remained the same for other women. During the same time period, breast cancer death rates declined among white, black, and Hispanic women.[3] In 2003, breast cancer caused 800,000 person-years of life lost, ranking second after lung cancer (2,403,000).[4] The rate of new cases of late-stage breast cancer continues to remain relatively stable, indicating that the impact of breast cancer screening on breast cancer stage at diagnosis must be examined further.[4]

The causes of breast cancer are not all known; however, some risk factors are well recognized. The major risk factors for breast cancer include:

- Age
- Genetic factors (personal or family history or genetic mutations)
- Hormonal factors
  - early menarche (early onset of menstruation)
  - late menopause
  - late parity (bearing children late)
  - nulliparity (not bearing children)
  - exogenous estrogen exposure
- High breast tissue density (a mammographic measure of the amount of glandular tissue relative to fatty tissue in the breast)
- Very high doses of radiation (such as that used in radiation therapy)[1,5]

High educational and socioeconomic levels are linked with greater risk, probably due to their association with reproductive risk factors. Jewish women are also known to be at higher risk of breast cancer, while black women have lower rates of the disease than do white women, except in younger age groups.

Estrogen exposure leading to increased risk of breast cancer includes the use of high-dose oral contraceptives (particularly in women with a family history of breast cancer), hormone replacement therapy after menopause, and factors leading to obesity (which increases circulating levels of estrogen).

Certain types of proliferative benign breast disease (such as radial scar, atypical hyperplasia, and proliferative fibrocystic change), and other factors, such as pesticide and other chemical exposures that mimic or modify the action of estrogens and gene-environment interactions, are being investigated.[1,6–8]

BREAST CANCER IN NEW JERSEY

In this section we discuss the status of breast cancer in New Jersey, including incidence, mortality, prevalence, survival, and prevention and early detection.

Incidence. The American Cancer Society estimates that, among women in the U.S., 178,480 cases of breast cancer will be newly diagnosed in 2007. In New Jersey alone, approximately 6,080 female breast cancer cases will be diagnosed in 2007.[1]

After continuously increasing for more than two decades, U.S. female breast cancer incidence rates leveled off from 2001–2003.[1] The female breast cancer incidence rates in New Jersey increased from 1979 to 1990, declined for a few years, and peaked again in 1997. The rate has generally been decreasing since 1997.[9] New Jersey females had higher incidence rates than U.S. females in 2003 (125.6 versus 119.3 per 100,000**). Incidence rates in white females were also higher in New Jersey than in the U.S. in 2003 (130.0 versus 121.1 per 100,000**). However, incidence rates in black females in New Jersey were lower than in the U.S. (105.7 versus 109.4 per 100,000**). The incidence rate for Hispanic women in New Jersey was lower than for both black women and white women (95.6 per 100,000** in 2003).[10]

According to 2004 data from the New Jersey State Cancer Registry, a lower proportion of Hispanic and black women were diagnosed in the early stages of breast cancer (in situ and localized) than was the case for non-Hispanic and white women (Figure 2).[10,11] In New Jersey, the percent of breast cancers diagnosed in the early stage has steadily increased in both black and white women in the past ten years. However, the percent of white women being diagnosed in the early stages is higher than that for black women in New Jersey (70.0% versus 61.4%) in 2004* (Figure 2).[10]

One type of breast cancer that is less well-known is called inflammatory breast cancer (IBC). IBC is a rare but very aggressive type of breast cancer in which the breast often looks swollen and red, or "inflamed". IBC accounts for 1 to 5 percent of all breast cancer cases in the U.S. It occurs more frequently and at a younger age in blacks than in whites. Symptoms of IBC may include redness, swelling, and warmth in the breast, often without a distinct lump in the breast.[12] According to data from the New Jersey State Cancer Registry, 39 women in New Jersey were diagnosed with IBC in 2004.[10]

It is important to note that breast cancer may occur in men. About 2,030 new cases of male breast cancer are expected in the U.S. in 2007.[1] According to data from the New Jersey State Cancer Registry, 69 cases of breast cancer occurred among New Jersey males in 2004.[10]

Mortality. The American Cancer Society estimates that in 2007, approximately 40,000 breast cancer deaths will occur among U.S. women, and 450 breast cancer deaths will occur among U.S. men. Death rates from breast cancer have steadily decreased in women since 1990, with larger decreases in women younger than 50. These decreases are due to a combination of earlier detection and prompt treatment. In New Jersey alone, approximately 1,350 women will die from breast cancer in 2007.[1] According to the

* Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

New Jersey State Cancer Registry, 15 New Jersey men died from breast cancer in 2003. Consistent with 2003 U.S. mortality rates, black women in New Jersey have a higher mortality rate compared to white women, despite lower incidence rates for black women (Figures 1 and 3). In 2003, white females had a higher rate of breast cancer mortality in New Jersey than in the U.S. (28.5 per 100,000** versus 24.6 per 100,000**, respectively). New Jersey breast cancer mortality rates in black females, however, are similar to U.S. rates (Figure 3). In 2003, breast cancer mortality in Hispanic females in New Jersey was less than one-half the mortality rate of non-Hispanics.[13,14]

Prevalence. Breast cancer accounts for the highest proportion of total cancer prevalence among New Jersey women, i.e., the proportion of New Jersey women alive who were ever diagnosed with breast cancer. Estimates indicate that on January 1, 2003, there were 72,595 or 1.6% of New Jersey women alive who had ever been diagnosed with breast cancer. As with other cancers, the prevalence of female breast cancer increases with age and is highest in the 65+ age group (6.3%). The prevalence of female breast cancer is approximately two times higher among whites than blacks (1.9% versus 0.9%).[15]

Survival. The five-year relative survival rate for female breast cancer diagnosed in New Jersey from 1994–1997 is approximately 85%. This rate is similar to that for the U.S. Although there is a high overall survival rate, disparities exist between black and white women. In New Jersey, as in the U.S., black women have a lower survival rate than white women (73.4% versus 85.8%, respectively).[16]

Female breast cancer survival rates are much higher for cancers diagnosed at the local stage than at the regional or distant stage. In New Jersey, from 1984–1997, the percentage of breast cancers diagnosed at the local stage increased from 47% to 58% for white women and from 46% to 50% for black women. Although the five-year survival rates improved from 1984 to 1997 for black women and white women with breast cancer diagnosed at the local or regional stage, it did not improve for women of either race diagnosed at the distant stage. In New Jersey, black women's survival remained lower than white women's for each stage at diagnosis.[16]

Prevention and early detection. Data from the New Jersey Behavioral Risk Factor Survey indicate that the percent of New Jersey women receiving mammography increased by almost 10% between 1995 and 2005. The number of women reporting that they had a mammogram and a breast exam increased in all age groups (Figure 4).[17] New Jersey mammography rates for 2004 were similar to the U.S. rates.[18]

Conclusion. New Jersey data from 2003 reveal that white women have a higher incidence rate of breast cancer than do black women.[10] However, black women continue to have a higher mortality rate from breast cancer.[13] These differences may result from genetic factors or the disparity observable by race in healthcare prevention and treatment services, which is reflective of access-to-care, prevention, education, and early-detection issues in New Jersey. The latter probable causes should be the focus of our efforts over the next several years.

* Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

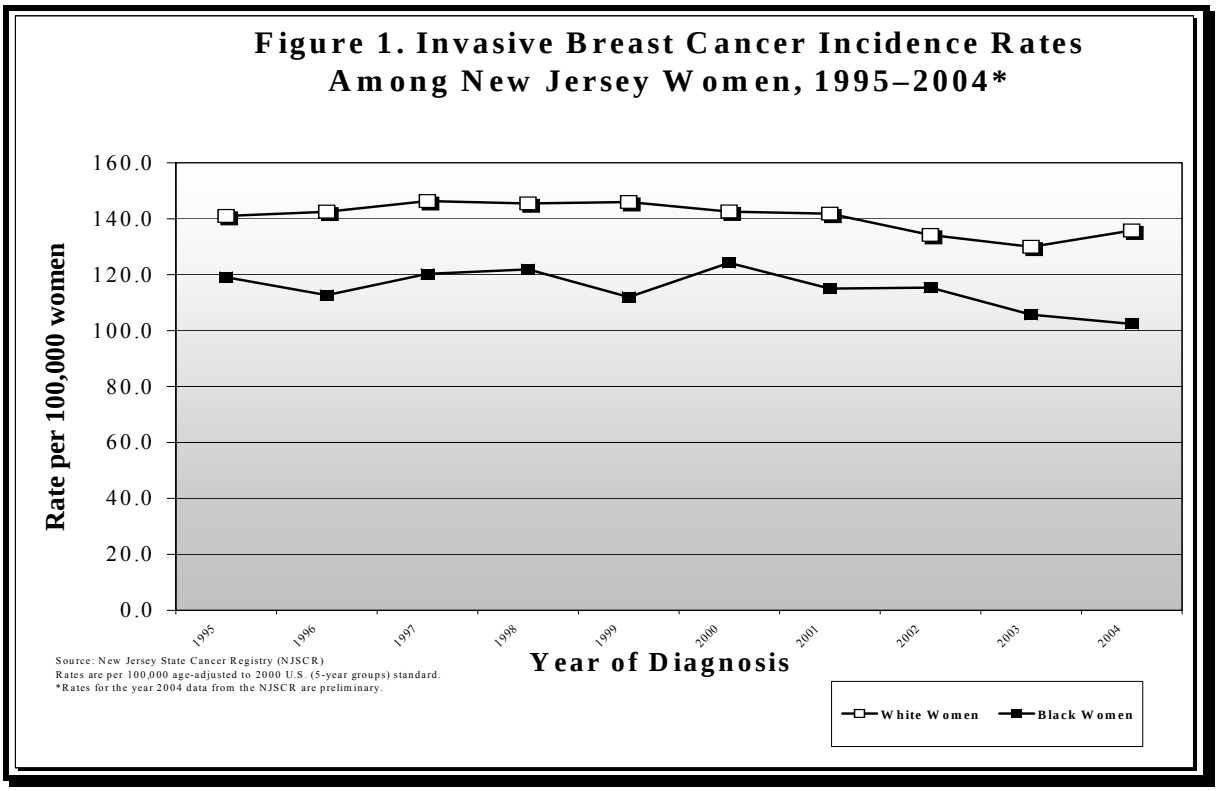


Figure 1. Invasive Breast Cancer Incidence Rates Among New Jersey Women, 1995–2004*
Rate per 100,000 women
160.0
140.0
120.0
100.0
80.0
60.0
40.0
20.0
0.0
1995
1996
1997
1998
1999
2000
2001
2002
2003
2004
Year of Diagnosis
Source: New Jersey State Cancer Registry (NJSCR)
Rates are per 100,000 age-adjusted to 2000 U.S. (5-year groups) standard.
*Rates for the year 2004 data from the NJSCR are preliminary.
White Women
Black Women

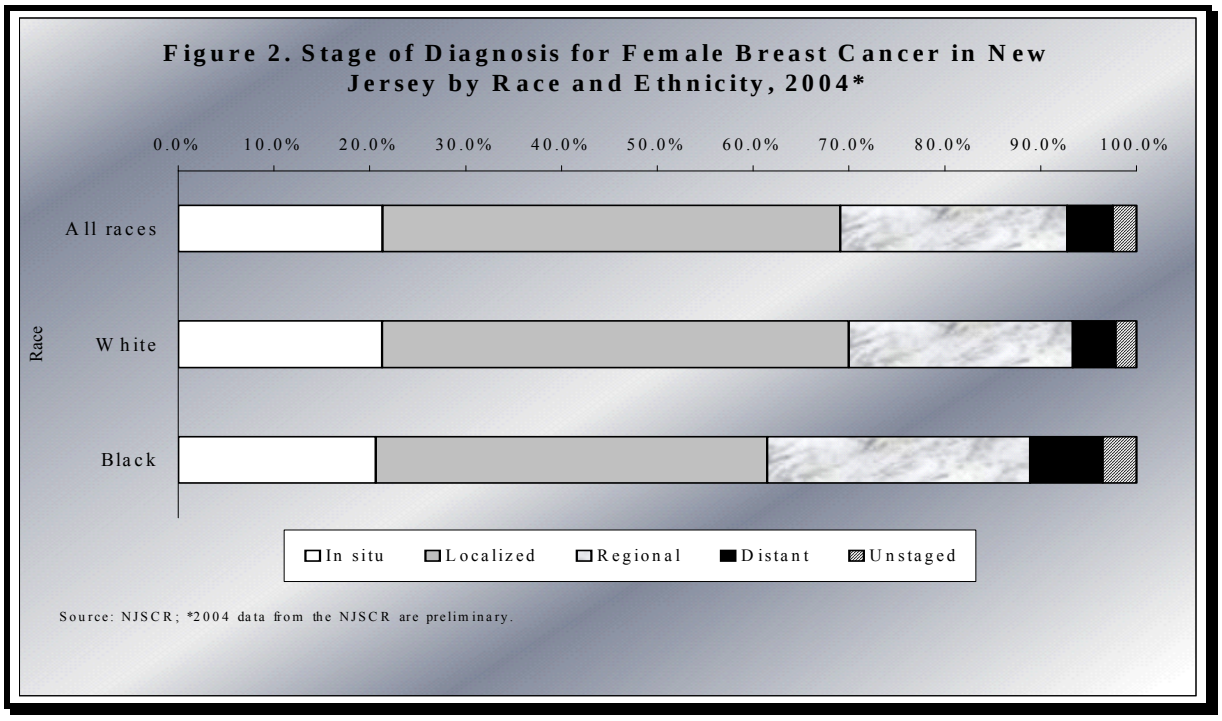
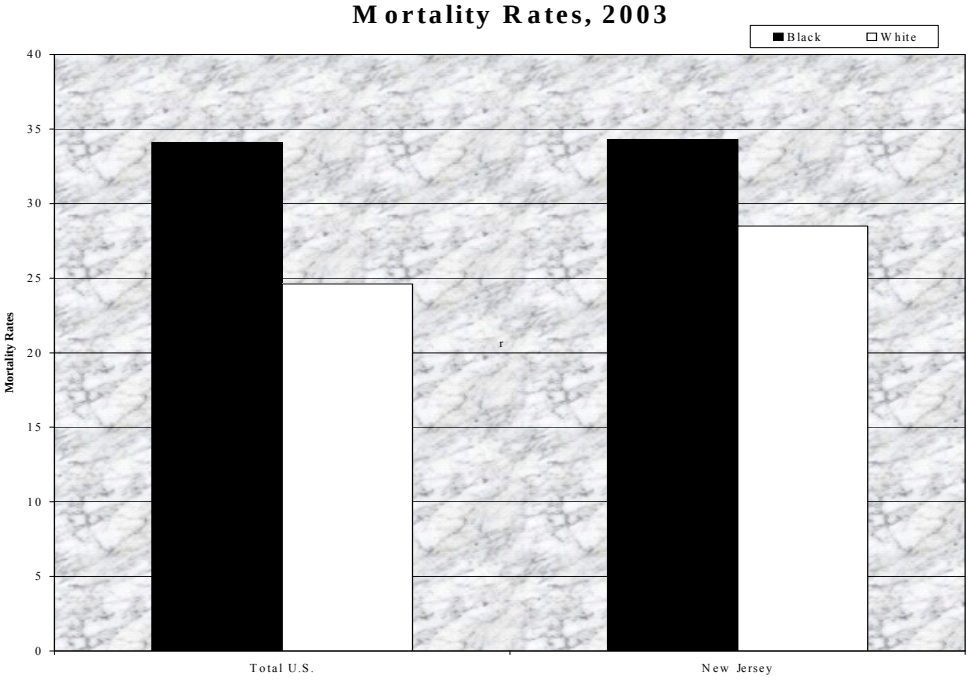


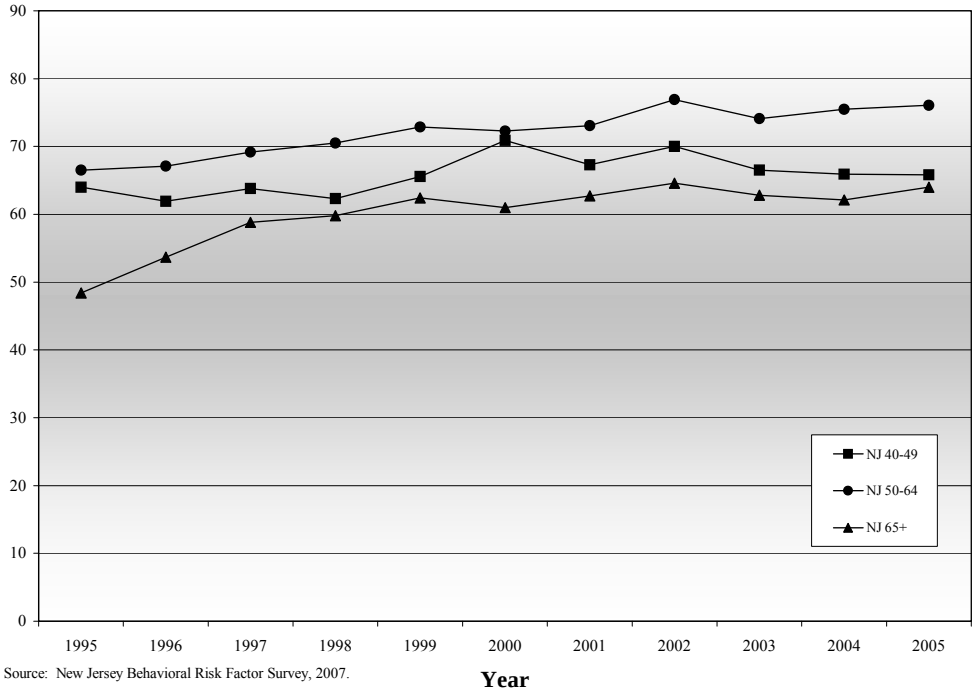
Figure 2. Stage of Diagnosis for Female Breast Cancer in New Jersey by Race and Ethnicity, 2004*
0.0%
10.0%
20.0%
30.0%
40.0%
50.0%
60.0%
70.0%
80.0%
90.0%
100.0%
Race
All races
White
Black
In situ
Localized
Regional
Distant
Unstaged
Source: NJSCR; *2004 data from the NJSCR are preliminary.

Figure 3. U.S. and New Jersey Female Breast Cancer Mortality Rates, 2003



Source: National Center for Health Statistics; rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) standard.

Figure 4. Female Respondents, aged 40 and older, who report having a mammogram and a breast exam within the past 2 years



Source: New Jersey Behavioral Risk Factor Survey, 2007.

HEALTHY NEW JERSEY 2010 GOALS

Healthy New Jersey Goal 1 Increase the percentage of females aged 40 and over who received a clinical breast examination and a mammogram within the past two years, by 2010.

Table 1. Women aged 40+ who received a clinical breast exam and mammogram within the past two years, New Jersey, 2000–2003, and Healthy New Jersey 2010 projected target rate.[19]

Population	2000	2001	2002	2003	Target	Preferred 2010 Endpoint
Total	68.0	67.8	70.7	67.9	75.0	85.0
White	67.9	69.6	70.8	69.3	75.0	85.0
Black	68.5	65.9	78.2	70.5	75.0	85.0
Hispanic	72.9	66.2	**	63.9	75.0	85.0
Asian/Pacific Islander*	**	**	**	43.2	***	***
Females 50–64	72.3	73.1	76.9	74.1	85.0	90.0
Females 65+	61.0	62.7	64.6	62.8	75.0	85.0
HMO enrolled females 52-69	68.3	71.4	73.1	69.9	85.0	90.0

* *Estimate has a relatively large standard error.*
** *Estimate is unreliable.*
*** *A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander do not include Hispanics.

Healthy New Jersey Goal 2 Increase the percentage of female breast cancers diagnosed in early (in situ/local) stage of disease, by 2010.

Table 2. Female breast cancers diagnosed in early stage, New Jersey, 1999–2002, and Healthy New Jersey 2010 projected target rates.[19]

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
Total	66.4	66.7	67.1	67.7	75.0	85.0
White	67.5	67.6	68.0	68.8	75.0	85.0
Black	57.5	58.7	60.0	59.8	75.0	85.0
Hispanic	65.0	65.2	64.5	66.4	75.0	85.0
Asian/Pacific Islander	*	*	*	*	**	**
Females 65+	67.3	66.3	67.4	67.6	75.0	85.0

* *The number of Asian/Pacific Islander cases is known to be understated.*
** *A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander include Hispanics and non-Hispanics.

Healthy New Jersey Goal 3	Reduce the death rate from female breast cancer among women 50 years of age and over per 100,000 female population by 2010.

Table 3. Death rate from female breast cancer, ages 50 and over, New Jersey, 1999–2002, and Healthy New Jersey 2010 projected target rates. [19]

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
Aged 50–64	53.9	55.5	55.2	51.4	45.0	20.0
Aged 65+	136.5	151.0	134.4	136.9	115.0	100.0

GOALS, OBJECTIVES, AND STRATEGIES

In 1995, a Breast Cancer Summit was held to gather New Jersey physicians, researchers, health professionals, and organizations to address the serious healthcare crisis in breast cancer. In a report of the Breast Cancer Summit,[20] *Breast Cancer Mortality in New Jersey: A Time for Action*, five areas for action were identified for New Jersey: early detection, therapeutics, research, healthcare policy, and data. Over a decade later in 2006, the Breast Cancer Workgroup concurs that these remain important priorities for the state. Therefore, the Breast Cancer Workgroup has used the action plan of the Breast Cancer Summit as a basis for addressing breast cancer mortality in this *Plan*.

In support of the Healthy New Jersey 2010 goals for breast cancer, the recommendations of the Breast Cancer Workgroup are summarized below for the following focal areas:

- Prevention
- Screening
- Research and surveillance

PREVENTION

There is currently no proven strategy for preventing breast cancer among women of average risk. However, among women identified as high risk for developing breast cancer, certain therapies may aid in breast cancer prevention.

Genetic testing for breast cancer risk is a relatively new field. The "breast cancer gene," BRCA1, was identified in 1994 and BRCA2 in 1995.[21,22] Testing positive for either of these genetic mutations indicates enhanced breast and ovarian cancer risk—either higher risk of an initial cancer (for unaffected women) or a recurrence or second primary cancer (for women already affected by cancer). While only 2–3% of all breast cancers are attributable to these mutations, women with BRCA1 or BRCA2 mutations have approximately a 33% to 50% risk of developing breast cancer by age 50.[23–25] By age 70, a mutation carrier's risk of developing breast cancer is 45% to 65%.[25–28] Identifying women at increased risk for developing breast cancer can help to target preventive strategies, such as increased surveillance, chemoprevention, prophylactic mastectomy, and prophylactic oophorectomy (where the ovaries are removed to prevent the production of hormones that may increase the risk of breast cancer).

Studies suggest that prophylactic mastectomy, or the surgical removal of both breasts prior to cancer diagnosis, is the most effective method of preventing breast cancer in women who carry the BRCA1 and BRCA2 germline mutations.[29] However, surgical intervention often has physical and psychosocial implications that make it an unacceptable option for many women. Another option for these women is to consider prophylactic oophorectomy, which reduces the risk of both ovarian cancer and breast cancer.

Tamoxifen, a selective estrogen-receptor modulator, has been used in the chemoprevention of breast cancer in high-risk women since the U.S. Food and Drug Administration (FDA) approved it for that use in 1998. Five-year adjuvant treatment with tamoxifen has also been shown to significantly reduce recurrence of secondary malignancies in early-stage breast cancer patients.[30] However, tamoxifen may also increase the risk of contracting other serious diseases, including endometrial cancer, stroke, and blood clots in veins and in the lungs.[5,31–33]

Recent research has shown that the drug raloxifene, used in the prevention and treatment of osteoporosis, is as effective as tamoxifen in preventing breast cancer. Studies also suggest that raloxifene may have a lower occurrence of serious side-effects.[5,31,32]

Other prevention strategies recognized by the National Cancer Institute include suppression of hormonal factors, reducing radiation exposure, and dietary factors.[34,35]

Women concerned that they may be at increased risk of developing breast cancer should talk with their doctor about appropriate screening modalities and preventive therapy.

GOAL BR-1	To increase the practice of breast cancer prevention strategies among women at high risk of developing breast cancer.

Objective BR-1.1

To increase public and professional awareness of the *factors that place women at high risk for developing breast cancer* through wide dissemination of culturally and linguistically appropriate educational materials and curriculum development.

Strategies

BR-1.1.1 Identify existing, and develop as needed, breast cancer educational materials and programs to use in reaching all women and promoting awareness of breast cancer risk factors. Disseminate multi-lingual, culturally appropriate materials to diverse communities as needed through appropriate community members who care for them (e.g., healthcare providers, laypersons, survivors, and community leaders).

BR-1.1.2 Create a curriculum with continuing education credits to provide information to healthcare practitioners on risk reduction and genetic risk factor assessment. This curriculum should be interactive and developed in different formats and media, e.g., internet, audiotape, CDs, etc. by partnering with professional organizations.

BR-1.1.3 Widely distribute and promote this breast cancer curriculum through, e.g., the Medical Society of New Jersey, and other professional and specialty groups.

Objective BR-1.2

To increase public and professional awareness of *breast cancer prevention strategies* for those at high risk through wide dissemination of culturally and linguistically appropriate educational materials and curriculum development.

Strategies

BR-1.2.1 Identify existing, and develop as needed, breast cancer educational materials and programs to use in reaching high-risk women and promoting awareness of the benefits of preventive therapies. Disseminate multi-lingual, culturally and linguistically appropriate materials to diverse communities as needed through appropriate community members who care for them (e.g., healthcare providers, laypersons, survivors, and community leaders).

BR-1.2.2 Create a curriculum with continuing education credits to provide information to healthcare practitioners on breast cancer prevention strategies for women at high risk. This curriculum should be interactive and developed in different formats and media, e.g., internet, audiotape, CDs, etc. by partnering with professional organizations.

BR-1.2.3 Widely distribute and promote this breast cancer curriculum through the Medical Society of New Jersey and other professional and specialty groups.

Objective BR-1.3

To educate women who come in for breast cancer screening about early detection and the need for appropriate follow-up, diagnostic testing, and annual rescreening.

Strategies

BR-1.3.1 Identify existing, develop as needed, and distribute widely, culturally and linguistically appropriate materials that describe the importance of rescreening and follow-up visits, where necessary, and highlighting the importance of using a mammography facility that is FDA-accredited.

BR-1.3.2 Identify existing, develop as needed, and distribute widely, culturally and linguistically appropriate information for dissemination to community groups and advocacy groups in order to publicize nationally recognized screening guidelines, where to go for screening, and the availability of programs for clients without health insurance, and to dispel fears and myths that exist around breast cancer.

Screening

Clinical Breast Examination (CBE) and mammography are the most common methods for screening and early detection of breast cancer. Most expert groups no longer recommend breast self-examination, but recommend mammography, with or without CBE, beginning at age 40, although guidelines for frequency of testing differ by organization.[36–39] Digital mammography is becoming a standard screening tool, especially for young women with dense breast tissue where an advantage is seen over film screen mammography. The role of ultrasound and breast magnetic resonance imaging (MRI)

for screening purposes is still unclear. For more information about screening guidelines for breast cancer see Appendix C.

Regular use of mammograms can reduce the chances of dying from breast cancer. Randomized clinical trials have demonstrated a 20% to 35% reduction in breast cancer mortality in women aged 50 to 69 years who are screened annually or biennially with mammograms.[7,36] For women in their 40s, the risk can be reduced by about 17%. It is estimated that for every 500 to 1,800 women 40 years of age who are routinely screened with mammography, one breast cancer death is prevented.[36] For women aged 70 and older, mammography may be helpful, although firm evidence is lacking.[36,39]

Breast cancers in women under 40 comprise approximately 5% of all new breast cancer diagnoses, or approximately 400 cases per year in New Jersey. However, routine screening with imaging is not recommended for women in this age group due to the high likelihood of false positives.[40] The American Cancer Society recommends clinical breast exams every three years for women under the age of 40.[1]

Since implementation of the Mammography Quality Standards Act in 1994, all U.S. mammography centers must be certified by the FDA.[7] A complete list of all certified mammography centers in New Jersey can be found at http://www.fda.gov/cdrh/mammography/certified.html. A current list of FDA-approved digital mammography centers in New Jersey can be found at http://www.hersource.com.

New breast cancer screening mechanisms, including digital mammography, computer-aided detection programs, MRI, and ultrasound are being evaluated for efficacy. While some of these new tests have been shown to be effective in women at high risk, it is unknown whether they will have any effect on breast cancer mortality among women of average risk.[36]

To increase screening for breast cancer, increase early diagnosis, and decrease death rates, the Breast Cancer Workgroup continues to identify education as a priority for New Jersey. The education process, developed under the first *Plan*, has four components: (1) developing a consensus message, (2) educating the public, (3) educating patients, and (4) educating healthcare professionals. An effective message will be one that encompasses all aspects of breast health and is adopted by professionals, communities, grassroots organizations, survivors, and advocacy groups through collaboration and partnerships. Although the Breast Cancer Workgroup discussed the importance of educating all New Jerseyans about breast health and quality breast cancer care, high-risk populations must be targeted first in order to address disparities apparent in the incidence and mortality data. See the Research and Surveillance component of this chapter for additional information about identification of high-risk populations for breast cancer.

Building Consensus

The process of education must begin with achieving consensus on approaches to breast cancer prevention, early detection, and treatment. Currently, several different messages are being disseminated about breast cancer screening. Most organizations recommend annual mammograms for women aged 40 and older based on strong evidence that mortality is reduced.[39,41,42] Yet recommendations for breast self-examination and clinical breast examination vary drastically. The U.S. Preventive Services Task Force (USPSTF) and the National Institutes of Health (NIH) conclude that evidence is insufficient to recommend for or against teaching or performing routine breast self-examination.[39,42] The USPSTF also found insufficient evidence to recommend for or against CBE alone to screen for breast cancer.[39] The American Cancer Society, however, recommends a clinical breast exam be considered part of a periodic health exam and that breast self-exam is an option for women beginning in their 20s.[43] Without a consensus message,

breast cancer education is inconsistent and sporadic, and awareness about the importance of prevention and early detection is not universal.

Awareness and Education for the Public

Data from the New Jersey State Cancer Registry (presented earlier in this chapter) demonstrates that some segments of the New Jersey population are affected disproportionately by breast cancer. Although white women in New Jersey have higher incidence of breast cancer, black women are dying from it at a higher rate. Focused efforts by private sector organizations and federal and state governments to educate women about the importance of breast cancer prevention and early detection and to provide opportunities for mammography screening have resulted in dramatic increases in mammography screening rates over the past two decades. According to data from the Behavioral Risk Factor Surveillance System, women in New Jersey are utilizing breast cancer screening at the same rate as the U.S. (75%).[18]

The New Jersey Cancer Education and Early Detection Program (NJCEED) provides free mammograms to uninsured and underinsured women living at or below 250% of the federal poverty level. Healthcare providers and New Jersey women should be made aware of the services provided by NJCEED, including education, outreach, diagnosis, treatment, and follow-up.

Many studies have been conducted to identify both barriers to screening and interventions needed to overcome barriers, such as cost,[44] lack of knowledge regarding screening,[45] physician recommendation,[46] language,[47] cultural sensitivity issues,[47] inaccessible screening sites, and transportation.[47] In a recent New Jersey study, participants revealed that they are not motivated to obtain screening services because "prevention is not a priority."[47]

Efforts to educate women about the need for breast cancer screening have varied in their ability to overcome barriers and increase screening rates. Some successful attempts to persuade women of the necessity of screening mammograms have used nurse practitioners, videotapes, in-person counseling delivered by nurses or peers, mailings, and telephone counseling.[48–53] Some have used social networks[54,55] and community or healthcare systems approaches[56,57] rather than focusing exclusively on individual behavior change.

Teaching breast self-care as breast changes occur in the adolescent girl can influence positive behaviors. Health promotion behaviors are often taught in high school, but little research has been conducted on teaching breast health in a high school setting, particularly breast cancer early detection and screening.[58] Another study found that educational lessons could improve knowledge and attitudes of adolescent girls with respect to breast self-examination.[59]

Interventions should focus not only on improving one-time screening but also on improving annual screening. Recent research found that "off-schedule" women (women screened at least once and non-adherent with recommended screening intervals) had greater knowledge and were more positive about mammography than women who had never been screened, but their measures on these indicators were lower than those for "on-schedule" women.[60] Brief interventions from healthcare providers emphasizing the importance of repeat screening should be delivered to "off-schedule" women.

Given both the importance and the complexity of the issues, women should have access to the best possible relevant information regarding both benefits and risks of screening, presented in an

understandable and usable form. In addition, educational information to accompany this risk-benefit information should be prepared to lead women step by step through a process of informed decision-making.[38] The Breast Cancer Workgroup also proposes that breast cancer screening and early detection be taught early to foster knowledge about lifelong breast health.

Awareness and Education for the Cancer Patient

Not only is it essential that awareness be increased in the general public, awareness must also be increased in the cancer patient population. For a number of reasons, follow-up for evaluation and treatment is often not completed. A recent study indicates that up to 20% of women do not receive timely recommended follow-up after an abnormal mammogram.[61] Lack of understanding by the patient about the next steps often contributes to incomplete follow-up, as does inconsistent sharing of information.[27] A recent intervention among low-income, ethnic minority women demonstrated that the use of a patient navigator and counseling are highly effective strategies to improve follow-up of abnormal mammograms.[62]

Primary care physicians hold a strategic position for the delivery of preventive care services because of their access to the patient population and their long-term relationship with patients. It has been shown that by implementing a multi-faceted intervention, patients are more likely to assume an active role in decision-making.[63] Pre-consultation education also appears to be an effective clinical strategy for helping patients gain an accurate understanding of treatment options before meeting with their physicians.[64] This information must be presented in an understandable and culturally appropriate format.

Awareness and Education for Healthcare Practitioners

Approximately 25% of New Jersey and U.S. women aged 40 and over reported no mammogram within the past two years.[18] These numbers must be improved to increase the early detection of breast cancer and effectively decrease mortality.

As noted earlier, primary care physicians are in a strategic position to influence the seeking of preventive care services. A review focusing on breast cancer screening concluded that several interventions, notably reminders and audit and feedback, can increase physician use of mammography.[63] Tailored interventions, using a package that addresses specific professional barriers that need to change in a particular setting, are recommended to improve delivery of preventive services in primary care. Additionally, research has shown that physicians can be assisted in their delivery of preventive services through group education, reminder devices, and changes to the organization of care.[63]

The Breast Cancer Workgroup recommends that healthcare professionals encourage women to use available screening methods for breast cancer. Given the observed variation among populations and different barriers for each population, interventions must be tailored. Below we present the Breast Cancer Workgroup's recommendations for a multi-dimensional approach to addressing breast cancer education in New Jersey.

GOAL BR-2	To improve public understanding of breast health, breast cancer, and screening to promote the value of early detection.

Objective BR-2.1

To build consensus on what the public message should be regarding breast cancer education, impact of certain health and lifestyle factors, screening and treatment, and the benefits and risks of early detection.

Strategies

BR-2.1.1 Convene a diverse group of breast cancer experts, advocates, and consumers at state and community levels.

BR-2.1.2 Review and summarize the most current scientific literature about breast cancer screening, early detection, and treatment.

BR-2.1.3 Develop an overall breast cancer message for the general public, as well as targeted culturally appropriate messages for high-risk, underserved, and special populations based on research findings. (See also Goal BR-7 Research and Surveillance.)

BR-2.1.4 Establish priorities to most effectively reach the targeted populations with breast cancer information.

Objective BR-2.2

To develop and implement a statewide breast cancer public awareness/media campaign to increase utilization of breast cancer screening services (in accordance with accepted public health practice and recommendations of the Centers for Disease Control and Prevention).

Strategies

BR-2.2.1 Coordinate current media campaigns with a consistent message specifically promoting the availability of no-cost breast cancer screenings for those eligible through the New Jersey Cancer Education and Early Detection Program. Develop media campaigns specifically promoting the Medicaid Breast and Cervical Cancer Treatment Program for eligible women that are screened and/or diagnosed through NJCEED.

BR-2.2.2 Collaborate with organizations and entities including healthcare professionals to communicate messages and effectuate the breast cancer campaign.

BR-2.2.3 Provide public service announcements and media information on breast cancer in English, Spanish, and other languages as needed.

BR-2.2.4 Identify and centralize a multi-level, multi-lingual, multi-cultural speakers bureau to implement community breast cancer education and screening activities. Ensure cultural sensitivity and consistency of the message.

BR-2.2.5 Coordinate promotional incentives to encourage women to undergo mammography and become educated about breast cancer by offering free or discounted items from local retailers.

BR-2.2.6 Publicize existing telephone numbers and websites that are clearinghouses for New Jersey cancer resources (i.e., 211 non-emergency helpline). Ensure that national telephone numbers and websites are provided with current data.

Objective BR-2.3

To develop and disseminate breast cancer educational materials and resources to increase knowledge, improve public understanding of the value of screening and early detection, and promote high-quality breast health, paying special attention to vulnerable, high-risk populations.

Strategies

BR-2.3.1 Partner with relevant organizations in providing comprehensive breast cancer educational materials to appropriate local and statewide community organizations for distribution to their constituencies.

BR-2.3.2 Recommend that organizations seek out professionals from various ethnic communities to provide breast cancer education and outreach in order that individuals can relate to their trainers.

BR-2.3.3 Distribute information about NJCEED sites to provide greater access to quality, no-cost breast cancer diagnostic and treatment services for uninsured women in the community.

BR-2.3.4 Expand culturally sensitive education and outreach programs for women in low-income, underserved communities who do not meet the NJCEED criteria.

BR-2.3.5 Provide cultural competency training to the individuals interfacing with the community (especially minority communities) for breast cancer awareness and education.

BR-2.3.6 Provide “faith-based” breast health and breast cancer education through a train-the-trainer program for church leaders in the black and Latino communities to provide ongoing

breast health and breast cancer education, screening, and support resources for all women in their communities, especially high-risk women.

Objective BR-2.4

To increase education of high school students on breast cancer prevention and early detection by identifying and promoting a curriculum on the life-saving value of good breast health habits.

Strategies

BR-2.4.1 Influence and encourage breast health education in New Jersey. Widely distribute high-school-focused breast educational materials for either assembly or classroom venues. Ensure that resources are readily available and teacher-friendly.

BR-2.4.2 Work with key personnel at school districts to advocate for full implementation of this breast health education in all New Jersey high schools.

BR-2.4.3 Identify thoughtful, age-appropriate resources and educational materials for teen-age students to teach breast health at an early age, including multi-media presentations, supporting posters, and brochures.

GOAL BR-3	To improve breast cancer patient awareness and education regarding outcomes about the importance of breast cancer rescreening and follow-up visits to maximize optimal outcomes.

Objective BR-3.1

To increase appropriate treatment and follow-up for women who receive abnormal mammograms and/or abnormal clinical breast exams.

Strategies

BR-3.1.1 Identify existing, and develop as needed, culturally appropriate materials to educate clients who receive abnormal screening results about the importance of appropriate and timely follow-up and treatment options available if they have been diagnosed with breast cancer, especially clinical trials.

BR-3.1.2 Identify existing, and develop as needed, culturally appropriate education materials for those clients who have completed breast cancer treatment about the importance of follow-

up care, especially about the risk of lymphedema and the importance of early lymphedema management. Distribute information widely.

BR-3.1.3 Improve existing, and develop as needed, resource guides for breast cancer including treatment centers that participate in clinical research, available support groups, and where financial assistance can be obtained. Make the resource guide readily available by using websites, a central hotline, and wide distribution to healthcare professionals, public libraries, and grassroots and community agencies that have contact with women.

BR-3.1.4 Encourage healthcare facilities to promote timely evaluation of abnormal screening tests, for example, by instituting patient navigation programs and designating facility staff and resources for this purpose.

GOAL BR-4	To improve the knowledge of healthcare practitioners about the importance of having an active provider role, assessing patients' risks of developing breast cancer, formulating a prevention plan based on that risk, and increasing the recommendations and utilization of screening mammograms.

Objective BR-4.1

To increase professional education on assessment, e.g., symptoms, risk factors, screening, risk reduction, and follow-up care for breast cancer.

Strategies

BR-4.1.1 Partner with identified organizations in creating a curriculum with continuing education credits to provide information to healthcare practitioners on the following: (1) screening guidelines, (2) risk reduction, (3) symptoms of breast cancer and follow-up care, (4) genetic risk factor assessment, and (5) cultural competency. Ensure that the curriculum addresses the need to use evidence-based, currently recognized community standards of care for those patients not enrolled in clinical trials. This curriculum should be interactive and developed in different formats and media, e.g., internet, audiotape, CDs, etc. by partnering with professional organizations.

BR-4.1.2 Widely distribute and promote this breast cancer curriculum through the Medical Society of New Jersey, physician membership, and nursing organizations, and other professional and specialty groups.

Objective BR-4.2

To encourage healthcare providers to increase referrals and improve patient awareness about breast cancer early detection and screening measures.

Strategy

BR-4.2.1 Educate healthcare providers regarding which patients are appropriate to receive mammograms, focusing on those providers serving ethnically diverse and minority communities.

RESEARCH AND SURVEILLANCE

Earlier in this chapter the risk factors for breast cancer and disparities surrounding breast cancer were identified. While the overall picture of breast cancer among New Jersey women is encouraging, there is need for improvement among specific groups of women. Statistics from the New Jersey State Cancer Registry indicate that the age-adjusted incidence and mortality rates for the years 1999–2003 varied among the 21 counties in New Jersey.[65] As is the case for disparities among states in the U.S., the disparities in mortality rates by county likely depend on stage of disease at diagnosis, socioeconomic status, access to care, and adequacy of medical care.[66]

It is well recognized that the incidence of breast cancer is generally higher for white than black women, with population-based data showing approximately a 20% higher rate for white women.[67] However, there is a reverse trend among women less than 35 years old.[68] The breast cancer incidence rate among black women under age 35 is greater than that of white women, and black women are consistently diagnosed in later stages of the disease.[69,70] While racial and ethnic disparities in breast cancer stage at diagnosis among older women are thought to be the result of differences in utilization of routine screening mammography among racial/ethnic minorities, the racial/ethnic differences in breast cancer incidence among women under age 35 are not well understood.[68,69] Further research into these disparities should be conducted to determine their underlying cause and potential solutions.

In 2006, the Susan G. Komen Breast Cancer Foundation, North Jersey Affiliate, completed an updated community needs assessment for the nine northern counties in New Jersey. The Central and South Jersey Affiliate also updated their community profile for the central and southern New Jersey counties in 2006. In 2003, the New Jersey Department of Health and Senior Services, Office of Cancer Control and Prevention, in conjunction with the University of Medicine and Dentistry of New Jersey School of Public Health, conducted a capacity and needs assessment of all 21 counties in New Jersey. Population maps, breast cancer incidence and mortality graphs, and provider inventory maps were created to identify unmet needs in the areas of prevention, early detection, and treatment for breast cancer. A study of this nature must be kept current for all of the counties in New Jersey to effectively identify unmet needs for breast cancer.

The Cancer Epidemiology Services, New Jersey Department of Health and Senior Services used their geographic information system (GIS), spatial statistical software, and cases of women diagnosed 1995–

1997 with breast cancer (n=20,703) to identify geographic areas in New Jersey with high proportions of distant-stage breast cancer. Two areas in northeastern New Jersey were identified, with relatively high proportions of black or Hispanic women and of linguistically isolated households in the population. Virtually all the women with breast cancer in these two areas were within two miles of a mammography facility.[71] The Cancer Epidemiology Services recently conducted a similar analysis to determine if these clusters remained several years later, using data on women diagnosed with breast cancer in 2001–2003. Statewide, the proportion of women with distant-stage diagnosis was lower than in 1995–1997 (4% versus 5%), and one of the earlier clusters of high proportions of late-stage diagnosis disappeared. However, the other larger cluster remained. Cancer Epidemiology Services is preparing a publication on the results.

Clinical trials are the major avenue for discovering, developing, and evaluating new therapies. However, only about 3% of all adult cancer patients participate in clinical trials. It is important to increase physician and patient awareness of, and participation in, clinical trials if we are to test new treatments more rapidly, find more effective treatments, and broaden the options available to patients.[4]

GOAL BR-5	To identify areas and populations at higher than expected risk of breast cancer incidence and mortality in New Jersey in order to learn where education and screening awareness efforts are most needed.

Objective BR-5.1

To identify areas in New Jersey where breast cancer mortality risk is greatest.

Strategies

BR-5.1.1 Using appropriate statistical models and tools, identify and describe geographic areas and population groups exhibiting high breast cancer mortality rates, using demographic, service utilization, and epidemiologic data.

BR-5.1.2 Assess barriers to breast cancer screening (cultural barriers, help-seeking behaviors, socioeconomic factors, transportation, etc.), provider-related barriers (accessibility, waiting time, capacity, communication, etc.), institution-related barriers, and system-level barriers (analysis of payer data, claims data, policies and regulations, and standards of care) in these identified areas and/or population groups.

BR-5.1.3 Assess other aspects of increased mortality.

GOAL BR-6	To increase accrual and broaden access to breast cancer clinical early detection and treatment trials for patients and physicians in New Jersey.

Objective BR-6.1

To support the National Cancer Institute's Clinical Trial Implementation Committee Goals for Clinical Trials for breast cancer.

Strategies

BR-6.1.1 Partner with educational programs that promote participation and enhance public visibility and understanding of important breast cancer clinical trials.

BR-6.1.2 Publicize the existence of a clinical trials website, particularly NJ Cancer Trials Connect (http://www.njctc.org), via the county cancer Coalitions and other avenues.

GOAL BR-7	To ensure that New Jersey residents and physicians remain up to date on the most currently available breast cancer preventive, diagnostic, and treatment technologies and resources.

Objective BR-7.1

To continue to monitor and disseminate current advances in breast cancer prevention, screening, diagnosis, and treatment.

Strategy

BR-7.1.1 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through continuing medical education offerings and other means.

Objective BR-7.2

To continue to monitor trends in breast cancer incidence, mortality, and survival.

Strategy

BR-7.2.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

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CHAPTER 5. Childhood Cancer

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CHILDHOOD CANCER

IMPORTANCE OF CHILDHOOD CANCER FOR CANCER PREVENTION AND CONTROL

Just as children are not "little adults," childhood cancer is different in many ways from adult cancer. The most common cancers in adults are breast, cervical, colorectal, lung, and prostate; children almost never contract any of these. Acute leukemia, central nervous system tumors, neuroblastoma, Wilms' tumor, and non-Hodgkin's lymphomas (NHL) constitute the top five diagnoses among children under 14 years of age. This is in contrast to Hodgkin's disease (HD), germ cell tumors, non-Hodgkin's lymphomas, osteosarcoma, Ewing's sarcoma, and soft tissue sarcomas, which are more frequent in adolescents and young adults 15 to 19 years of age (Table 1). Contrary to adult cancers, which have identified risk factors and may be preventable, very little is known about the causes and prevention of childhood cancers. Hence, the primary focus of cancer control in childhood cancers is survivorship and the prevention and early detection of long-term effects of treatment.

Today, thanks to advances in cancer treatment, about 80% of children with cancer will be long-term survivors. However, survivorship varies considerably by cancer type, with only 66% of patients with neuroblastoma surviving beyond five years from diagnosis. Regardless of cancer type, childhood cancer survival has shown significant improvement over the last three decades.[1] It has been estimated that by the year 2010, one in every 250 young adults will be a survivor of childhood cancer. Even though cancers among children represent only about 1% of all cancers, their patterns in the population also merit special attention.[2]

As the number of childhood cancer survivors increases, particular attention must be paid to the unique needs of this population. While most adults have completed their education, are employed (or even retired), and often have children before being diagnosed with cancer, many children have not had the opportunity to even begin to realize their life's goals before they are diagnosed with cancer. Some have not yet started school, and most still have years ahead of them during which they should be achieving physical and mental maturity. Ideally a child who survives cancer would be able to grow and develop normally, complete an education, obtain gainful employment, and eventually have children. However, ongoing aggressive treatment with chemotherapy and, in selected patients, radiation therapy and/or stem cell transplantation that improves the probability of survival can also have profound effects on a child's physical and psychosocial development and future opportunities. For these reasons the Childhood Cancer Workgroup in contributing to this *Plan* has been challenged to develop solutions for the survivors of childhood cancer in New Jersey.

CHILDHOOD AND YOUNG ADULT CANCER IN NEW JERSEY AND THE U.S.

In this section we discuss the status of childhood cancer in New Jersey, including incidence, mortality, age patterns, prevalence, survival, and risk factors.

Cancer in children and young adults is relatively rare. An estimated 9,500 new cases are expected to occur among children aged 0–14 in 2006 in the U.S., compared to 1,399,790 adults.[1] In New Jersey, the 2003 childhood cancer incidence rate for children 14 years of age and under was slightly higher compared to U.S. children (15.8 versus 14.4 per 100,000**, respectively). The total childhood cancer

** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

rate for 2003 among boys in New Jersey was higher than that among girls (16.1 versus 15.5 per 100,000** for the 0- to 14-year age group and 22.1 versus 21.4 per 100,000** for the 15- to 19-year age group). U.S. data for 2003 also indicates that childhood cancer rates for 0- to 19-year-olds are higher for boys than for girls (16.6 versus 15.3 per 100,000**, respectively).[3,4] The incidence of cancer among white children and adolescents in New Jersey in 2004 was higher than among black children and adolescents (15.0 versus 13.4 per 100,000** for the 0- to 14-year age group and 25.2 versus 10.4 per 100,000** for the 15- to 19-year age group).[3,4]

Mortality rates for childhood cancer in New Jersey have declined from 1995 to 2003 (from 3.1 to 2.1 per 100,000** for 0- to 14-year-olds and from 4.0 to 2.6 per 100,000** for 15- to 19-year-olds).[5] The largest declines in mortality have occurred for Hodgkin's lymphoma, soft tissue sarcoma, and leukemia (acute lymphoblastic leukemia, in particular). These trends reflect dramatic successes in the treatment of childhood cancer.[6] An estimated 1,545 deaths from cancer are expected to occur in the U.S. among children aged 0–14 in 2007, about one-third of them from leukemia. Despite its rarity, cancer is the chief cause of death by disease in children between ages 1 and 14.[1]

Table 1. Incidence rate of most common cancers in 0- to 14-year-old children and 15- to 19-year-old adolescents, New Jersey, 2002–2004**

Cancer Type	<15	15–19
Total childhood cancers	15.8	21.6
Acute lymphoblastic leukemia (ALL)	3.7	1.7
Acute myeloid leukemia (AML)	0.9	0.9
Hodgkin's disease	0.5	3.5
Non-Hodgkin's lymphoma	0.8	1.4
Central nervous system tumors	3.5	2.0
Neuroblastoma	1.0	0.0
Wilms' tumor	0.8	0.2
Germ cell tumor	0.5	2.5
Osteosarcoma	0.4	0.6
Ewing's sarcoma	0.3	0.5

Source: New Jersey State Cancer Registry[4]
** Rates are per 100,000 age-adjusted to 2000 U.S. (5-year groups) standard.

Age patterns. Incidence patterns for different types of cancer in children vary dramatically by age. For example, the incidence of acute lymphoblastic leukemia increases to a peak before age 5 and declines thereafter, whereas the incidence of acute myeloid (non-lymphoblastic) leukemia is constant throughout childhood. The incidence of Hodgkin's lymphoma increases throughout childhood and is highest in adolescence. Neuroblastoma, retinoblastoma, and Wilms' tumor incidence rates are highest between birth and age 1 and decline with increasing age.[6]

**Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Prevalence. Childhood cancer prevalence counts (i.e., the number of people alive who have ever been diagnosed with childhood cancer) are not available for New Jersey. However, estimates from the National Cancer Institute indicate that in the United States on January 1, 2003, there were 57,723 survivors of childhood cancer who had been diagnosed within the previous five years. Prevalence counts were slightly higher for males than females (30,378 versus 27,345, respectively). Whites accounted for the highest overall prevalence (48,687), followed by blacks (5,798) and then Asian/Pacific Islanders (1,897). Hispanics accounted for 8,930 of the childhood cancer survivors.[7]

Survival. New and improved treatments have been responsible for greatly improving the five-year relative survival rate over the past 30 years from less than 50% before the 1970s to nearly 80% today. For the time period 1996–2002, the five-year survival rate for neuroblastoma is 69%; brain and other nervous system, 74%; bone and joint, 72%; leukemia, 81%; non-Hodgkin's lymphoma, 86%; Wilms' tumor, 92%; and Hodgkin's lymphoma, 95%.[1]

Risk factors. Overall, the causes of most childhood cancers remain unknown. Several types of pediatric cancers are related to genetic conditions. However, most pediatric cancers appear to develop spontaneously, with no relationship to carcinogens or inherited syndromes. Considerable research has been conducted to explore the effects of environmental contaminants associated with childhood cancer, although direct causation has not been proven.[8–10]

GOALS, OBJECTIVES, AND STRATEGIES

The recommendations of the Childhood Cancer Workgroup are summarized below for the following focal areas:

- Adolescent and young adult treatment
- Health-related consequences of childhood cancer and its treatment
- Pain and palliative care
- Family support
- Education

OVERALL GOAL	To enhance the quality of life of the child, adolescent, and/or young adult patient with cancer from diagnosis through treatment to survivorship across the life span.

ADOLESCENT AND YOUNG ADULT TREATMENT

Cancer survival in children under 14 is a great success story of the 20th century. Before the 1970s, the five-year survival rate for a child diagnosed with cancer was less than 50%. By the 1990s this had risen to almost 80%.[1]

From 1975 to 2002 there have been substantial gains in survival in the 15- to 19-year age group. However, this gain lagged behind the significant improvements seen in the younger age group. For the period 1975–1977, the older group had a survival rate of 68% versus 58% for children 0–14 years of age. For the period 1996–2002, this increased to 80% and 79% for the respective groups, showing relatively greater improvement in the younger age group (Table 2).[7]

This may be attributable to the greater proportion of children under age 15 being treated at pediatric cancer centers, with over 60% participating in national clinical trials. Comparatively, fewer than 35% of 15- to 21-year-olds are entered into clinical trials.[11]

Table 2. U.S. five-year survival rates in 0- to 14-year-old children with selected diagnoses

Time Period	1975–1977 (%)	1996–2002 (%)
Acute lymphoblastic leukemia (ALL)	57.6	87.0
Leukemia	50.3	81.0
Hodgkin's lymphoma	80.5	95.3
Non-Hodgkin's lymphoma (NHL)	42.6	86.0
Bone and joint	51.3	71.6
Brain and other nervous system	56.9	74.1

Source: National Cancer Institute. *SEER Cancer Statistics Review, 1975–2003*[7]

However, survival for the older group may improve through their increased participation in national clinical trials. Many advances in childhood cancer treatment are the result of participation in clinical trials. Perhaps the greatest success has been seen in the treatment of acute lymphoblastic leukemia (ALL), for which survival rates have risen from 15% to 80% in the last 40 years, largely due to the high number of patients participating in clinical trials. It is hoped that, through further clinical research, the same success can be achieved for all childhood cancers, including those in the 15–19 age group.[12] The Children's Oncology Group (a national organization), as well as National Cancer Institute (NCI)-designated cancer centers such as the Cancer Institute of New Jersey, offer many childhood cancer clinical research trials, characterized by close oversight and a high standard of care.

To investigate the differences between childhood cancer in ages 0–14 and childhood cancer in ages 15–19 and to further the successful treatment of all pediatric malignancies, the Childhood Cancer Workgroup suggests that more clinical research should be directed toward patients with cancer through the age of 21. Physicians, patients, and families need to be made aware of the importance of participation in clinical trials. Pediatric patients treated at pediatric cancer centers are nearly twice as likely to be enrolled in clinical trials as patients treated at non-pediatric centers.[11] As there has been a direct correlation between participation in national protocols and being treated at pediatric cancer centers, the Childhood Cancer Workgroup also recommends that physicians be educated about the importance of referring patients to pediatric cancer centers.

GOAL CC-1	To improve care for adolescents and young adults diagnosed with cancer through encouraging participation in clinical trials.

Objective CC-1.1

To educate healthcare providers about the availability of existing clinical research protocols and the referral of young adults through the age of 21 to pediatric oncology centers.

Strategy

CC-1.1.1 Collaborate with other organizations to develop and distribute educational materials about the availability and importance of existing clinical research protocols and the need to refer young adults through the age of 21 to pediatric oncology centers.

Health-related Consequences of Childhood Cancer and its Treatment

Many of the treatments that have been instrumental in reducing mortality from childhood cancer can, themselves, have serious health consequences for the survivor. The late effects of childhood cancer treatment include organ malfunction, secondary cancers, and cognitive disorders.[1,13,14] Two-thirds of childhood cancer survivors experience at least one late effect, while one-fourth experience severe or life-threatening late effects.[14] Adult survivors of childhood cancer have a higher mortality rate than the general population.[15] In fact, a recent study found that adult survivors of childhood cancer are 14 times more likely to develop a secondary malignancy than their siblings; 15 times more likely to

develop congestive heart failure; 10 times more likely to have severe cognitive dysfunction; and greater than 50 times more likely to have major joint replacement.[13]

Survivors of childhood cancer represent a growing population. This pool is expanding because of the increase in survival and cure rates. It is estimated that 1 in 640 individuals between 20 and 39 years of age are survivors of childhood cancer.[14] This number is projected to reach 1 in 250 young to mid-aged adults by 2010.[2,16] This population will challenge their healthcare providers to address the medical, emotional, and societal sequelae of cure. Healthcare professionals dealing with this special population must be diligent in surveillance for late effects. The Institute of Medicine's National Research Council recently made the following recommendations regarding childhood cancer late effects:

1. *Develop evidence-based clinical practice guidelines for the care of survivors of childhood cancer.*
2. *Define a minimum set of standards for systems of comprehensive, multidisciplinary follow-up care that link specialty and primary care providers, ensure the presence of such a system within institutions treating children with cancer, and evaluate alternate models of delivery of survivorship care.*
3. *Improve awareness of late effects and their implications to long-term health among childhood cancer survivors and their families.*
4. *Improve professional education and training regarding late effects of childhood cancer and their management for both specialty and primary care providers.*
5. *The Health Resources and Services Administration's Maternal and Child Health Bureau and its partners should be fully supported in implementing the Healthy People 2010 goals for Children with Special Health Care Needs. These efforts include a national communication strategy, efforts at capacity building, setting standards, and establishing accountability. Meeting these goals will benefit survivors of childhood cancer and other children with special health care needs.*
6. *Federal, state, and private efforts are needed to optimize childhood cancer survivors' access to appropriate resources and delivery systems through both health insurance reforms and support of safety net programs such as the Health Resources and Services Administration's Community and Migrant Health Centers.*
7. *Public and private research organizations (e.g., NCI, National Institute of Nursing Research, American Cancer Society) should increase support for research to prevent or ameliorate the long-term consequences of childhood cancer. Priority areas of research include assessing the prevalence and etiology of late effects; testing methods that may reduce late effects during treatment; developing interventions to prevent or reduce late effects after treatment; and furthering improvements in quality of care to ameliorate the consequences of late effects on individuals and families.*[14]

Organ malfunction. Many common childhood cancer treatments, such as chemotherapy and radiation, can result in severe and permanent damage to vital organs, including the brain, heart, lungs, kidneys, and endocrine systems.[15]

Cognitive disorders as a result of cancer treatments are perhaps the most severe late effect of childhood cancer and are discussed in detail later in this chapter under a separate heading.

Certain childhood cancer treatments are known to have toxic effects on cardiac tissue. Survivors who have undergone these treatments should be screened for early onset of cardiovascular disease and counseled on the particular importance of practicing heart-healthy behaviors, including eating a diet low in fats and avoiding tobacco use.[13,15]

The impact of childhood cancer treatment on endocrine system function can result in abnormal physical development (i.e., delayed or accelerated onset of puberty), obesity, and reproductive failure.[13,15,17]

Childhood cancer survivors should be counseled on the potential long-term effects of treatment and monitored not only for these outcomes, but also for the psychosocial effects of organ malfunction.

Secondary cancers. Second malignant neoplasms (SMN) are rare events, but they exact a considerable emotional toll on young adult survivors and their families. Recent studies have estimated the cumulative risk of developing an SMN to be approximately 12% within 25 years of initial diagnosis.[15]

These findings emphasize the need for surveillance to detect and intervene early in the occurrence of SMN. All primary care physicians who treat survivors of childhood cancer should have an increased index of suspicion for an SMN based upon the survivor's individual risk profile. With identification of specific high-risk factors among the survivors, surveillance is more focused, providing an opportunity for early prevention and treatment. The list of high-index suspicion subsets should be inclusive to single out those survivors needing special consideration for increased surveillance by primary care providers.[18]

Cognitive disorders. Healthcare professionals are increasingly accepting the need for psychological assessment and care for childhood cancer survivors. Recent research has shown that survivors of childhood cancer often develop psychological distress, thought to be related to diminished social functioning as a result of cancer or treatment. Distress may be manifested as anxiety, posttraumatic stress, depression, and suicidal ideation.[19] Less severe, but no less deserving of attention, are symptoms of lowered self-esteem and body image and other concerns over the long-term effects of cancer treatment.[20–22] Prolonged illness and treatment may result in isolation from peers and overdependence on caregivers during the adolescent years when children usually strive for independence. This contradiction often leads to unrecognized and unmanaged feelings of frustration, anger, depression, and rebelliousness in the survivor.[23] The incidence and severity of psychological symptoms and suicidal ideation may increase with age due to an increasing burden of responsibility and the demands of adulthood.[20,21,24]

GOAL CC-2	To reduce incidence and impact of late effects of childhood cancer and its treatment.

Objective CC-2.1

To identify guidelines for screening of individuals who have been diagnosed with childhood cancer.

Strategies

CC-2.1.1 Conduct a literature review and interview experts in order to compile guidelines for screening of childhood cancer survivors.

CC-2.1.2 Convene a consensus conference and produce a report that will contain a consensus statement and the development of screening guidelines for childhood cancer survivors where needed.

CC-2.1.3 Disseminate screening guidelines for childhood cancer survivors through the development of a publication to be distributed to all healthcare providers and patients.

Objective CC-2.2

To disseminate healthy lifestyle information to childhood cancer survivors to reduce factors contributing to late effects.

Strategy

CC-2.2.1 Develop a media campaign and brochures to educate childhood cancer survivors on risk factors for late effects.

PAIN AND PALLIATIVE CARE

The World Health Organization affirms that palliative care should be incorporated into the care of all children with cancer utilizing a multidisciplinary approach.[25] There has been some confusion, however, over the term *palliative care*, since this term is often associated with terminal illness where there is no hope for survival and where the treatment shifts from curative intent to providing comfort for the last few weeks of life. However, palliative care has in recent years undergone a paradigm shift (see Chapter 3 Palliation). As recently as 1987, when palliative care was first recognized as a medical specialty, the focus was on patients whose prognosis was poor and was limited to maximizing quality of life at the end of life. A more global approach was suggested by the World Health Organization in 1990:

"… control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment." More recently, in 2001, a white paper produced by the Children's International Project on Palliative/Hospice Services stated: "Palliative care is the science and art of lessening physical, psychosocial, emotional, and existential suffering. Palliative care can benefit patients and families whether the overall goals of care are to cure, prolong life, maximize the quality of life that remains or ease the pain of bereavement. Thus, palliative care may be provided concurrently with, or as an alternative to life sustaining medical intervention … A palliative care knowledge base exists that can substantially improve the experience of children living with life threatening conditions. However, because this knowledge is not widely taught in health professors' training programs, and in part because it is care that is currently unpaid, pediatric palliative care is not widely available."[26] Concurring with these positions, the Childhood Cancer Workgroup recommends that healthcare professionals be made aware of the importance of incorporating palliative care into the treatment of all children with cancer, beginning at the time of diagnosis.

Beyond addressing the emotional impact of the cancer diagnosis, implicit in this broader concept of palliative care is the intent to deal with multiple complications related to both the underlying disease and the treatment of the cancer. These symptoms include diarrhea and constipation, nausea and vomiting, fatigue, anorexia, dyspnea, and pain.[27]

Pain continues to be of paramount importance in that it is very often the prevalent symptom from the time of diagnosis and throughout treatment. Pain is multi-factorial; it can be related to the cancer itself, the invasive procedures used to diagnose or treat the cancer, or the therapies used such as surgery, chemotherapy, or radiation. It is also very often the most important issue for the child dying of cancer. Studies have shown that a significant number of childhood cancer patients experience pain from the time of diagnosis, and this pain is insufficiently managed.[27,28]

GOAL CC-3	To promote awareness of palliative care strategies for the child with cancer among healthcare professionals, patients, and families. Pain management can be used as an example of how these strategies can be implemented successfully.

Objective CC-3.1

To educate healthcare professionals, childhood cancer patients, and families about palliative care strategies in the management of cancer-related symptoms including pain.

Strategy

CC-3.1.1 Partner with providers, childhood cancer patients, and family members to promote a statewide educational forum that will include palliative care and pain management strategies.

FAMILY SUPPORT

Every pediatric oncology medical treatment program in New Jersey should provide emotional support services to a patient's siblings and parents as well as to the patient.

The literature documents the negative impact on siblings and parents when a child is diagnosed with cancer. Much of the literature has focused on posttraumatic stress in relation to the family after a childhood cancer diagnosis, with an indication of parental symptoms consistent with Post-Traumatic Stress Disorder (PTSD) (e.g., avoidance, intrusive thoughts, hypervigilance, etc.). Kazak et al. completed a study comparing symptoms of anxiety and posttraumatic stress in parents of children and adolescents diagnosed with cancer with a control group of parents whose children and adolescents were not diagnosed with a chronic illness.[29] The study, involving 130 cancer survivors and their parents with a comparison group of 155 children and their parents, included five measures of anxiety and stress, with two of the measures involving family functioning and social support. The results of the study revealed significantly higher levels of posttraumatic stress symptoms in parents of children diagnosed with cancer as compared to those parents whose children have not been diagnosed with a chronic illness. Moreover, study findings linked parents' perceived higher levels of social support to fewer posttraumatic stress symptoms. This confirms the notion that quality of life of survivors, siblings, and parents can be improved by addressing impact at time of treatment and subsequently through psychosocial support at treatment centers.

The services of the child life/creative arts specialist are essential to meeting the goals of providing emotional support, age-appropriate explanations of the diagnosis and treatment, preparation for procedures, and the modalities with which the child may express his or her anxieties, frustrations, and anger over interruption of "normal" life. These modalities include the use of art, music, dance, and play, with which the therapist seeks to engage the child in counseling and comfort consistent with their developmental age. The effects of such interventions are often beneficial to the family's coping, to siblings' well-being and interactions, and allow for more time- and cost-efficient delivery of healthcare.

The Academy of Pediatrics has recognized the importance of child-life services and recommended that such services should not be withheld because of financial constraints. Child-life services represent an important foundation for providing a better quality of life for the youngster during treatment and help ensure that child survivors meet the emotional and social milestones of their peers.

Literature supports the nature and severity of stressors, reactions, and coping strategies that point toward possible interventions. Stuber and Kazak[30] found that clinical interventions during treatment reduced not only the family's immediate stress levels, but also continue to provide emotional benefits after acute care. In keeping with current research, Stuber and Kazak recommended reducing family stress levels by assisting the family in "developing a realistic but hopeful understanding of life threat and reducing the perception of treatment intensity."[30] In addition, the study recommended "adequate and developmentally appropriate explanations and preparations for procedures and treatment, and careful control of pain and nausea." Interventions can be specific in terms of types of professionals used (psychologists, social workers, creative life therapists) and ratio of patients to professionals recommended/required. Delivery of services can also be measured in terms of groups/programs offered at a given institution. Studies document the poor quality of life related to sibling/parent anxiety, grief (losses, not only death), and perseverance over problems lasting over time. The literature also compares parent populations only by child's disease severity or prognoses, not by geography, ethnicity, etc.

GOAL CC-4	To foster the psychosocial health of the child with cancer and the family.

Objective CC-4.1

To maximize the quality of life of the child with cancer and the family.

Strategies

CC-4.1.1 Conduct a statewide survey to identify existing psychosocial support mechanisms at each pediatric oncology treatment center.

CC-4.1.2 Identify community resources for psychosocial support for children with cancer and their families in conjunction with a capacity and needs assessment.

Objective CC-4.2

To assess the psychosocial mechanisms utilized in treatment centers and the community.

Strategies

CC-4.2.1 Conduct a literature review to investigate psychosocial standards of care.

CC-4.2.2 Collaborate on a consensus statement for psychosocial standards of care with key stakeholders.

Objective CC-4.3

To ensure that appropriate and continuous psychosocial support is provided for every child with cancer and the child's family.

Strategies

CC-4.3.1 Through a legislative initiative, require the assignment of a professional caseworker to provide *ongoing* psychosocial assessment and intervention of every child and his/her family as per standard of care.

CC-4.3.2 Research existing reimbursement policies and mechanisms to evaluate current trends in non-reimbursement for psychosocial services.

CC-4.3.3 Partner with the insurance industry to further reimbursement of psychosocial services on an *ongoing* outpatient basis.

EDUCATION

According to estimates in the U.S. college-age population, in the year 2010, approximately 67,000 individuals between the ages of 18 and 21 will be childhood cancer survivors. Some reports suggest that up to 50% of survivors are likely to have late effects of their cancer therapy, which may lead to significant disabilities that alter quality of life. This brings to light the need to screen childhood cancer survivors for late effects of their past treatment.

Many survivors see their pediatric oncologists, either regularly or on an occasional basis, after completing treatment for the underlying malignancy, so that they can be monitored and screened for late effects of their therapy. Their primary medical care is managed by pediatricians, family practitioners, internists, and nurses. It is extremely important for these caretakers to be aware of the consequences of survivors' previous treatments for normal tissues and organ systems. A medical passport that includes a short summary of medical history and treatment can be a useful tool for monitoring late effects.

The available literature has well documented late effects of treatment for survivors of childhood cancer, whether surgically, chemotherapy-, or radiation-induced. Adverse effects have been shown on many organ systems, such as the central nervous system, neuroendocrine, ocular, dental, musculoskeletal, cardiovascular, pulmonary, gastrointestinal, hormonal function, fertility, and risks of secondary malignancies.

Central nervous system. Neurocognitive deficit (difficulty reading, language, verbal and non-verbal memory, arithmetic, receptive and expressive language, decreased speed of mental processing, attention deficit, decreased IQ, behavior problems, poor school attendance, poor hand-eye coordination); leukoencephalopathy (seizures, neurologic impairment); focal necrosis (headaches, nausea, seizures, papilledema, hemiparesis, speech, learning and memory deficits); stroke; blindness; ototoxicity (abnormal speech development, hearing loss); myelitis (paresis, spasticity, altered sensation, loss of sphincter control); peripheral neuropathy (generalized weakness, localized weakness, lack of coordination, tingling and numbness).

Neuroendocrine. Growth hormone deficiency (poor growth/growth retardation); adrenocorticotropic hormone (ACTH) deficiency (muscular weakness, anorexia, nausea, weight loss, dehydration, hypotension, abdominal pain, increased pigmentation); thyrotropin-releasing hormone (TRH) deficiency (hoarseness, fatigue, weight gain, dry skin, cold intolerance, dry brittle hair, alopecia, constipation, lethargy, poor linear growth, menstrual irregularities, pubertal delay, bradycardia, hypotension); precocious puberty (early growth spurt, false catch-up, premature sexual maturation); gonadotropin deficiency (delayed or absent pubertal development, testicular atrophy, infertility, abnormal menses, estrogen deficiency); hyperprolactinemia (abnormal menses, infertility, galactorrhea, osteopenia, loss of libido, hot flashes, impotency).

Ocular system. Dry, red eyes; tearing; ulcerations; tortuous vessels; pain; decreased visual acuity; cataracts.

Head and neck/dental. Decreased saliva, dental decay, thrush, ulcerations, chronic rhinitis, facial pain, headache, hearing impairment, chronic ear infections, hair loss.

Musculoskeletal. Muscular hypoplasia, spinal abnormalities (scoliosis, kyphosis, etc.), limb length discrepancy, pathological fracture, osteoporosis, osteonecrosis, osteo-cartilaginous exostoses, slipped capito-femoral epiphysis.

Cardiovascular. Cardiomyopathy, valvular damage, pericardial damage, coronary artery disease.

Pulmonary. Pulmonary fibrosis**.**

Gastrointestinal. Enteritis, adhesions, esophageal strictures, fibrosis of small and large intestines, hepatic fibrosis/liver failure.

Thyroid dysfunction. Hypothyroidism, thyroid nodules, hyperthyroidism.

Infertility. Ovarian failure, premature menopause, decreased or absent sperm production, testicular atrophy.[31,32]

With the longer life span and increasing numbers of survivors of childhood cancer, it is important to help educate primary care physicians, pediatricians, family practitioners, internists, and nurses on these late effects, the need for screening, and treatment/referral recommendations.[31–33]

GOAL CC-5	To increase awareness by healthcare providers of late effects in childhood cancer.

Objective CC-5.1

To identify guidelines for screening and management of late effects of childhood cancer.

Strategies

CC-5.1.1 Collate and condense guidelines for referral and/or management recommendations of childhood cancer survivors for primary care physicians including a summary of medical care.

CC-5.1.2 Disseminate condensed guidelines for management of childhood cancer survivors through the New Jersey Department of Health and Senior Services, Office of Cancer Control and Prevention website and/or printed updates for all practitioners. Update as new information becomes available.

GOAL CC-6	To increase the awareness of neurocognitive and psychosocial deficits in childhood cancer patients.

Objective CC-6.1

To educate patients and families on neurocognitive deficits in childhood cancer patients post treatment.

Strategy

CC-6.1.1 Collaborate with other organizations to maintain a statewide educational forum for educators, childhood cancer survivors, and family members that would address the issue of neurocognitive deficit.

ADVOCACY

Advocacy for individual childhood cancer patients and their families should begin at the time of diagnosis. Education and advocacy are inextricably intertwined. Parents who are still in shock after being told their child has cancer must suddenly deal with a multitude of problems. They must learn the unfamiliar skills involved in taking care of their sick child, such as administering medications on schedule and taking care of central venous catheters. They must learn how to interact with the school system to ensure their child receives an appropriate education and is not penalized for having to miss school. They must also continue to meet the ongoing, day-to-day needs of the patient's siblings. One parent may need to take a leave of absence from work, or even relinquish a job to devote additional time to their sick child.

Legislation passed in the mid-1990s has given patients and their families some new rights regarding education and health insurance. Parents should learn what Family Medical Leave Act benefits entail in order to obtain a leave of absence from work without penalty.

Education. The various legal protections, programs, and designations available to children with cancer and their families are well described in Keene et al.,[33] Weiner et al.,[34] and Monaco et al.[35] For various reasons, some schools and systems are easier to work with than others. Parents may need help in negotiating with an individual school system. Fortunately, the guidelines in these references are reasonably clear and straightforward. A child receiving treatment should be eligible for a number of programs designed to permit continuation of schooling. Because of the late effects of some types of treatment (e.g., cranial irradiation), children may not experience learning difficulties until years after conclusion of treatment. A child who has always managed to do well in grade school by working hard may be unable to handle the additional work required in junior high or high school. Not all child study teams or school psychologists (to say nothing of teachers) are aware of the learning problems children with cancer or survivors of childhood cancer may face.

Employment. Keene et al.,[33] Weiner et al.,[34] and Monaco et al.[35] also explain the legal protections and practicalities of employment. The fact is noted, for example, that a potential employer has no right to ask health history questions or to require a physical examination until after a preliminary job offer has been made. The importance of accurate assessment of cancer survivors' abilities and appropriate vocational counseling is also mentioned. It is particularly important that survivors left with neuropsychological problems and/or neurodevelopmental delay be given adequate support, as they are at increased risk of being unable to secure or maintain a job. Unfortunately, many survivors who have had brain tumors or who have required high doses of cranial irradiation are left with such neurological deficits.

Insurance (during the child's treatment). Few people are familiar with all the nuances of their health insurance coverage. Such dearth of knowledge is further complicated by the changes frequently made in these plans requiring prior authorization or requiring laboratory tests to be performed at designated facilities. Different insurance companies and health maintenance organizations (HMOs) vary greatly in their procedures and requirements related to the patient's care. Sometimes the procedures required by the insurance companies actually delay a patient's care. One program that many New Jersey residents are unaware of is the New Jersey Department of Human Services Catastrophic Illness in Children Relief Fund. This fund provides financial assistance for children's medical expenses that are not fully covered by insurance, state, federal programs, or other sources and meet the program's income requirements.

Insurance (for the cancer survivor). Vann et al.[36] found that young adult survivors of childhood cancer were "more likely to be denied health insurance than their siblings, with an adjusted odds ratio of 15.1" and "had health insurance policies that excluded care for pre-existing medical conditions more often than their siblings (OR = 5.5)." Now the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) have improved the situation for cancer survivors and their families. If a parent of a child diagnosed with cancer or a cancer survivor changes jobs, these laws protect them from losing their health insurance. If a family (or patient) does not have insurance in effect at the time of diagnosis, it can still be extremely difficult to obtain insurance. If a young adult who has survived childhood cancer no longer qualifies for coverage under his parent's insurance, he may find it nearly impossible to obtain health insurance coverage without a substantial waiting period (usually a year) for coverage of pre-existing conditions. Private individual insurance may be prohibitively expensive; an insurer cannot refuse to issue a policy, but the premiums may be very high because of an individual's health history. The guide by Keene et al. advises the cancer survivor not to look for a job in a small company: "The easiest way to get insurance is for you or your spouse to work for a large corporation or government agency that provides a group health insurance policy. The larger the pool of employees, the less likely you are to be rejected from health coverage… ."[33]

Despite some progress, cancer survivors have more difficulty obtaining insurance than their peers, and this situation is not likely to improve. The results of several studies of five-year (and more) survivors of childhood cancer have reported the incidence of secondary malignancies in these patients and an increased late mortality experience, e.g., deaths due to late effects of chemotherapy and radiation, not just to relapsed cancer or secondary malignancies.[37] A program to follow survivors of childhood cancer will use the results of these studies to plan for screening for cardiac or pulmonary dysfunction, as well as secondary malignancies.[18] Will insurance pay for these tests? Will an insurer consent to enroll a new client with these documented additional risks?

An increasing number of "cancer genes" have also been identified. Li's exemplary discussion of the dilemmas posed by detecting one of these genes in an individual (and in a family) includes the RB1

retinoblastoma gene.[38] Fortunately, it is very rare: an infant who inherits the RB1 gene has a 90% likelihood of developing retinoblastoma, usually in both eyes. The child who survives hereditary retinoblastoma has an increasing chance of subsequently developing another cancer; a 50% likelihood of developing another cancer by age 50 (compared to a 5% risk of a second cancer in a patient with sporadic retinoblastoma). As each new cancer gene is identified, the dual opportunity appears. The physician can potentially identify a patient who should have earlier and more frequent screening for particular cancers, thereby increasing the probability of early detection (and, hopefully, cure) of cancer. Yet the insurer can also potentially identify a high-risk participant. Although legislation has been developed to protect the privacy of patients, and various attempts have been made to prevent insurance companies from obtaining the results of tests for cancer genes, legal protections need to be developed to allow physicians to order appropriate screening for at-risk individuals without breaking confidentiality requirements.

Long-term follow-up. Oeffinger et al. sent a brief questionnaire to the 219 institutional members of the Children's Cancer Group and Pediatric Oncology Group; 182 members responded.[39,40] Only 80 of the institutions who responded had long-term follow-up clinics. Although 44% had a mechanism for following up adult survivors, only 15% of the programs had established a formal data base for young adults. The institutions were asked which of several factors interfered with long-term cancer-related follow-up for young adults, and responses included patients' uncertainty about the need for follow-up (76%), patients' unwillingness to come (66%), and lack of insurance (63%). The same group found that among the 99 patients participating in the long-term follow-up program, 69% had at least one late effect (36% had two or more) and 30% had a CTCv2 Grade 3 or 4 late effect (Common Toxicity Criteria, version 2, of NCI). Sklar reported that of 650 survivors followed in the Long Term Follow-Up Clinic at Memorial Sloan-Kettering Cancer Center, "the most common sequelae are endocrine complications, which are seen in 40% of the patients."[41] Strickland et al. reported that among those surviving patients transfused between 1961 and March 1992, 66% were found to be infected with Hepatitis C.[42]

With HMOs dropping Medicare populations and then Medicaid populations because of the expense involved in their care, protecting these "predictably expensive" childhood cancer patients and survivors will be a difficult undertaking.

Conclusions. The importance of educating cancer survivors cannot be overemphasized. Blacklay et al. describe providing an information booklet to 50 adult survivors of cancer in childhood.[43] The booklet for survivors over the age of 14 included "information about treatment of cancer, general advice about a healthy lifestyle, the rationale for long-term follow-up, and information about employment and life insurance problems." A small survey was then administered to these patients to evaluate whether the booklet had been effective. Over three-quarters of the patients reported they had learned new information from the booklet and better understood the risks of sunbathing and the importance of follow-up.

Perhaps the simplest solution to the problems of educating patients and families about the complications and possible late effects of the disease, as well as about problems likely to be encountered in education, employment, and insurance, would be to distribute a copy of the book by Keene, Hobbie, and Ruccione.[33] It is remarkably comprehensive, practical, and easy to read. Published in 2000, it includes numerous helpful references and websites, as well as email addresses of two of the authors to assist patients in locating follow-up clinics.

GOAL CC-7	To increase advocacy for childhood cancer, especially on issues related to long-term survivorship, education, employment, and insurance coverage.

Objective CC-7.1

To educate legislators and key decision-makers about issues in childhood cancer.

Strategies

CC-7.1.1 Collaborate with grassroots childhood survivorship organizations to advocate for childhood cancer issues.

CC-7.1.2 Develop and obtain funding for an advocacy campaign on childhood cancer concerns targeting legislators.

Objective CC-7.2

To educate childhood cancer survivors and families about issues in childhood cancer.

Strategies

CC-7.2.1 Investigate established models for teaching childhood cancer advocacy to the lay community. Host a statewide conference for parents and childhood cancer survivors utilizing the model with demonstrated effectiveness for teaching advocacy.

CC-7.2.2 Collaborate with multi-disciplinary organizations, e.g., American Cancer Society, Inc., New Jersey Education Association, New Jersey State School Nurses Association, to re-institute educator conferences on childhood cancer survivorship issues.

Objective CC-7.3

To educate insurance companies about issues in childhood cancer.

Strategy

CC-7.3.1 Utilize the grassroots childhood cancer survivorship organization to educate insurance companies on the cost effectiveness of surveillance.

GOAL CC-8	To ensure that New Jersey residents and physicians remain up to date on currently available childhood cancer technologies and resources.

Objective CC-8.1

To continue to monitor and disseminate current advances in childhood cancer diagnosis and treatment.

Strategies

CC-8.1.1 Conduct periodic literature reviews to determine the state of the science in childhood cancer research and to identify potentially promising new technologies.

CC-8.1.2 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through CME offerings.

Objective CC-8.2

To continue to monitor trends in childhood cancer incidence, mortality, and survival.

Strategy

CC-8.2.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

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CHAPTER 6. Colorectal Cancer

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COLORECTAL CANCER

IMPORTANCE OF COLORECTAL CANCER FOR CANCER PREVENTION AND CONTROL

Colorectal cancer is the third most common cancer among both men and women in the United States. The American Cancer Society estimates that in 2007 in the United States there will be 153,760 new cases of colorectal cancer diagnosed, accounting for approximately 10% of all cancers among men and 11% among women. Colorectal cancers account for about 9% of cancer deaths in men and women, with an estimated 52,180 deaths in 2007. Nationwide, the lifetime risk for developing colorectal cancer is approximately 1 in 18 persons. Between 1998 and 2003 colorectal cancer incidence rates declined 2.1% per year. Mortality rates from colorectal cancer have declined at a similar rate over the last two decades as a result of decreasing incidence, early detection, and improvements in treatment.[1,2,3,4]

The risk of colorectal cancer increases with age, with the majority diagnosed in individuals over the age of 50. Blacks are more likely than other racial and ethnic groups to develop colorectal cancer. Other non-modifiable risk factors include inherited genetic syndromes, personal or family history of colorectal cancer or polyps, or a personal history of inflammatory bowel disease. However, some risk factors—such as obesity, lack of physical activity, smoking, heavy alcohol consumption, or a diet high in fat and low in fiber—can be modified to reduce an individual's risk of developing colorectal cancer.[1]

While the incidence of colorectal cancer is decreasing in the U.S. and New Jersey, less than 40% of all colorectal cancers are diagnosed in the early stages when treatment is most effective. Patients diagnosed in the early stages have a survival rate of approximately 90%. Survival declines rapidly with more advanced diagnoses.[1,5] For this reason, screening and early detection are important factors in decreasing incidence and mortality from colorectal cancer.

Colorectal cancers develop slowly, beginning with a polyp, a benign growth that rarely causes symptoms. Detecting and removing polyps before they become cancerous is the optimal method of reducing the incidence and mortality of colorectal cancer. Several methods are currently available to screen for colorectal cancer: digital rectal exam (DRE), fecal occult blood test (FOBT), flexible sigmoidoscopy (FSIG) or sigmoidoscopy, double contrast barium enema (DCBE), and colonoscopy. The DRE examines only a limited portion of the rectum and is not recommended as a screening method when used alone. The FOBT is not specific to colorectal cancer or polyps, but may be used to determine whether a more specific test is needed. A sigmoidoscopy provides a view of the rectum and part of the distal colon and has been shown to reduce colorectal cancers of that site by up to 60%.[5] Only the colonoscopy and double contrast barium enema can provide a view of the entire colon and rectum, and these are therefore the only screening tests able to detect cancers of the proximal, as well as the distal colon and the rectum.[6,7] The DCBE, however, is no longer recommended due to its lower sensitivity. The colonoscopy is the only screening method that can not only detect cancerous and pre-cancerous polyps, but can also remove them in the same procedure. Since almost every colorectal cancer begins with a polyp, the unique ability of the colonoscopy to remove polyps provides a significant measure of prevention against the development of cancer. An emerging technology in the field of colorectal cancer screening is the virtual colonoscopy. The virtual colonoscopy is a noninvasive test that examines the colon using computerized imaging. One disadvantage of the virtual colonoscopy compared to the colonoscopy is the fact that the procedure shows less detail, such that smaller lesions may go undetected. A second disadvantage is that the physician cannot take tissue samples or remove polyps during a virtual colonoscopy. Thus, if abnormalities are found, a conventional colonoscopy must be performed.
See Table 1 below for a summary of current colorectal cancer screening options.

Table 1. Centers for Disease Control and Prevention current colorectal cancer screening guidelines for average-risk individuals over age 50*[1,6,8]

Test Type	General Frequency**	Benefits	Limitations***
Fecal Occult Blood Test (FOBT) or Fecal Immunochemical Test (FIT)	Every year	• 33% mortality reduction (FOBT only) • Low cost • No bowel preparation	• Performed at home and subject to patient error • Not specific for colorectal cancers • Pre-test dietary restrictions (for FOBT) • Will miss some polyps • Additional procedures needed if positive
Flexible Sigmoidoscopy (FSIG)	5 years	• 60% mortality reduction from distal colon/rectal cancers • Minimal preparation/ moderate discomfort	• No reduction in deaths from proximal colon cancers • Views approximately one-third of colon • Small risk of infection or bowel tear • Additional procedures needed if positive
Colonoscopy	10 years	• Provides view of entire colon • 66% reduction of new cancers; most accurate test for detecting polyps • Can biopsy and remove polyps • Can diagnose other disease • Minimal discomfort	• Can miss small polyps • Sedation needed • Subject to provider capability • Potential risk of infection or bowel tears • Full bowel preparation needed
Double Contrast Barium Enema (DCBE)	5–10 years	• Provides view of the entire colon • Few complications • No sedation needed	• Can miss small polyps • Lower sensitivity to detecting polyps than colonoscopy • Full bowel preparation needed • Additional procedures needed if positive

* For average-risk individuals. Individuals with increased or high risk should begin screening before age 50. See Appendix C for additional information.

** Suggested frequencies vary and may change as new information becomes available. See Appendix C for a list of screening guideline resources. Patients should consult a physician to determine the best screening program to meet their needs. A colonoscopy should always follow a positive result from any other test.

*** Information on the limitations of screening tests is from both the Centers for Disease Control and Prevention[8] and the American Cancer Society.[1]

Although screening and early detection are important in the successful prevention and treatment of colorectal cancer, colorectal cancer screening is less widely used than screening for other cancers. (See Table 2 below for the percent of New Jersey residents who have had an FOBT, a sigmoidoscopy, or a colonoscopy.) These numbers reflect the need for efforts to increase education and awareness of colorectal cancer screening and prevention.[6]

Table 2. Percent of New Jersey residents Aged 50 and over who have had colorectal cancer screening New Jersey versus U.S. by gender, 2002 and 2004

TYPE OF SCREENING	PERCENT OF MALES				PERCENT OF FEMALES			
	2002		2004		2002		2004	
	NJ	US	NJ	US	NJ	US	NJ	US
Had a home blood stool test in the past two years?*	31.1	30.4	26.9	27.5	29.7	25.7	25.0	26.0
Ever had a sigmoidoscopy/ colonoscopy?*	48.7	47.8	59.3	52.5	47.7	47.9	54.5	53.2
Had sigmoidoscopy/ colonoscopy in the past 10 years?**	46.3	–	56.4	–	44.0	–	50.6	–
Had home blood stool test in the past year or sigmoidoscopy/ colonoscopy in the past 5 years?**	52.8	–	58.1	–	50.0	–	52.7	–

* Source: Centers for Disease Control and Prevention. *Behavioral Risk Factor Surveillance System Survey Data*. Atlanta, GA: Centers for Disease Control and Prevention, 2007.
** Source: Center for Health Statistics. *New Jersey Behavioral Risk Factor Survey* [unpublished data]. Trenton, NJ: New Jersey Department of Health and Senior Services, 2007.
Note: U.S. data not available for sigmoidoscopy/colonoscopy in past 10 years or home blood test in past year/ sigmoidoscopy/colonoscopy in past 5 years.

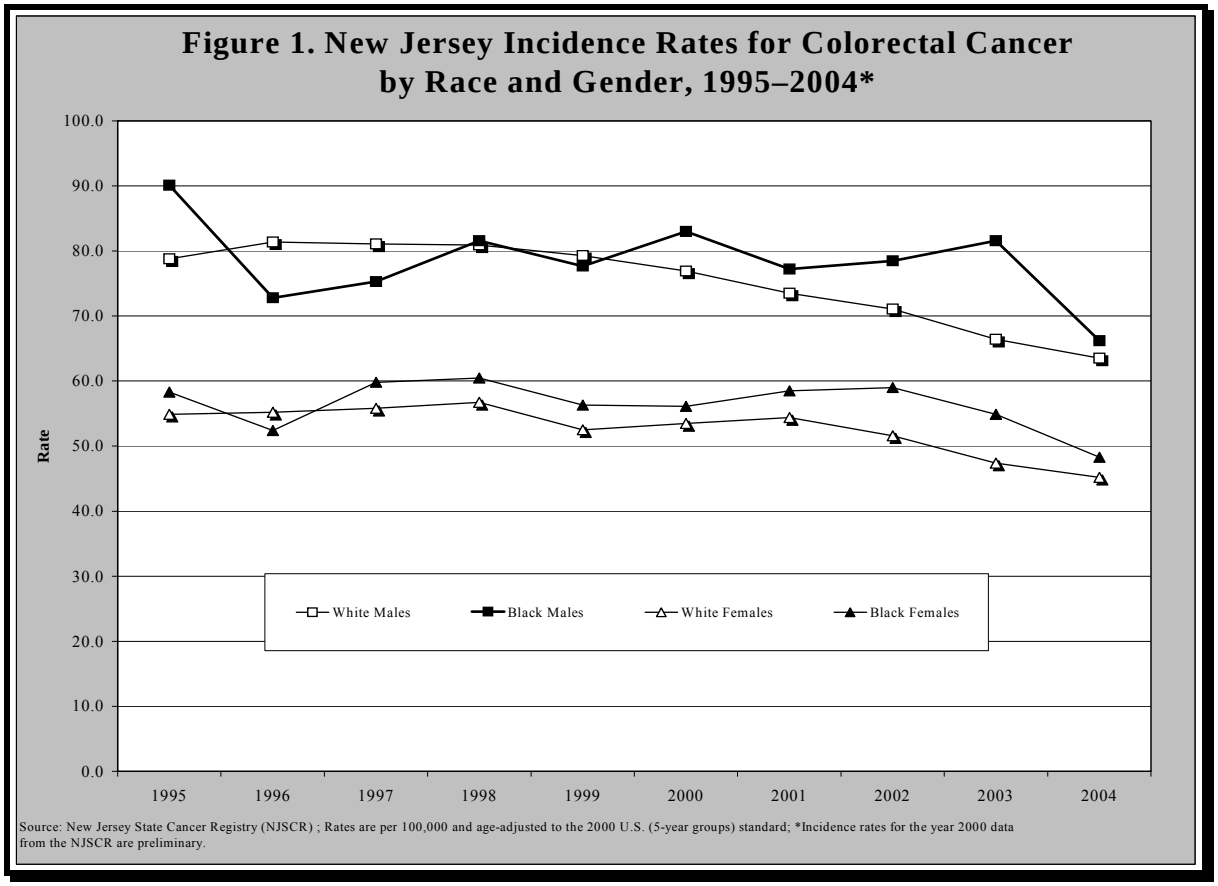
COLORECTAL CANCER IN NEW JERSEY

In this section we discuss the status of colorectal cancer in New Jersey, including incidence, mortality, prevalence, and survival.

Incidence. Consistent with U.S. colorectal cancer incidence rates, rates in New Jersey have declined since 1979 among all race and gender groups, with the exception of black males. Although the number of colorectal cancer cases is approximately equal for men and women (principally because women live longer than men), men have consistently had higher incidence rates than women, regardless of race (Figure 1). According to 2004 data from the New Jersey State Cancer Registry, the incidence rate of colorectal cancer among New Jersey men (all races combined) was 63.2 per 100,000**; the incidence rate for white males was 63.5 compared to 66.2 per 100,000 for black males. Incidence rates among New Jersey females (all races combined) was 45.5 per 100,000**; the incidence rate for white females was 45.2 compared to 48.3 per 100,000** for black females in 2004*. The incidence rate for Hispanic females in New Jersey was 41.0, and the incidence rate for Hispanic males was 66.3 per 100,000** in 2004.[9] The American Cancer Society estimates that, in 2007, 5,160 new colorectal cancer cases will be diagnosed in New Jersey.[1]

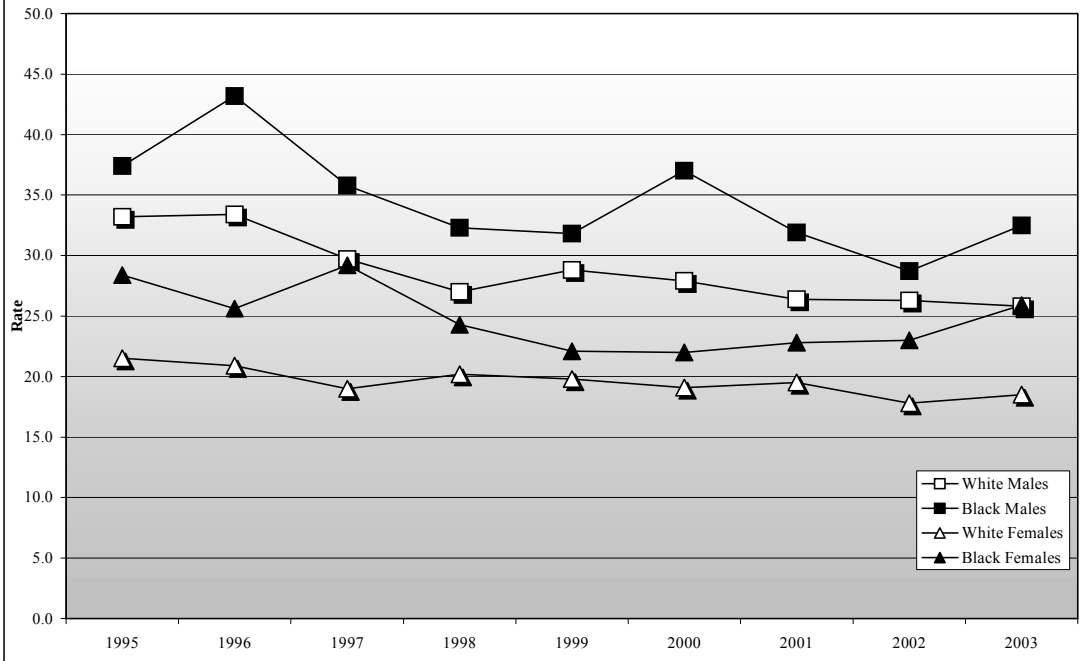
* Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary
** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Mortality. Mortality from colorectal cancer comprises approximately 10% of all cancer deaths in New Jersey.[1,2] According to the New Jersey State Cancer Registry, colorectal cancer mortality rates for New Jersey males (all races combined) decreased from 33.4 per 100,000** in 1995 to 25.7 per 100,000** in 2003 (Figure 2). This decrease was evident in mortality rates for both white males and black males. Similarly, mortality rates for New Jersey females (all races combined) decreased from 22.0 per 100,000** in 1995 to 19.0 per 100,000** in 2003 (Figure 2). This decrease was evident in both white females and black females in New Jersey. The mortality rate for Hispanic males in New Jersey increased from 10.9 per 100,000** in 1995 to 20.0 per 100,000** in 2003. The mortality rate for Hispanic females, however, remained relatively stable from 1995 to 2003 (10.6 versus 9.1 per 100,000**, respectively).[10] The American Cancer Society estimates that, in 2007, there will be 1,680 deaths in New Jersey due to colorectal cancer.[1]



**Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Figure 2. New Jersey Colorectal Cancer Mortality Rates by Race and Gender, 1995–2003



Source: National Center for Health Statistics; rates are per 100,000 and age-adjusted to the U.S. 2000 standard population.

Prevalence. Estimates indicate that on January 1, 2003, there were 38,510 or 0.4% of New Jersey men and women alive who had ever been diagnosed with colorectal cancer. As with other cancers, the prevalence of colorectal cancer increases with age and is highest in the 65+ age group (2.7%). The prevalence of colorectal cancer is slightly higher in whites than in blacks (0.5% versus 0.3%, respectively).[11]

Survival. The five-year relative survival rate for colorectal cancer diagnosed in New Jersey from 1994–1997 is 60.6%. This rate is slightly lower than the U.S. rate of 62.5%. Disparities in survival exist between blacks and whites. In New Jersey, as in the U.S., black women have a lower survival rate than white women (52.1% versus 60.3%, respectively) and black men have a lower survival rate than white men (48.2% versus 63.2%, respectively).

Colon cancer survival rates are much higher for cancers diagnosed at the local stage than at the regional or distant stage. For example, in New Jersey from 1994–1997, the five-year survival rate for local-stage colorectal cancers was 90.7% for men and 86.3% for women, whereas that for regional-stage was 65.0% for men and 62.5% for women, and that for distant-stage was 6.0% and 9.1% for men and women, respectively.[12] In New Jersey, white males have a higher percentage of local-stage colorectal cancers diagnosed than black males (46.01 versus 38.76%, respectively), whereas the percentage of local-stage colorectal cancers is similar for white females and black females (42.82 versus 43.26%, respectively).[9]

HEALTHY NEW JERSEY 2010 GOALS

Healthy New Jersey Goal 1	Reduce the age-adjusted death rate from colorectal cancer per 100, 000 standard population* to: 19.0 for the total population (age-adjusted), 19.0 for whites (age-adjusted), 22.0 for blacks (age-adjusted) and 124.0 for persons 65+, by 2010.

Table 3. Age-adjusted death rate from colorectal cancer per 100,000 standard population, New Jersey, 1999–2002, and Healthy New Jersey 2010 projected target rates.

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
Total	23.3	23.0	22.4	21.5	19.0	13.0
White	23.4	22.8	22.4	21.4	19.0	13.0
Black	25.8	27.7	26.3	25.1	22.0	13.0
Hispanic	13.5	14.7	15.6	12.8	***	***
Asian/Pacific Islander*	**	4.7	**	8.8	***	***
Persons 65+	145.0	144.0	142.7	134.9	124.0	81.0

Source: New Jersey Department of Health and Senior Services, Center for Health Statistics, Healthy New Jersey 2010: Update 2005.
* *The number of Asian/Pacific Islander cases is known to be understated.*
** *Figure does not meet standard of reliability or precision.*
*** *A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander include Hispanics and non-Hispanics.

GOALS, OBJECTIVES, AND STRATEGIES

In support of the Healthy New Jersey 2010 goal for colorectal cancer, the recommendations of the Colorectal Cancer Workgroup are summarized below for the following focal areas:

- Awareness and education
- Screening
- Research and surveillance

AWARENESS AND EDUCATION

The impact of colorectal cancer on the morbidity and mortality of American citizens in general, and on New Jersey residents in particular, is alarming. New Jersey has the highest incidence rate of colorectal cancer in the country for males and the third highest rate for females. The mortality rates are more optimistic, with New Jersey seventh in the nation for males and fourth for females.[1] Yet despite these statistics, colorectal cancer has not received the same level of attention paid to breast and prostate cancers.

It is well established that early detection of cancer through screening tests offers significantly improved chances for survival. Research suggests that the recent steady decline in colorectal cancer incidence and mortality rates may be due to increased screening and polyp removal preventing the progression of polyps to invasive cancers.[3,13,14] Nationally, the Behavior Risk Factor Surveillance System (BRFSS) shows an increase in colorectal cancer screening rates nationwide of 3% between 2002 and 2004. Although this seems to be a small increase, recent data from the BRFSS, Medicare, and the National Committee on Quality Assurance (NCQA) indicate that concerted efforts to improve colorectal cancer screening rates have begun to demonstrate success. While only 7 states had colorectal cancer screening rates of 60% or greater in 2002, by 2004 there were 15 states at that level, and 7 were over 65%.[15] During that period, 11 states had an increase in endoscopy rates of 7% or greater. Two had increases of 12%.[16–17] While improvement varied from state to state, nationwide overall screening rates increased by 3%.[15] Medicare screening rates demonstrated significant increases from 2000 and 2003.[18] In Medicare managed care plans, rates rose from 49.5% in 2003 to 53.9% in 2005, and in commercial managed care plans from 47.4% in 2003 to 52.3% in 2005.[19]

Yet despite established screening and treatment guidelines, widespread availability of testing, and widespread agreement among professional societies and the scientific community that screening can prevent colorectal cancer and reduce mortality, screening rates remain relatively low for the population as a whole. The concentration of particularly low screening rates in certain subgroups (e.g., the uninsured and the medically underserved) contributes to higher colorectal cancer mortality in these populations.[13,14,19–22] Barriers to colorectal cancer screening have been identified, including inadequate health insurance coverage, lack of awareness of screening, and lack of physician referral.

Colorectal cancer screening rates are low for a number of reasons. Some reasons are associated with the individual patient. Colorectal cancer and colorectal cancer screening tests are unpopular subjects. The public views the tests as distasteful and as likely to be painful. Most people know little about the tests and are confused about what test to have and when and are often unaware of how to schedule screening.[23] Most also report that their doctors do not talk to them about colorectal cancer or their

screening options. Awareness of colorectal cancer screening options is an important determinant of whether or not an individual is appropriately screened. Individuals with health insurance are significantly more likely than the uninsured to be aware of colorectal cancer screening.[24] As a result, the Colorectal Cancer Workgroup aims to increase awareness of colorectal cancer screening options among all New Jersey residents, particularly the uninsured, as a means of increasing colorectal cancer screening rates and decreasing the incidence and mortality of the disease.

Other reasons for low colorectal cancer screening rates are associated with healthcare providers. Providers cite a lack of training and/or experience in testing, lack of time to discuss the subject with their patients, a desire to avoid inconveniencing their patients, and concern that the tests are not effective. Further reasons these tests are not performed include inadequate reimbursement, high costs, and limited access to centers or providers who can perform the tests.[25]

Evidence suggests that when a screening recommendation comes directly from the clinician, compliance with colorectal cancer screening can be quite high.[3,4,13,21,24,26] As indicated earlier, colorectal cancer is a highly curable disease when detected early. When diagnosed at an early stage, the five-year relative survival is 90%; yet less than 40% of incident cases are diagnosed while still localized,[2] and disparities among racial and ethnic minorities continue to be of concern. To alleviate this public health burden, a commitment among healthcare professionals to preventive screening is necessary. Of primary importance is the fact that clinicians recommend at least one of the appropriate screening options for all eligible patients; the role of the healthcare provider in recommending and conducting preventive screening is a strong predictor of preventive service use.[3,4,13,14,20,21,24,27] At this time, economic and healthcare system disincentives to screening are limiting the choices available to physicians and patients, and studies indicate that many physicians are unaware of the appropriate timing and frequency for screening.[27] However, as familiarity and screening skills grow in the broader medical community, and as insurance and cost obstacles are removed, a greater range of options will be made available.[3] The Colorectal Cancer Workgroup recommends that educational efforts be targeted at physicians to increase awareness and implementation of published screening guidelines. To achieve this requires commitment and collaboration among healthcare providers, insurance companies, and regulatory agencies.

Cancer screening rates continue to be low among groups that lack health insurance or a usual source of care, and large disparities in cancer incidence and mortality across racial and ethnic groups persist.[3,4,13,14,20,23] Blacks and other minority groups are more likely to be diagnosed with more advanced colorectal cancer than their white counterparts.[14] Similarly, persons with limited education and lower socioeconomic status infrequently participate in screening programs in general and have very low rates of colorectal cancer screening in particular.[3,4,20,23,28] To be effective, preventive initiatives focusing on colorectal cancer must be inclusive of the general population as well as those at increased risk for developing colorectal cancer and must include the screening options currently available for the detection of colorectal cancer.

As cost is often cited as a barrier to screening, accurate and cost-efficient options must be available to the healthcare practitioner as well as to the community. Several screening options exist for cost containment while maximizing the benefits of screening.[3] Insurance coverage for age- and risk-appropriate screening must be available in order to reduce the incidence of colorectal cancer and increase the efficacy of screening interventions by identifying early disease for optimal health benefits. Therefore, screening efforts combined with broader, more aggressive educational initiatives must be part of a complete and comprehensive prevention program that integrates age-related screening with the promotion of healthy lifestyles.[19]

In addition, barriers to screening (e.g., lack of knowledge or awareness, accessibility, language, and cultural sensitivity) need to be addressed in order to make awareness of colorectal cancer and screening opportunities as common as awareness of mammography for breast cancer and prostate-specific antigen (PSA) tests for prostate cancer. The most effective modalities appear to be simple, straightforward patient education materials that include brief, hopeful messages about the purpose of screening and its benefits.[21,29] Access to screening, clinician recommendations, and education can be effectively combined for favorable impact on screening rates to reduce the debilitating effects of colorectal cancer on our communities.

The public must also be made aware of the inherent and modifiable risk factors associated with colorectal cancer. Efforts to encourage a healthy diet and increased physical activity, as well as to discourage the use of alcohol and tobacco products could lead to a reduction in incidence of colorectal and other cancers. Individuals with a personal or family history of colorectal polyps, cancer, or inflammatory bowel disease, in particular, should be made aware of their increased risk of developing colorectal cancer and should be encouraged to speak with a physician about early screening.[1]

In recent years, colorectal cancer has received increased attention due in part to the efforts of advocates and organizations such as the Task Force to increase public and professional awareness. Colorectal screening must become a focused health initiative, as is already the case with breast and prostate cancer screening. Only through recognition of colorectal cancer as a major health problem will we be able to effectively influence incidence and mortality rates.

Clearly, one of the most important priorities for action is to improve public awareness about colorectal cancer as a preventable and curable cancer, about the benefits of colorectal cancer screening, and about the specifics of screening options. Efforts must focus on providers' systematic referral and reminder practices targeting and reaching multiple audiences—including those at increased risk, the uninsured, and other underserved audiences—with messages that encourage specific behavior change. However, education and awareness should not focus solely on those eligible for screening. Evidence suggests that beginning such education among younger populations may increase its effectiveness and lead to better screening outcomes.[30] Identifying these audiences and designing effective messages will require a strong research foundation. Collecting data about the public's knowledge, attitudes, and behaviors concerning colorectal cancer will be critical for developing effective communications with the public in general as well as with specific target audiences. In addition to proactive public awareness efforts, professional awareness strategies will be critical in encouraging providers to discuss colorectal cancer and the benefits of screening with their patients, as well as increasing the number of providers who are themselves screened.

Education and awareness activities—for the public, for payers, as well as for healthcare professionals—must continue in order to open and facilitate dialogue between patients and their healthcare providers as a means to increase usage of colorectal cancer screening tests and reduce the burden of disease among New Jersey residents. Outreach programs must be developed to eliminate the personal, social, and economic barriers to colorectal cancer screening.

GOAL CO-1	To raise awareness about colorectal cancer for all residents of New Jersey of *at least* high school age by 2006, with regard to effective measures available for prevention, detection, and treatment to improve the quality of life and survival rates for those diagnosed.

Objective CO-1.1

To target specific educational efforts for subpopulations, including but not limited to, lower socioeconomic status (SES) and high-risk groups, in order to increase awareness of colorectal cancer.

Strategies

CO-1.1.1 Review the content of the curriculum the New Jersey Department of Education is developing—as supported by Title 18A:40–32 Cancer Awareness Week and Title 18A:40–33 Cancer Awareness Program for School-aged Children—as it relates to colorectal cancer.

CO-1.1.2 Provide recommendations to the Department of Education for curriculum development for high-school-aged students, specific to colorectal cancer, which would be included with the general cancer education program.

Objective CO-1.2

To increase the knowledge and change the behaviors of women and men with regard to the importance of colorectal cancer screening and the need to request it.

Strategies

CO-1.2.1 Assess knowledge of colorectal cancer among target populations by conducting qualitative research about New Jersey residents.

CO-1.2.2 Identify targeted educational interventions to reduce gaps in awareness and behaviors around colorectal cancer screening among men and women 50 years of age and older residing in New Jersey.

CO-1.2.3 Develop educational interventions for widespread dissemination of messages about colorectal cancer through multi-faceted delivery mechanisms.

Objective CO-1.3

To increase the knowledge and change the behaviors of healthcare providers with regard to the importance of colorectal cancer screening and the need for patient education.

Strategies

CO-1.3.1 Recommend that healthcare professional organizations educate their members based on identified knowledge gaps regarding screening for colorectal cancer.

CO-1.3.2 Collaborate with insurers to provide appropriate patient and provider educational materials regarding colorectal cancer screening.

SCREENING

Early detection of colon and rectal cancers is paramount because almost all of these cancers can be cured when discovered in their earliest growth phases. Currently, fewer than 40% of these cancers are diagnosed in the early stages when treatment is most effective.[2] Screening for colorectal cancer must be promoted and performed for all adults aged 50 years and older and for higher risk younger individuals in New Jersey.

While several screening methods have been tested and used, only colonoscopy can not only detect cancer and pre-cancerous polyps throughout the entire length of the colon, but also remove them, thus preventing development of invasive cancers. As cancers of the proximal colon are more likely to be diagnosed in later stages than those in the distal colon, use of the colonoscopy is increasingly important.[31]

While the colonoscopy may one day be hailed as the "gold standard" in colorectal cancer screening, other screening modalities are currently available. The digital rectal exam (DRE) examines the anus and a very small portion of the rectum. While DRE is always performed at the time of colonoscopy, it is not recommended as a screening method when used alone. Fecal occult blood test (FOBT) or fecal immunochemical test (FIT) have some value when multiple stool samples are tested by an outpatient. However, FOBT is sensitive, highly non-specific for colon cancer, and "false positives" are common, leading to the need for additional testing. FIT is more patient-friendly and has an equal or lower likelihood of false positives than FOBT. Flexible or, especially, rigid sigmoidoscopy examines only a limited part of the entire colon, potentially missing a majority of colon cancers possibly present. Double contrast barium enema (DCBE) is better than sigmoidoscopy but markedly inferior to colonoscopy, while requiring a similar preparation of the colon. Refer to Table 1 for the benefits and limitations of all available colorectal cancer screening mechanisms.

The American Cancer Society recommends that average-risk individuals begin screening at age 50 with one of the following options:

- A fecal occult blood test or fecal immunochemical test every year, OR
- Flexible sigmoidoscopy every 5 years, OR
- An FOBT or FIT every year plus FSIG every 5 years, OR
- Double-contrast barium enema every 5 years, OR
- Colonoscopy every 10 years

The combined use of FOBT or FIT with FSIG every 5 years is preferable to the use of either FOBT or FIT or FSIG alone. A colonoscopy should be performed following a positive result from any other screening option.[32]

Despite sufficient evidence that screening and early detection reduces the incidence and mortality of colorectal cancer, screening rates remain low compared to screening for other cancers. Lack of adequate health insurance is a major barrier to colorectal cancer screening.[24] Colorectal cancer screening rates among those without any form of health insurance have been estimated to be as low as 32.7%.[†] According to the 2004 New Jersey Behavioral Risk Factor Survey, only 25.9% of New Jersey respondents reported having had a recent FOBT (within the past two years) and 53.2% reported having had a recent sigmoidoscopy or colonoscopy (within the preceding ten years).[33] These percentages are in stark contrast to the 77.8% of women who reported a mammogram in the last two years.[34] Contrary to the national trend, New Jersey colorectal cancer screening rates do not differ significantly by race.[34]

The New Jersey Cancer Education and Early Detection (NJCEED) program provides free and low-cost colorectal cancer screening to uninsured and underinsured individuals at or below 250% of the federal poverty level. Much of the eligible population may be unaware of the services offered by NJCEED. Further, the NJCEED program is funded to provide screening to only a portion of the eligible population, and no funding mechanism exists to provide treatment for those diagnosed under the program. Thus, the Colorectal Cancer Workgroup recommends not only working to increase public awareness of the NJCEED program, but also advocating for expanded funding for NJCEED to cover screening the eligible population, as well as treating those diagnosed.

While lack of adequate health insurance has been identified as a significant barrier to colorectal cancer screening, evidence suggests that even those with health insurance are not taking advantage of the proven benefits of screening. In 2005, only 52.3% of eligible adults with commercial health insurance and 53.9% of eligible Medicare recipients received any kind of colorectal cancer screening.[‡][35] Among the insured population, physician recommendation is a significant factor in colorectal cancer screening. Physicians should be provided with the tools to facilitate discussing colorectal cancer screening with their patients, including physician reminders, health maintenance flow sheets, prevention stickers and stamps, chart reminders, and shared responsibility among office staff.[36]

[†] Includes FOBT during the past 1 year; flexible sigmoidoscopy during the past 5 years; or colonoscopy or DCBE during the past 10 years.

[‡] Includes FOBT during the past 1 year; flexible sigmoidoscopy or DCBE during the past 5 years; or colonoscopy during the past 10 years.

GOAL CO-2	To increase colorectal cancer screening rates among New Jersey residents.

Objective CO-2.1

To increase colorectal cancer screening rates, particularly among the uninsured and underinsured population in New Jersey.

Strategies

CO-2.1.1 Partner with NJCEED to educate and change behaviors of target populations regarding measures available for prevention, detection, and treatment of colorectal cancer.

CO-2.1.2 Promote awareness of the NJCEED program and its services among New Jersey residents.

CO-2.1.3 Advocate for increased funding for screening and treatment under the NJCEED program.

Objective CO-2.2

To increase colorectal cancer screening rates among the insured population in New Jersey.

Strategies

CO-2.2.1 Assess the knowledge, attitudes, and practices of healthcare providers regarding colorectal cancer screening through a statewide survey.

CO-2.2.2 Promote the use of screening reminders and other interventions designed to increase colorectal cancer screening recommendations by physicians.

Research and Surveillance

Effective treatment for colorectal cancer at any stage is available and leads to improved survival and/or quality of life. Disparities in treatment and their causes need to be identified so remedies can be devised.[37] Outcomes of New Jersey residents with colorectal cancer can be improved by ensuring that high-quality care is available to all New Jersey residents with colorectal cancer. The Colorectal Cancer Workgroup proposes that high-quality colorectal cancer treatment in New Jersey be improved by increasing the number of patients enrolled in clinical trials.

Clinical trials are the major avenue for discovering, developing, and evaluating new therapies. However, only about 3% of all adult cancer patients participate in clinical trials. It is important to increase physician and patient awareness of, and participation in, clinical trials if we are to test new treatments more rapidly, find more effective treatments, and broaden the options available to patients.[38] New Jersey residents with colorectal cancer should have information about and access to clinical trials.

In 1999, members of the New Jersey Association of Health Plans, which represents the state's nine largest health insurers, agreed to voluntarily cover the routine healthcare costs of any of their members enrolled in a Phase I, II, and III approved cancer clinical trial. In addition, the year 2000 Medicaid contract includes this service, and payment has been authorized for routine costs of clinical trials under Medicare. However, this mandate is not carried over to all insurers, although all companies offering coverage in New Jersey have been invited to participate in the agreement. Patients should contact their insurer prior to entering a clinical trial to obtain specific information about covered benefits.[39]

The Colorectal Cancer Workgroup proposes that participation in clinical trials can be increased in New Jersey if awareness is heightened in the public and among professionals. Additionally, insurance coverage of treatment through clinical trials could be improved by increasing the number of insurance companies offering to cover clinical trial participation.

Ongoing surveillance of new and emerging prevention, early detection, and treatment modalities is important to ensure that physicians remain up to date on the most current methods to reduce the incidence and mortality of colorectal cancer. Virtual colonoscopy and capsule endoscopy, for example, are emerging technologies that are currently being studied for the early detection of colorectal cancer. Close monitoring of emerging data is integral to assessing the efficacy of the strategies set forth in this chapter.

GOAL CO-3	To increase the participation of persons with colorectal cancer in clinical trials.

Objective CO-3.1

To increase awareness of the availability and importance of clinical trials among New Jersey residents with colorectal cancer and their healthcare providers.

Strategies

CO-3.1.1 Promote participation in and enhance public visibility and understanding of important clinical trials for colorectal cancer.

CO-3.1.2 Promote medical professional training and education on clinical trials to ensure that physicians are able to convey information accurately on the need for and procedures for enrolling in clinical trials.

GOAL CO-4	To ensure that New Jersey residents and physicians remain up to date on the most currently available colorectal cancer technologies and resources.

Objective CO-4.1

To continue to monitor and disseminate current advances in colorectal cancer prevention, screening, diagnosis, and treatment.

Strategies

CO-4.1.1 Conduct periodic literature reviews to determine the state of the science in colorectal cancer research and to identify potentially promising new technologies.

CO-4.1.2 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through CME offerings.

Objective CO-4.2

To continue to monitor and disseminate current advances in colorectal cancer prevention, screening, diagnosis, and treatment.

Strategy

CO-4.2.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

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CHAPTER 7. GYNECOLOGIC CANCER

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CERVICAL CANCER

IMPORTANCE OF CERVICAL CANCER FOR CANCER PREVENTION AND CONTROL

Cervical cancer is a highly preventable and curable disease. Most cervical cancers develop over a relatively long period of time, allowing for early detection and treatment.[1,2] The Papanicolaou (Pap) test, which detects cervical cancer as well as pre-cancerous abnormalities, is the most common test used to screen for cervical cancer. The Pap test is widely available and covered by most insurance plans and government programs. Cervical cancer incidence and mortality rates have declined considerably (Figure 1), and screening rates have increased in the United States over time. Adenocarcinoma of the cervix, a more rare form of cervical cancer, has increased in incidence despite screening efforts. Even with the tremendous progress made with cervical cancer screening, it is estimated that 11,150 U.S. women will be diagnosed with cervical cancer and 3,670 will die from this disease in 2007.[1]

Deaths from cervical cancer began falling dramatically, beginning in 1970 with the development of screening programs utilizing the Pap test to detect cervical cancer in its early and most treatable stages.[1] However, nearly one-half of all U.S. women with invasive cervical cancer are diagnosed at a late stage.[3] Most cervical cancer deaths occur in women who have never had a Pap test.[4] Case control studies clearly demonstrate that women with invasive cervical cancer were less likely to have been screened,[5,6] and decreased mortality and incidence of invasive cervical cancer have been described in populations following implementation of Pap screening.[7] Compared to other cancers, cervical cancer is not a leading cause of mortality; however, it remains a priority and important issue because it is nearly 100% preventable with early detection and may now be preventable with human papillomavirus vaccines. It should be noted that cervical precancers add a significant financial and emotional burden to the healthcare system.

Infection with oncogenic (cancer-causing) types of human papillomavirus (HPV) is the most significant cause of cervical cancer. HPV DNA is present in 99% of cases involving cervical cancer and its precursor lesions.[8,9]

Obesity and tobacco use have also been shown to increase the risk of developing cancer of the cervix.[10,11] Research has shown that women from minority groups, especially populations of color, are at particular risk for the disease, as are women for whom access to routine healthcare services is at best a challenge and at worst non-existent.[12]

HPV is a virus with more than 100 types, over 30 of which infect the genital tract. Some non-oncogenic types of HPV can cause genital warts, while others may have no symptoms. There are approximately 15 oncogenic types of HPV. Women at risk for contracting HPV and subsequently developing cervical cancer are those who are or who ever have been sexually active, had an early onset of sexual intercourse, or have a history of multiple partners.[1,8,13] Up to 80% of women will contract some form of HPV by the age of 50, and approximately one-half of them will be infected with cancer-causing HPV.[14]

Although there is currently no cure for HPV infection, providers can treat the warts caused by non-oncogenic HPV types. Precancerous cell growths caused by oncogenic HPV types can also be treated, potentially preventing them from developing into cancer. However, given the availability of early detection and treatment procedures for cervical cancer, major risk factors for death are lack of appropriate screening and lack of prompt follow-up for abnormalities.[15]

In 2006, the U.S. Food and Drug Administration (FDA) approved the use of a quadrivalent vaccine to prevent infection by four of the most common types of HPV. The approved vaccine is designed to prevent infection from HPV types 16 and 18, which cause approximately 70% of all cases of cervical cancer worldwide; and types 6 and 11, which cause approximately 90% of all cases of genital warts.[16] A second vaccine designed with a novel adjuvant system to prevent infection from HPV types 16 and 18 is currently under review by the FDA. The CDC's Advisory Committee on Immunization Practices (ACIP) recommends the use of the quadrivalent vaccine in females aged 11 to 12, with catch-up vaccination recommended for females aged 13 through 26. The ACIP recommends no change in cervical cancer screening practices for females receiving the HPV vaccine.[16]

In October 2000, the federal government passed the Breast and Cervical Cancer Prevention and Treatment Act of 2000. It was adopted in New Jersey as of July 1, 2001. Under provisions of this Act, women who are qualified and screened using federal or state funds through the New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection Program (NJCEED), and who are diagnosed with breast or cervical cancer, are eligible for treatment under Medicaid. (See Appendix B for further information on NJCEED.)

Although Pap smear screening remains the best available method of reducing the incidence and mortality of invasive cervical cancer,[2] screening programs have not completely eradicated this cancer in any population.[17] Despite the recognized benefits of Pap smear screening, substantial subgroups of American women have not been screened or are not screened at regular intervals.[2] Reasons offered for failure to eradicate the disease have focused on either lack of regular screening or inadequate follow-up and treatment of precancerous changes found during routine screening.[1,12] Clearly needed are a better understanding of and increased attention to the reasons why women are not utilizing this screening procedure more effectively. With the availability of HPV vaccines, there are also questions as to the best method to utilize this preventive technology.

CERVICAL CANCER IN NEW JERSEY

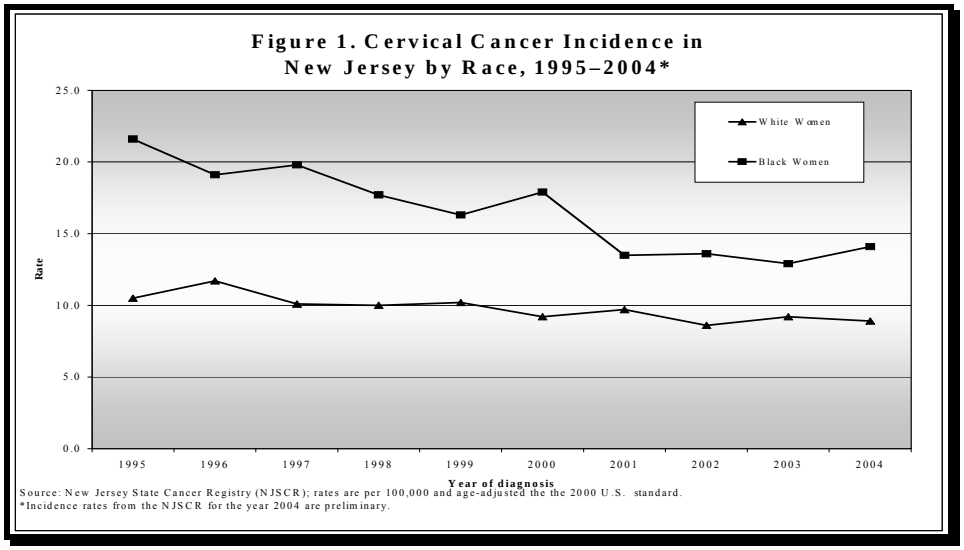
In this section we discuss the status of cervical cancer in New Jersey, including incidence, mortality, prevalence, survival, and screening.

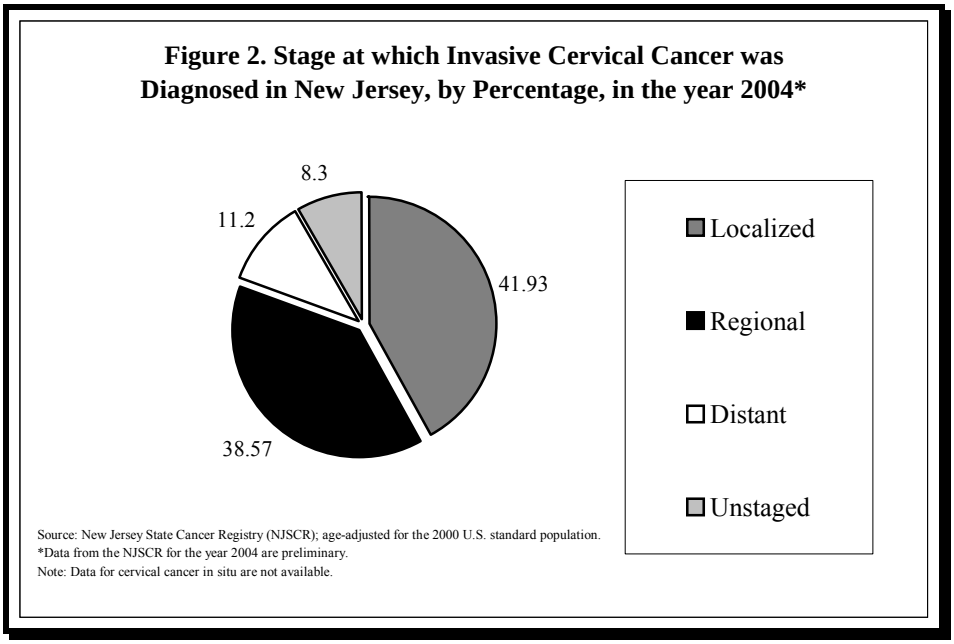
Incidence. The American Cancer Society estimates that, in 2007, there will be 350 new cervical cancer cases in New Jersey.[1] Since 1979 incidence rates for invasive cervical cancer have been decreasing in the U.S. and New Jersey. While the cervical cancer incidence rate (all races combined) in New Jersey has declined from 14.4 per 100,000** women in 1979 to 9.3 per 100,000** women in 2004*, population subgroups have experienced substantially different rates (Figure 1). Despite the decline in incidence rates, black women in New Jersey still had a higher incidence rate than did white women (14.1 versus 8.9 per 100,000**, respectively) in 2004*[18] (Figure 1).

*Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
**Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Of the 9.3 per 100,000** new cases of invasive cervical cancer diagnosed in 2004*, more than one-third (38.6%) were diagnosed at the regional stage, a stage at which these women statistically have only a 47% chance of surviving five years. In addition, 11.2% of new cervical cancer diagnoses are at the distant metastasis stage, a stage at which women statistically have only an 8% chance of surviving for five years (Figure 2).[18,19]

The rate of cervical cancer for Hispanic women in New Jersey has declined from 21.8 per 100,000** in 1995 to 16.3 per 100,000** in 2004* (Figure 2). Although the Hispanic rate has decreased, it is still almost twice as high as the non-Hispanic rate (8.6 per 100,000**).[18] Data from 2002 shows a slightly lower rate for U.S. Hispanic women (13.1 per 100,000**).[20]

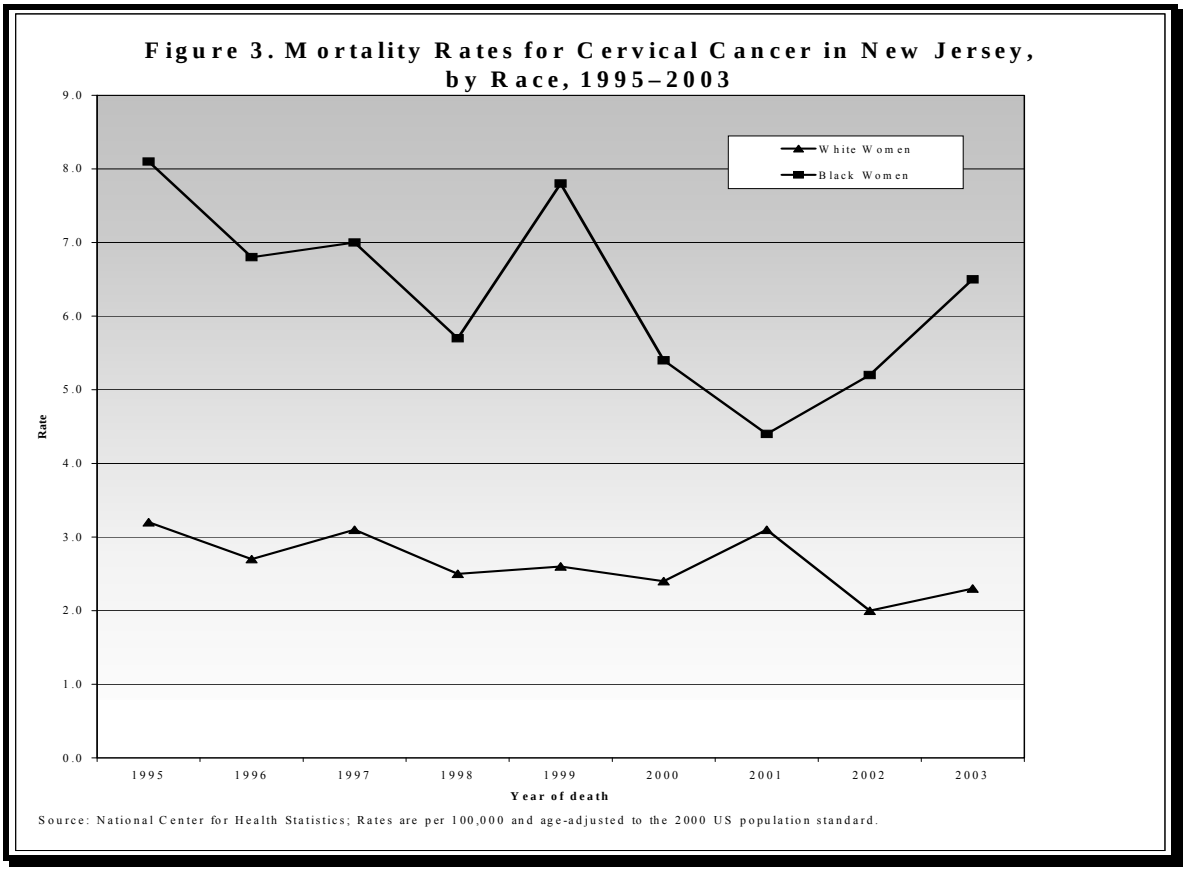




*Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
**Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Mortality. Mortality rates from cervical cancer in New Jersey and the U.S. generally have declined since 1995. Despite the overall decline in cervical cancer mortality in New Jersey, rates among black women were more than twice as high as the rates among white women. In 2003, the New Jersey mortality rates were 2.3 per 100,000** in white women and 6.5 per 100,000** in black women (Figure 3).[21]

Data from the New Jersey State Cancer Registry indicates that the patterns vary from those reported on incidence. The age-adjusted cervical cancer mortality rate among Hispanics during 1995–2003 was 3.1 per 100,000 Hispanic women, compared to 2.7 among white and 6.2 among black women. The cervical cancer mortality rate among Hispanics is lower than that among blacks, while the reverse is true for cancer incidence (Figure 3). This pattern is consistent with that observed for the rest of the U.S.[21]



Prevalence. Estimates indicate that on January 1, 2003, there were 9,184 or 0.2% of New Jersey women alive who had ever been diagnosed with cervical cancer. As with other cancers, the prevalence of cervical cancer increases with age and is highest in the 65+ age group (0.4%). The prevalence of cervical cancer is the same in whites and blacks (0.2%).[22]

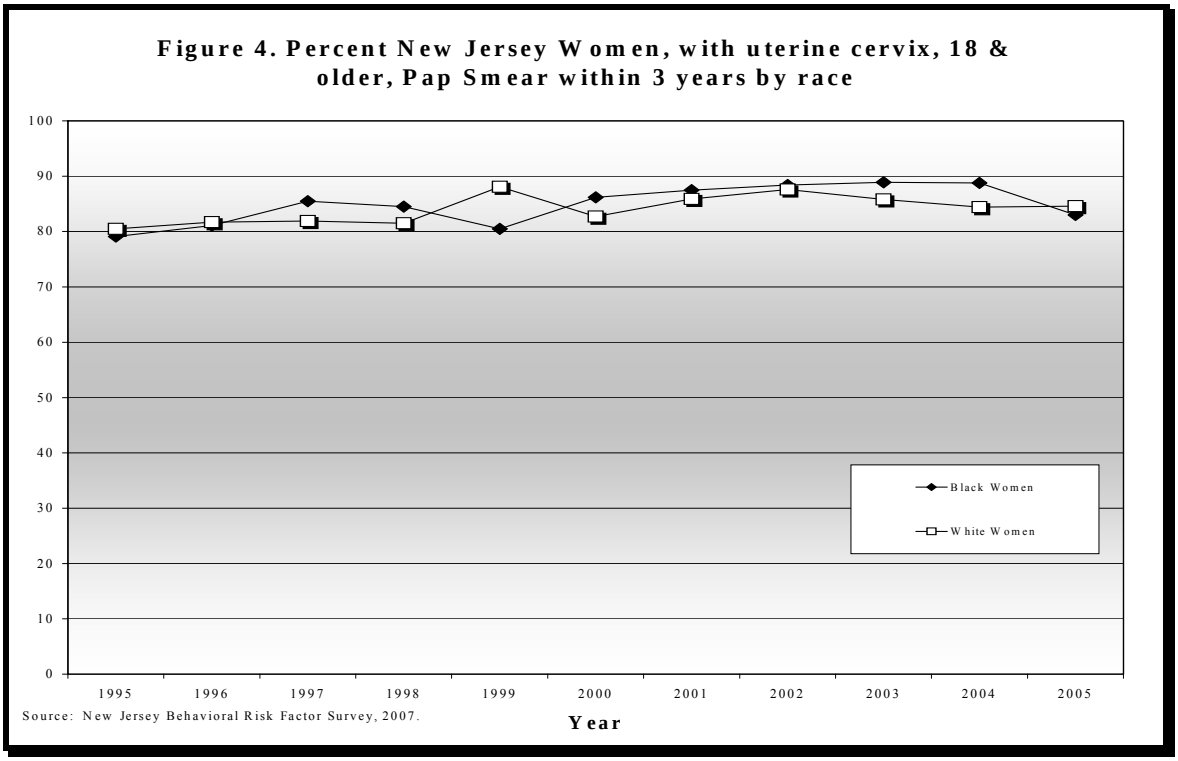
**Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Survival. The five-year survival rate for cervical cancer diagnosed in New Jersey from 1994–1997 is 66.3%. This rate is lower than the U.S. rate of 73.4%. Disparities in survival exist between black and white women. In New Jersey, as in the U.S., black women have a lower survival rate than do white women (58.5% versus 68.1%, respectively).

Cervical cancer survival rates are much higher for cancers diagnosed at the local stage than at the regional or distant stage. For example, in New Jersey from 1994–1997, the five-year survival rate for local-stage cervical cancer was 87.2%, whereas that for regional-stage was 46.6% and for distant-stage, 7.6%.[23]

Screening. Although the screening rates for women reported in various national studies are generally high, they vary across subgroups. Women at highest risk for cervical cancer are least likely to utilize screening.[24] National data from the 2004 Behavioral Risk Factor Surveillance Survey (BRFSS) indicate that 84.3% of all women aged 18 years and older reported having had a Pap test within the previous three years.[25] New Jersey reported rates for having had a Pap test within the past three years are lower for white women (84.4%) than for black women (88.8%) and Hispanic women (87.0%) (Figure 4). The proportion of women who report having had a Pap test within the past three years declines rapidly after age 64; rates are 88.0% for women 18 to 49, 87.2% for women 50 to 59, 83.5% for women 60 to 64, and 66.6% for women aged 65 or older.[26]

The high rates of screening in all populations (Figures 4) are nevertheless inadequate when one considers the effectiveness of the Pap test in reducing incidence and mortality from cervical cancer. Although New Jersey black women report receiving Pap tests at higher rates than white women, the incidence and mortality rates of invasive cervical cancer are much higher in black women. Equal targets have been set by Healthy New Jersey 2010 for all tracked populations to decrease the disparity in the incidence rate of cervical cancer discovered at the more serious late stage.



WHAT CAN BE DONE ABOUT CERVICAL CANCER IN NEW JERSEY?

Until the recent FDA approval of the vaccine to prevent HPV infection, screening and early detection were the most effective approaches to lowering cervical cancer incidence and mortality rates. Although screening and early detection continue to be important in effecting a reduction in the burden of disease, comprehensive cervical cancer control must also aim to educate the public about the benefits of vaccination against HPV.

While widespread use of the HPV vaccine carries the potential to reduce cervical cancer incidence and mortality significantly, a focus on screening, addressing barriers to screening, and follow-up care must continue. HPV infects an estimated 64% to 82% of sexually active adolescent girls, many of whom are at an increased risk of developing cervical cancer.[27]

To these ends, the Gynecologic Cancer Workgroup of the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey has devised strategies that include numerous opportunities for those from high-risk populations to work side by side with representatives of medical specialties, nursing, allied health professional groups, voluntary health organizations, healthcare systems, public health entities, and other interested parties to address barriers to vaccination as well as to screening and early detection.

The Gynecologic Cancer Workgroup believes that the accomplishment of the goals, objectives, and strategies outlined in this chapter will have a positive and lasting impact on the health of the affected populations and, ultimately, will lower the social, personal, and economic toll cervical cancer exacts from the citizens of New Jersey.

HEALTHY NEW JERSEY 2010 GOALS

Healthy New Jersey Goal 1	Increase the percentage of women aged 18 and over with intact cervix uteri who had a Pap test within the past two years to 75.0% for females 65+, and 85.0% for all other groups, by 2010.

Table 1. Percentage of women aged 18 and over with intact cervix uteri who had a Pap test within the past two years, New Jersey, 2000–2003, and Healthy New Jersey 2010 projected target rates.

Population	2000	2001	2002	2003	Target	Preferred 2010 Endpoint
Total	78.8	79.8	82.0	80.9	85.0	90.0
White	79.3	81.8	84.0	81.6	85.0	90.0
Black	81.2	83.2	85.6	86.2	85.0	90.0
Hispanic	78.6	77.7	75.2	78.9	85.0	90.0
Asian/Pacific Islander*	**	**	57.8	61.6	***	***
Females 65+	57.2	66.2	65.0	59.2	75.0	85.0

Source: New Jersey Department of Health and Senior Services, Center for Health Statistics, Healthy New Jersey 2010: Update 2005
* *Estimate has a relatively large standard error.*
** *Estimate is unreliable.*
*** *A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander include Hispanics and non-Hispanics.

Healthy New Jersey Goal 2	Reduce the age-adjusted incidence rate of invasive cervical cancer in females per 100,000 standard population to 6.8, by 2010.

Table 2. Age-adjusted incidence rate of invasive cervical cancer, New Jersey, 1999–2002, and projected Healthy New Jersey 2010 target rates.

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
Total	10.5	9.9	10.0	9.1	6.8	2.7
White	10.1	9.1	9.7	8.3	6.8	2.7
Black	16.3	17.5	13.2	13.9	6.8	2.7
Hispanic	16.3	13.9	14.6	15.4	**	**
Asian/Pacific Islander	*	*	*	*	**	**

Source: New Jersey Department of Health and Senior Services, Center for Health Statistics, Healthy New Jersey 2010: Update 2005
* *The number of Asian/Pacific Islander cases is known to be understated.*
** *A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander include Hispanics and non-Hispanics.

Healthy New Jersey Goal 3	Reduce the age-adjusted death rate from cervical cancer per 100,000 standard population to 1.6 for all females (age-adjusted), 1.6 for white females (age-adjusted), 6.0 for black females (age-adjusted), and 6.5 for females age 65+, by 2010.

Table 3. Age-adjusted death rate from cervical cancer, New Jersey, 1999–2002, and Healthy New Jersey 2010 projected target rates.

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
Total	3.2	2.8	3.1	2.3	1.6	0.8
White	2.6	2.4	3.1	2.0	1.6	0.8
Black	7.7	5.4	4.4	5.1	6.0	0.8
Hispanic	*	*	*	*	**	**
Asian/Pacific Islander	*	*	*	*	**	**

Source: New Jersey Department of Health and Senior Services, Center for Health Statistics, Healthy New Jersey 2010: Update 2005
** The number of Hispanic and Asian/Pacific Islander deaths is known to be understated.*
*** A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander include Hispanics and non-Hispanics.

GOALS, OBJECTIVES, AND STRATEGIES FOR CERVICAL CANCER

In support of the Healthy New Jersey 2010 goals for cervical cancer, the recommendations of the Gynecologic Cancer Workgroup are summarized below for the following focal areas:

- Access to care
- Public awareness and education
- Patient awareness and education
- Professional awareness and education
- Research and surveillance
- Prophylactic HPV vaccination

ACCESS TO CARE

Cervical cancer incidence and mortality can be reduced effectively through adherence to the ACIP recommendations for HPV vaccination, as well as early detection using the Pap test. The decline in death rates from cervical cancer in the United States thus far has been widely attributed to use of Pap tests for early detection.[1] The Pap test is routinely performed by a wide range of health professionals, obstetrician/ gynecologists, family physicians, internists, nurse practitioners, physician assistants, certified nurse midwives, and nurses working in hospitals, clinics, offices, and industrial settings in private and public sectors. The HPV vaccine has the potential to eliminate 70% of cervical cancer cases, and researchers expect to see an eventual decline in both cervical cancer incidence and mortality with its widespread use.[25,28]

New Jersey Public Law 1995, Chapter 415 requires health service, hospital service, and medical service corporation contracts, as well as group health insurance policies (providing hospital or medical expense benefits for groups with greater than 49 persons) to provide coverage for Pap tests.[29,30] This law also applies to health maintenance organizations in the state.

Additionally, NJCEED sites provide free cervical cancer screening to those who qualify (Appendix B). However, as discussed above, many New Jersey women are not being screened consistently (Figure 3).

Lack of awareness of risk factors, cost, hassles with the healthcare system, prevention not being a priority, inconvenience of professional services, language, transportation, childcare, cultural sensitivity, and feelings of embarrassment and discomfort related to the Pap test have been identified as barriers to cervical cancer screening among New Jersey women. Many women are unaware that risk increases with age.[31,32] This fact is reflected in the decrease in screening rates after age 50. Similar barriers were also identified in nationwide studies and varied across subpopulations—lack of knowledge about cervical cancer and the need for regular screening, fear of finding cancer, and embarrassment about screening are negatively associated with screening.[33,34]

In addition to identifying barriers to access to cervical care, we need to better understand what populations are not receiving adequate care. Although some data have been compiled to determine the characteristics of the underserved populations, these data are largely incomplete.[35] The Gynecologic

Cancer Workgroup proposes that populations at highest risk in New Jersey be identified and investigated to determine why they are not being screened for cervical cancer.

Once the high-risk populations for New Jersey have been identified, specific programs for screening, education, and treatment must be identified or developed. Specific populations without direct access to cervical cancer screening can be identified and solutions developed. Recognizing that this plan is merely a point of departure in the drive to reduce cervical cancer incidence and mortality by increasing screening rates, the Gynecologic Cancer Workgroup proposes the following goal, objectives, and strategies to improve access to cervical cancer screening and treatment.

GOAL GY-1	To improve access to cervical cancer screening and treatment in New Jersey.

Objective GY-1.1

To identify populations not being screened for cervical cancer in New Jersey.

Strategy

GY-1.1.1 Use Geographic Information Systems (GIS) technology and other appropriate methods to identify and map population subgroups with a high risk for developing cervical cancer.

Objective GY-1.2

To increase access to cervical cancer screening and treatment for New Jersey populations identified as high risk.

Strategies

GY-1.2.1 Identify and refer New Jersey populations to existing programs for screening, education, and treatment for cervical cancer.

GY-1.2.2 Develop solutions for those not qualified for existing New Jersey programs to enable them to obtain Pap smears/pelvic exams and/or treatment by seeking additional funding, finding sources of care, and finding sources of insurance.

PUBLIC AWARENESS AND EDUCATION

Awareness of risk factors was identified earlier as a barrier to cervical cancer screening in New Jersey women. Many women fail to recognize age as a risk factor and believe that women in higher age groups are too old to contract cervical cancer. Evidence suggests that postmenopausal women may underestimate their risk of cervical cancer and therefore forgo routine Pap tests. Other common misconceptions include the belief that poor personal hygiene is risk factor for cervical cancer and that Pap tests are only necessary if a woman is currently engaging in sexual activity.[31]

Data from the New Jersey Behavioral Risk Factor Survey indicate that, in 2004, approximately 15.6.% of New Jersey females (over 18 with an intact cervix) had not had a Pap test in the past three years.[26] The screening rate has not shown significant improvement over the past several years (Figures 4). According to a recent study, the most common reason women report for not having had a recent Pap test (in the past 3 years) is that a doctor did not recommend it. Other reasons include expense and lack of awareness of the need for the test.[36]

To combat the lack of education and awareness in New Jersey, NJCEED is one of several programs that provide education about cervical cancer screening and treatment. NJCEED emphasizes education for risk factors, screening/early detection practices, and treatment regimens in order to provide New Jerseyans with sufficient information to make informed choices about cancer screening and treatment.[37] Research has shown that the rate of cervical cancer screening can also be increased through worksite education programs and peer interventions.[38]

To address these issues, the Gynecologic Cancer Workgroup proposes that a public education program be developed and disseminated to all New Jersey women. It is recommended that community-based approaches be used to reach diverse populations and that these approaches include reliance upon community leaders and community members to assess attitudes and concerns prior to instituting education programs. Culturally sensitive and linguistically compatible staffing for outreach and education programs is a key component.[2]

In addition to educational programs, the workgroup proposes that insurance companies educate their clients about screening, which will ultimately reduce health care costs by preventing invasive cervical cancer or diagnosing cervical cancer at earlier stages. The workgroup further proposes that patient compliance with screening guidelines, a behavior-driven issue, can be ingrained at an earlier age by educating school-aged young women using progressive and appropriate materials.

Most importantly, the Gynecologic Cancer Workgroup notes that these steps represent only a beginning in a comprehensive approach to cervical cancer prevention and control in New Jersey and that thorough evaluation of programs and continuous quality improvement methods will help the public education component of this plan evolve.

GOAL GY-2	To increase public awareness and education about cervical cancers among all women, especially increased-risk populations.

Objective GY-2.1

To educate the public about cervical cancer by using culturally sensitive educational materials and programs to reach all women, especially those at increased risk.

Strategies

GY-2.1.1 Identify, and develop where needed, educational materials and programs that are effective for populations with an increased risk of cervical cancer, including media campaigns, key spokespeople, and enhancing events during Cervical Cancer Awareness Month (currently in January).

GY-2.1.2 Outreach to increased-risk populations with culturally sensitive, cervical cancer educational materials and programs by partnering with key people, other social/intervention/entitlement programs, federal and state agencies, local organizations, and businesses that work within the areas and populations identified.

GY-2.1.3 Design a progressive, age-appropriate cancer prevention core curriculum in schools, stressing the importance of cervical cancer screening and early detection, especially targeting populations at increased risk as identified above.

GY-2.1.4 Encourage insurance companies to educate their clients, especially high-risk individuals, about cervical cancer screening and early detection through the use of reminder systems and distribution of educational materials.

Patient Awareness and Education

While public education is an important means to increase awareness of cervical cancer, the HPV vaccine, and the need for screening, patient education is equally important as a means to increase awareness of rescreening, follow-up, and treatment options.

Receiving notification of abnormal test results often has negative psychological consequences on the patient and, unless addressed, may result in failure to comply with both treatment and future screening tests. Special intervention procedures that make use of telephone calls or in-person visits to find and remind women to return for follow-up have obtained compliance rates of 33% to 95%.[39] Barriers, such as cost of follow-up treatment, beliefs about cancer, lack of trust in the medical system, lack of access to transportation, perceived conflicts with a partner, and staff attitudes at healthcare facilities, all contribute to patients' reactions to abnormal test results and may influence whether follow-up recommendations are followed.[40]

Educational resources specifically addressing the importance of rescreening, timely follow-up, and treatment options must consider the patient as the receiver of the communications. Consideration should be given to developing and using strategies to communicate with patients with varying demographic characteristics, such as years of education and literacy. The communication provided could greatly affect the psychosocial impact on the woman from hearing the results and her willingness to seek further care.[12] The Gynecologic Cancer Workgroup proposes that different modes of education be utilized to address all populations, including media, computer, and paper-based materials.

There is strong evidence that women experience significant anxiety and stress when informed of abnormal results.[40] The method and manner of notification can often mediate these reactions. Upon receipt of laboratory results, the provider has the responsibility of informing the patient. The usual methods of notification are in writing, over the telephone, or in person. Written forms, usually letters or post cards, may not be understandable to the patient because of the reading level of the message or because of terminology that is foreign or not clearly defined.[41] Telephone counseling is more costly but could be used in explaining serious cases and might reduce the chance of severe psychological reactions to test results. Method of communication should be carefully considered and measured for effectiveness when reaching out to women about follow-up care.

Another method to improve rescreening and follow-up is to increase the effectiveness of follow-up after abnormal Pap tests. Research has shown that cognitive interventions utilizing interactive counseling improve compliance by 24% to 31%. Behavioral interventions, such as patient reminders, increase follow-up by 18%.[42]

To begin to increase patient awareness about the importance of cervical cancer rescreening, follow-up care, and treatment options, the Gynecologic Cancer Workgroup proposes that patients be educated using multi-media interventions that are updated continuously. Additionally, the workgroup proposes that current systems for Pap test result notification and patient reminder systems be evaluated and the best systems shared with healthcare professionals in New Jersey. To accomplish these goals, the Gynecologic Cancer Workgroup recommends the following goal, objective, and strategies as important next steps.

GOAL GY-3	To improve patient education about cervical cancer, screening, follow-up care, and treatment options, including clinical trials.

Objective GY-3.1

To educate patients about cervical cancer, screening guidelines, follow-up care, and treatment options at all medical facilities where they may seek medical attention, including but not limited to healthcare providers, hospitals, clinics, and health departments.

Strategies

GY-3.1.1 Make educational brochures and posters on guidelines, risk factors, and symptoms for cervical cancer available to appropriate healthcare professionals for display at medical facilities. Provide contact information for reordering.

GY-3.1.2 Survey medical facilities and laboratories to learn about the methods they use to notify patients of their Pap smear results, particularly to determine whether they use an electronic follow-up/diagnostic Pap test reminder and, if so, what methodology they employ for this system and how well it works. Based on survey findings, determine the method(s) easiest for patients to understand, and encourage the appropriate medical facilities and laboratories to implement these methodologies.

Professional Awareness and Education

The Gynecologic Cancer Workgroup identified Professional Education as the third arm of the education recommendations. Issues identified included the importance of physician referrals and the high error rate of Pap tests. To improve cervical cancer incidence and mortality in New Jersey, the Gynecologic Cancer Workgroup proposes solutions to each of these issues.

It has been estimated that 10% to 61% of women with abnormal Pap smears fail to comply with follow-up recommendations.[43] Appropriate follow-up and treatment may not occur because of issues of patient education and understanding, provider promotion, psychological distress, access, or cost.[12,43]

As with screening for other cancers, a physician recommendation is a very strong motivator for obtaining a Pap test.[36,44,45] In a recent study, 87% of unscreened, eligible women who had had a doctor visit in the past year reported that their physician did not recommend a Pap test.[44] These findings suggest that, although women are visiting physicians and are open to receiving medical advice, recommendations are not provided consistently. Reasons for lack of physician recommendation include *provider characteristics*, such as knowledge of the guidelines, specialty, gender, time constraints, forgetfulness, and inconvenience; *patient characteristics*, such as age and perceived refusal; and *provider constraints*, such as lack of supplies and cost of the test.[45,46] Given the importance of physician recommendation in patient adherence to cervical cancer screening guidelines and the demonstrated lack of adequate recommendation, the Gynecologic Cancer Workgroup proposes that healthcare professionals continue to receive education and materials designed to increase their awareness of cervical cancer and the importance of discussing screening with patients.

The Gynecologic Cancer Workgroup further recommends that a comprehensive cancer assessment be a standard component of the patient chart to assure that patients are receiving cancer education and screenings as appropriate.

A successful screening program must also emphasize accuracy in diagnosis. The effectiveness of the Pap test depends heavily on proper sample collection, submission, and interpretation by trained professionals.[47] A single Pap test has a false-negative rate estimated to be between 15% and 30%.[2,48] False negatives can be due to inadequate specimen sampling, failure to identify the abnormal cells or to interpret them correctly.[47] At least one-half to two-thirds of false negatives are the result of patient

conditions present at the time of sample collection and submission and the skill and knowledge of the individual who obtains the sample.[49] Encouraging improvements in sampling technique and laboratory accuracy represent an opportunity to reduce incidence and mortality from cervical cancer.

Attention has been focused on quality control in cytopathology laboratories in an attempt to reduce the problem of false negative Pap tests.[47,50] The quality of the reading of the test is primarily dependent upon the level of expertise of those interpreting the slide. Cytotechnologists are in high demand and short supply and, because of salary competition, the workforce is quite mobile. Any shortages are likely to impact negatively on the turn-around time for receiving Pap test results and can possibly overburden existing staff.[12,50] The Clinical Laboratory Improvement Amendments (CLIA) of 1988 applied workload limits to slides screened per hour in any given 24-hour period. Cytotechnologists may examine up to 100 slides per 24 hours (average 12.5 slides/hour) and in not fewer than eight hours.[49] In accordance with recommendations by the Agency for Healthcare Research and Quality, the Gynecologic Cancer Workgroup proposes that screening rates be monitored to ensure compliance with the workload limits established for each individual.

One critical aspect of quality assurance in cervical cytology is communication of cytopathologic findings to the referring physician in unambiguous diagnostic terms that have clinical relevance. In the past, terminology used has been varied, resulting in confusion about the clinical implications of reports. The Bethesda System for reporting the results of cervical cytopathology was developed in 1991 as a uniform system of terminology that would provide clear guidance for clinical management.[51–53] In 2001, the Bethesda System was updated to reflect increased utilization of new technologies and findings from research.[53] More than 90% of U.S. laboratories use some form of the Bethesda System in reporting cervical cytology.[54] In accordance with the National Institutes of Health, the Gynecologic Cancer Workgroup encourages the use of the Bethesda System 2001 as a method to increase uniformity of Pap smear reporting and decrease error.[2]

CLIA 1988 regulations specify that at least 10% of samples interpreted as negative by each cytotechnologist be rescreened by a pathologist or a qualified supervisory cytotechnologist prior to reporting. Specimens from women considered to be at increased risk for cervical cancer must be included in the review process.[49] Recent developments[55] in specimen processing and interpretation may substantially improve the Pap smear as a diagnostic test for cervical cancer and cancer precursors. Thin-layer cytology aims primarily to fix sampling error, whereas computerized rescreening targets detection error.[50] Thus, the Gynecologic Cancer Workgroup recommends that continuous quality improvement methods be increased to further decrease error rates.

By implementing the following goal, objectives, and strategies to educate providers and decrease error rates, the Gynecologic Cancer Workgroup hopes to decrease incidence and mortality from cervical cancer in New Jersey.

GOAL GY-4	To increase the awareness of healthcare professionals concerning cervical cancer, risk factors, screening guidelines, follow-up, and treatment options.

Objective GY-4.1

To educate healthcare professionals about the importance of cervical cancer, screening, risk factors, follow-up, treatment options, and cultural sensitivity.

Strategies

GY-4.1.1 Identify, or develop as needed, cervical cancer educational brochures appropriate for dissemination among healthcare providers.

GY-4.1.2 Partner with professional organizations to offer incentives to healthcare professionals for completion of cervical cancer educational modules/in-services. This can be in the form of CME credits and/or recognition.

GY-4.1.3 Survey general practitioners, obstetricians/gynecologists, family practice physicians, internists, and advanced practice nurses to identify providers who administer a "health assessment survey" to capture patient history of Pap smears, as well as other cancer screening and regular check-ups. Based on survey findings, develop and distribute a standardized "health assessment survey" to all general practitioners, obstetricians/ gynecologists, family practice physicians, internists, and advanced practice nurses for possible adoption.

GY-4.1.4 Disseminate clinical guidelines for cervical cancer screening and follow-up to appropriate healthcare providers.

Objective GY-4.2

To improve sampling techniques, supporting methods, and follow-up after abnormal Pap smears.

Strategies

GY-4.2.1 Educate clinicians on optimal conditions for obtaining a Pap smear and appropriate methods for collecting and handling Pap smears.

GY-4.2.2 Recommend that laboratories standardize the system for reporting cervical cytopathology results using Bethesda 2006.

RESEARCH AND SURVEILLANCE

The recent FDA approval of the HPV vaccine to prevent cervical cancer is evidence of the important role of research in reducing morbidity and mortality from cancer. Continued cervical cancer research is warranted in many areas, including the areas of behavior change, improving accuracy and interpretation of cytologic sampling techniques, molecular biomarkers for early detection, screening methods, and HPV vaccine implementation.

Clinical trials are the major avenue for discovering, developing, and evaluating new therapies. However, only about 3% of all adult cancer patients participate in clinical trials. It is important to increase physician and patient awareness of, and participation in, clinical trials if we are to test new treatments more rapidly, find more effective treatments, and broaden the options available to patients.[56]

Research must be conducted to learn why New Jersey women do not participate in clinical trials. Then, solutions to the barriers must be addressed. The Gynecologic Cancer Workgroup suggests the following goal, objectives, and strategies as next steps.

GOAL GY-5	To foster the development of and to improve awareness of clinical research for cervical cancer and increase participation in clinical research available in New Jersey and/or available to New Jersey residents.

Objective GY-5.1

To attract and encourage participation in new and existing clinical research in New Jersey and/or available to New Jersey residents, especially in preventive and treatment measures in cervical cancer.

Strategies

GY-5.1.1 Link the state website to agencies such as NJ Cancer Trial Connect (www.njctc.com) to make cervical cancer clinical trials more accessible to New Jersey residents.

GY-5.1.2 Collaborate with key associations/organizations to publicize cervical cancer clinical trials in New Jersey.

GY-5.1.3 Outreach to healthcare providers and community leaders to improve client participation in cervical cancer clinical trials.

GY-5.1.4 Collaborate with the New Jersey Commission on Cancer Research and others to support cervical cancer clinical trials in New Jersey.

GOAL GY-6	To ensure residents and healthcare professionals of New Jersey remain up-to-date on the most currently available cervical cancer technologies and resources.

Objective GY-6.1

To continue to monitor and disseminate current advances in cervical cancer prevention, screening, diagnosis, and treatment.

Strategies

GY-6.1.1 Conduct periodic literature reviews to determine the state of the science in cervical cancer research and to identify potentially promising new technologies.

GY-6.1.2 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through CME offerings.

Objective GY-6.2

To continue to monitor trends in cervical cancer incidence, mortality, and survival.

Strategy

GY-6.2.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

PROPHYLACTIC HPV VACCINES

The first quadrivalent HPV vaccine was approved by the FDA in 2006 for use in the U.S. A second, bivalent, HPV vaccine is in development with approval sought in 2007. These vaccines both protect against the two most common HPV types implicated in cervical cancer worldwide, types 16 and 18, which are responsible for approximately 70% of cervical cancers globally. The quadrivalent vaccine also includes protection against HPV types 6 and 11, responsible for more than 80% of genital warts.[57]

The Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices recommends routine vaccination with three doses of quadrivalent HPV vaccine for females 11–12 years of age. The vaccination series can be started in females as young as 9 years of age. Catch-up vaccination is recommended for females 13–26 years of age who have not been vaccinated previously or who have not completed the full vaccine series. Ideally, the vaccine should be administered before potential

exposure to HPV through sexual contact. The quadrivalent vaccine should be administered before onset of sexual activity (i.e., before women are exposed to the viruses), but females who are sexually active should still be vaccinated.[16]

While studies have shown that young women, parents, and healthcare providers are interested in the HPV vaccine, barriers to vaccine program implementation may yet be encountered.[58] Vaccine acceptability is largely associated with knowledge of HPV and the associated risks. However, awareness of HPV is not improving. A recent study found that 33% of women and 50% of men had never heard of HPV.[59]

Surveys have found that many young women are interested in receiving the HPV vaccine. Factors associated with vaccine acceptance include knowledge about HPV and the vaccine; perceived peer approval; high number of sexual partners; and perceived provider, partner, and parental approval.[59] However, awareness of HPV is lacking. These results support the need to educate young women about the risks associated with HPV and the benefits of vaccination.

Due to the sexual nature of HPV infections, vaccine implementation may encounter unique barriers to parental consent. In addition to barriers against other vaccines, such as concern over side-effects, religious, or philosophical objections, parents may fear that vaccination against a sexually transmitted infection (STI) may encourage their adolescent daughters to engage in sexual activity.[58–60] This fear, however, is unfounded. Evidence suggests that widespread HPV vaccination will not alter sexual practices.[25]

Evidence also suggests that when parents are educated about HPV and the HPV vaccine, they are significantly more likely to be in favor of HPV vaccination.[59] Factors that may increase parental acceptance of HPV vaccination include school requirements[59]; physician endorsement[58,59]; knowledge of HPV[58,59]; and personal attitudes and beliefs.[58,59,61,62]

Recommendations by healthcare professionals and professional organizations have been identified as a significant factor in parental acceptance of HPV vaccination. However, healthcare professionals may be reluctant to recommend the vaccine to the parents of preadolescent girls due to perceived parental attitudes. Educational efforts aimed at healthcare professionals have been shown to be effective in increasing vaccine acceptance.[59]

GOAL GY-7	To improve awareness and encourage utilization of the HPV vaccine in the indicated populations.

Objective GY-7.1

To determine a strategy for HPV vaccine implementation in New Jersey.

Strategies

GY-7.1.1 Partner with stakeholders to inform providers of the ACIP recommendations regarding HPV vaccines.

GY-7.1.2 Advocate for the Vaccines for Children program to cover the cost of the vaccine.

GY-7.1.3 Encourage managed care organizations operating within the state to offer vaccination for their insured.

GY-7.1.4 Partner with the New Jersey Department of Education to promote education through core curriculum standards.

GY-7.1.5 Advocate for access to HPV vaccination for age-appropriate populations, especially those who are uninsured or underinsured.

Objective GY-7.2

To educate healthcare professionals about the importance of recommending HPV vaccination for eligible patients.

Strategies

GY-7.2.1 Identify, or develop as needed, HPV vaccine educational brochures appropriate for dissemination among healthcare providers.

GY-7.2.2 Partner with professional organizations to offer incentives to healthcare professionals for completion of HPV vaccine educational modules/in-services. This can be in the form of CME credits and/or recognition.

Objective GY-7.3

To educate parents and young women about the risk of HPV-associated disease and the benefits of vaccination.

Strategies

GY-7.3.1 Identify, and develop where needed, educational materials and programs that are effective for the target population.

GY-7.3.2 Partner with other stakeholders to outreach to the target populations with HPV educational materials and programs.

GY-7.3.3 Encourage insurance companies to educate their clients about HPV vaccination through the use of reminder systems and distribution of educational materials.

OVARIAN CANCER

IMPORTANCE OF OVARIAN CANCER FOR CANCER PREVENTION AND CONTROL

Ovarian Cancer is the seventh leading cause of cancer (excluding cancers of the skin) and the fifth leading cause of cancer death among women in the U.S. It is estimated that 22,430 new cases of ovarian cancer will be diagnosed nationwide in 2007, and 15,280 women will die of the disease. Ovarian cancer is responsible for more deaths than any other gynecologic cancer. A woman has a 1.7% chance of developing ovarian cancer over her lifetime.[1,63,64]

While 93% of women diagnosed with ovarian cancer in the early, localized stage survive five years beyond diagnosis, less than 20% of cases are found early. Women diagnosed with regional- and distant-stage ovarian cancer have five-year relative survival rates of 68% and 30%, respectively.[1,63]

Factors that act to increase a woman's risk of developing ovarian cancer include age, hereditary factors, a personal or family history of ovarian or breast cancer, nulliparity (bearing no children), physical inactivity, a diet high in animal fats and low in fruits and vegetables, and smoking.[65–69] Research has shown that using oral contraceptive pills (OCP) reduces the risk of ovarian cancer.[65,70]

It is a myth that ovarian cancer is most often asymptomatic. Many women diagnosed with ovarian cancer recall experiencing symptoms of the disease several months before diagnosis. However, they were usually unaware that the symptoms could be associated with ovarian cancer.[71] Symptoms of ovarian cancer may include enlargement of the abdomen; abdominal bloating or pain; abnormal vaginal bleeding (rarely); fatigue; change in bowel habits, digestive disturbances, or inability to eat normally; pelvic pain; constipation; back pain and urinary frequency or incontinence; and unexplained weight loss or gain. Symptoms are usually sudden and persist despite home treatment. However, often these symptoms are not recognized as cause for concern, and many patients and healthcare professionals attribute them to other conditions.[69,72,73]

There currently exists no effective screening mechanism to detect ovarian cancer. Contrary to what many women believe, the Pap test, which screens for cervical cancer, is not effective in detecting ovarian cancer. Because ovarian cancer often has no significant signs or symptoms until the later stages, it is difficult to diagnose the disease in its earliest stages when it is most treatable.

OVARIAN CANCER IN NEW JERSEY

In this section we discuss the status of ovarian cancer in New Jersey, including incidence, mortality, prevalence, survival, and screening.

Incidence. In 2004, there were 677 cases of invasive ovarian cancer diagnosed in New Jersey. White women have consistently higher age-adjusted ovarian cancer incidence rates than do black or Hispanic women (13.9 versus 10.1 and 11.5 per 100,000, respectively, in 2004)[18] (Figure 5). Between 1979 and 2003, ovarian cancer incidence rates declined more than 20% to just under 15 per 100,000 in 2003. [†][71]

[†] Part of the decreases in 2001 through 2003 are due to borderline ovarian cancer cases not being included because of a change in the coding rules between the second and third editions of the International Classification of Diseases for Oncology (ICD-O).

Despite this decline, however, New Jersey ovarian cancer incidence rates in 2003 (all races and ethnicities combined) was slightly higher than those of the U.S. as a whole (14.4 versus 13.0, respectively).[18,74]

Mortality. In 2003, there were 512 ovarian cancer deaths in New Jersey. From 1979 through 2003, ovarian cancer mortality rates remained fairly stable, though slightly higher than the U.S. rate. The New Jersey mortality rate in 2003 was higher for white women than for black and Hispanic women (10.3 versus 7.6 and 4.9 per 100,000**, respectively) (Figure 6).[21]

Prevalence. Estimates indicate that on January 1, 2003, there were 6,059 or 0.1% of New Jersey women alive who had ever been diagnosed with ovarian cancer. As with other cancers, the prevalence of ovarian cancer increases with age and is highest in the 65+ age group (0.4%). The prevalence of ovarian cancer is twice as high in whites as in blacks (0.2% versus 0.1%, respectively).[22]

Survival. The five-year relative survival rate for ovarian cancer diagnosed in New Jersey from 1994–1997 is 49.3%. This rate is higher than the U.S. rate of 44.6%. Disparities in survival exist between black and white women. In New Jersey, as in the U.S., black women have a lower survival rate than do white women (44.8% versus 49.6%, respectively).[23]

New Jersey specific survival data for ovarian cancer by stage are not available. However, as with other cancers, ovarian cancer survival rates are much higher for cancers diagnosed at the local stage than at the regional or distant stage. According to the American Cancer Society, when diagnosed at the local stage, the five-year relative survival rate is 94%.[1] Similar to the U.S., only about 17% of ovarian cancers in New Jersey are diagnosed at the local stage.[18] Survival rates also vary by age, with women younger than 65 being about twice as likely to survive five years following diagnosis than women 65 and older, 57% and 28%, respectively.[1]

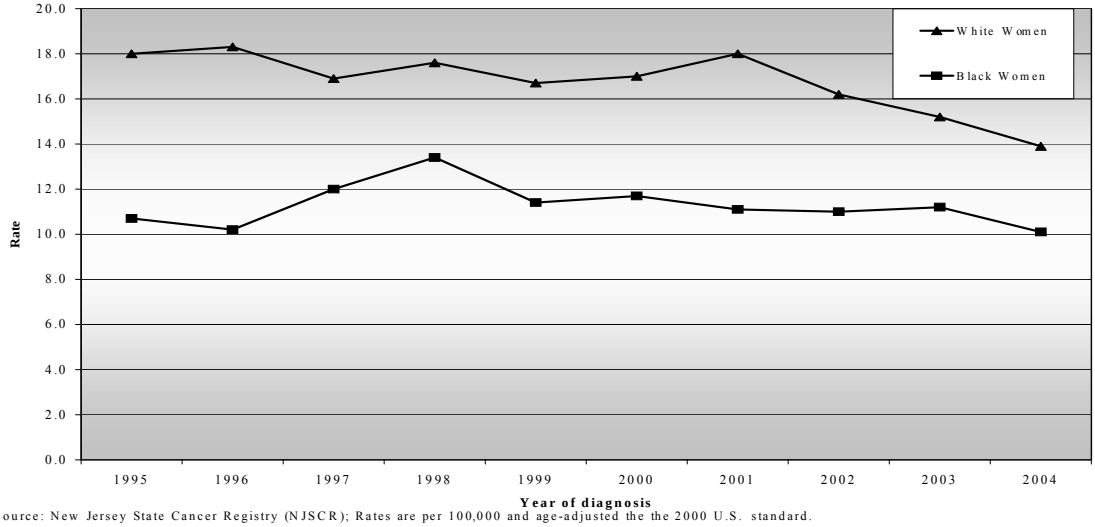
Screening. There are tests that can detect ovarian cancer, such as pelvic examination, transvaginal ultrasound, and CA-125 antigen. However, due to the high rate of false positives among average-risk women, current recommendations indicate transvaginal ultrasound and CA-125 only for those women at highest risk.

WHAT CAN BE DONE ABOUT OVARIAN CANCER IN NEW JERSEY?

Unfortunately, the majority of the risk factors associated with ovarian cancer (excluding smoking and nutrition and physical activity) are not modifiable, so little can be done to prevent the disease. While oral contraceptive pill use has been shown to protect against ovarian cancer in some women, there are other risks associated with OCP use.

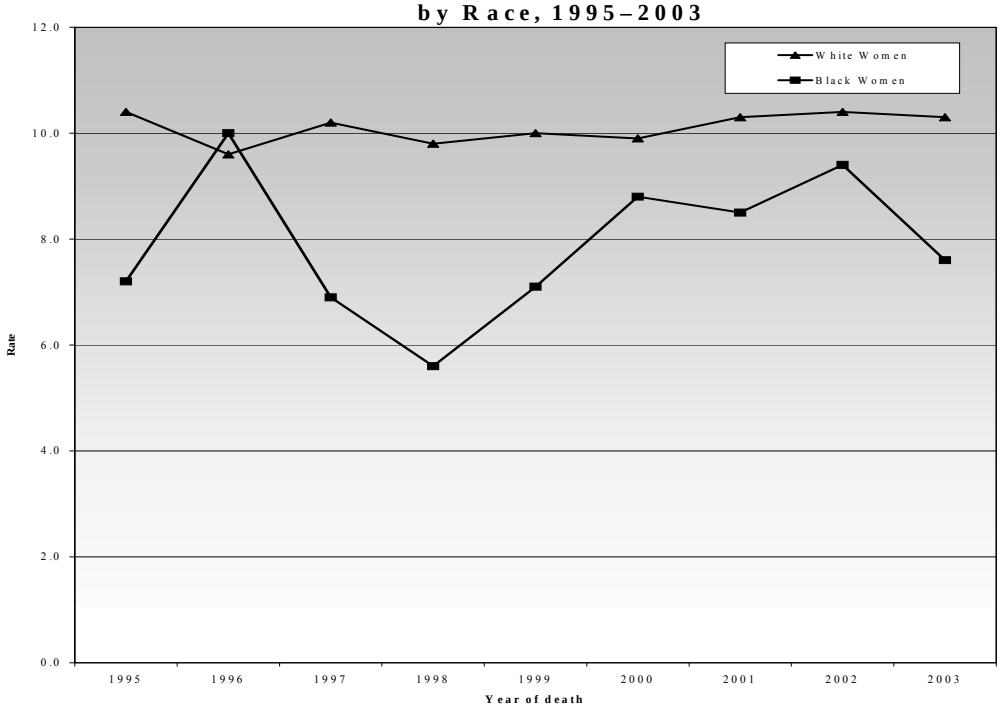
However, women who are aware of their risk of developing ovarian cancer due to one or more risk factors may be more likely to notice early symptoms of the disease and seek medical care, leading to earlier diagnosis. Educating women and healthcare professionals about the risk factors and symptoms associated with ovarian cancer is currently the only means to decrease morbidity and mortality from the disease.

Figure 5. Ovarian Cancer Incidence in New Jersey by Race, 1995–2004*



Source: New Jersey State Cancer Registry (NJSCR); Rates are per 100,000 and age-adjusted the the 2000 U.S. standard.
*Incidence rates from the NJSCR for the year 2004 are preliminary.

Figure 6. Mortality Rates for Ovarian Cancer in New Jersey, by Race, 1995–2003



Source: National Center for Health Statistics; Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

GOALS, OBJECTIVES, AND STRATEGIES FOR OVARIAN CANCER

In support of the Healthy New Jersey 2010 goals for ovarian cancer, the recommendations of the Gynecologic Cancer Workgroup are summarized below in the following focal areas:

- Awareness and education
- Research and surveillance

AWARENESS AND EDUCATION

Over 75% of ovarian cancers are diagnosed in the regional or distant stages, when the chances for successful treatment and survival are diminished.[63] Many women experience symptoms, even with early-stage disease.[71] However, several factors stand in the way of early diagnosis. Healthcare providers and patients alike are often unaware of the signs and symptoms of the disease and commonly attribute them to other conditions.[69,72,73] Delays in the diagnosis of ovarian cancer occur in the self-care and primary provider care phases of the diagnosis-seeking process.[72,75] Both phases present opportunities to improve the early detection of ovarian cancer. The Gynecologic Cancer Workgroup is in agreement with the American College of Obstetricians and Gynecologists (ACOG), which recommends that, in order to increase the early diagnosis of ovarian cancers, both patients and clinicians must be educated about symptoms associated with ovarian cancer and must have a high index of suspicion of the disease in symptomatic women. ACOG also recommends that physicians perform a physical examination, including a pelvic examination, in evaluating symptomatic women.[76] Referral to a gynecologic oncologist is an important step if suspicion is aroused by the pelvic exam, elevated CA-125, or abnormal ultrasound findings.

Educational programs must be targeted at women, emphasizing the importance of recognizing the early symptoms of ovarian cancer and the need for an annual pelvic exam. Women should also be educated about self-monitoring strategies for ovarian health as a strategy for reducing diagnosis delays during self-care.[75]

In addition, clinicians must be educated with state-of-the-science ovarian cancer health programs that emphasize recognition of early signs and symptoms and the risk of misdiagnosis.[75]

GOAL GY-8	To increase awareness of the early signs, symptoms, and risk factors associated with ovarian cancer.

Objective GY-8.1

To obtain, or develop as needed, information for developing ovarian cancer public awareness initiatives.

Strategy

GY-8.1.1 Partner with organizations and universities to obtain, or develop as needed, appropriate public education and awareness materials.

Objective GY-8.2

To collaborate with organizations to promote public awareness of ovarian cancer early signs, symptoms, and risk factors.

Strategy

GY-8.2.1 Distribute public awareness and education materials at health fairs and other public events.

Objective GY-8.3

To educate healthcare professionals about the early signs and symptoms of ovarian cancer.

Strategies

GY-8.3.1 Partner with organizations and universities to obtain, or develop as needed, appropriate professional education and awareness materials and messages.

GY-8.3.2 Work with stakeholders to disseminate appropriate professional education and awareness materials and messages and encourage collaboration between primary care and gynecologic oncologists through CME offerings.

RESEARCH AND SURVEILLANCE

Currently, a number of research studies are ongoing into developing more effective screening and early diagnostic tests for ovarian cancer. Studies of new tumor markers are in progress, but it is not yet known whether these will be successful in detecting ovarian cancer tumors at earlier stages or in reducing mortality.[71]

Clinical trials are the major avenue for discovering, developing, and evaluating new therapies. However, only about 3% of all adult cancer patients participate in clinical trials. It is important to increase physician and patient awareness of, and participation in, clinical trials if we are to test new treatments more rapidly, find more effective treatments, and broaden the options available to patients.[56]

Research must be conducted to learn why New Jersey women do not participate in clinical trials. Then, solutions to the barriers must be addressed. The Gynecologic Cancer Workgroup suggests the following goal, objectives, and strategies as next steps.

GOAL GY-9	To ensure that New Jersey residents and physicians remain up-to-date on the most currently available ovarian cancer technologies and resources.

Objective GY-9.1

To monitor ongoing research regarding the possible efficacy of screening/detection methods for ovarian cancer and formulate and distribute recommendations as warranted by such research.

Strategies

GY-9.1.1 Conduct periodic literature reviews to determine the state of the science in ovarian cancer screening/detection and to identify potentially promising new technologies.

GY-9.1.2 Work with stakeholders to disseminate, as they become available, evidence-based advances in ovarian cancer screening/detection to healthcare providers through CME offerings for professionals and awareness campaigns for the public.

Objective GY-9.2

To monitor and disseminate current advances in ovarian cancer prevention and treatment.

Strategies

GY-9.2.1 Conduct periodic literature reviews to determine the state of the science in ovarian cancer research and to identify potentially promising new technologies.

GY-9.2.2 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through CME offerings.

GY-9.2.3 Work with stakeholders to disseminate, as they become available, evidence-based advances to the public.

Objective GY-9.3

To monitor trends in ovarian cancer incidence, mortality, and survival.

Strategy

GY-9.3.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

GOAL GY-10	To foster the development of and to improve awareness of clinical and translational research for ovarian cancer and increase participation in clinical research available in New Jersey and/or available to New Jersey residents.

Objective GY-10.1

To identify existing research being done for ovarian cancer available in New Jersey and/or available to New Jersey residents.

Strategies

GY-10.1.1 Partner with the pharmaceutical industry and medical organizations to improve the number and breadth of current clinical trials for ovarian cancer in New Jersey.

GY-10.1.2 Identify a department within the state that practitioners can use as a resource for identifying ovarian cancer clinical trials in New Jersey for which their patients are eligible.

Objective GY-10.2

To attract and encourage participation in new and existing clinical research in New Jersey and/or available to New Jersey residents, especially in screening and treatment measures in ovarian cancer.

Strategies

GY-10.2.1 Link the state website to agencies such as NJ Cancer Trial Connect (www.njctc.com) to make ovarian cancer clinical trials more accessible to New Jersey residents.

GY-10.2.2 Collaborate with key associations/organizations to publicize ovarian cancer clinical trials in New Jersey.

GY-10.2.3 Outreach to healthcare providers and community leaders to improve client participation in ovarian cancer clinical trials.

GY-10.2.4 Collaborate with the New Jersey Commission on Cancer Research and others to support ovarian cancer clinical trials in New Jersey.

GY-10.2.5 Collaborate with the New Jersey Commission on Cancer Research and others to educate healthcare professionals about the importance of enrolling patients in ovarian cancer clinical trials in New Jersey.

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CHAPTER 8. Lung Cancer

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LUNG CANCER

IMPORTANCE OF LUNG CANCER FOR CANCER PREVENTION AND CONTROL

Lung cancer is the leading cause of cancer death among U.S. men and has been the leading cause of cancer death among women since surpassing breast cancer in 1987.[1–3] It is estimated that in 2007 there will be 213,380 new cases of lung cancer diagnosed in the U.S. and 160,390 deaths. Lung cancer will account for 15% of all cancer diagnoses and 29% of all cancer deaths.[1,2] Throughout their lifetime, men have a 1 in 12 chance of developing lung cancer, and women, a 1 in 16 chance. The 5-year relative survival rate for lung cancer is only 16%.[1,2]

Smoking is the single most preventable cause of death and disease and the leading cause of lung cancer. Tobacco smoking is responsible for 87% (almost 9 out of 10) of lung cancer deaths.[4] The 2004 Surgeon General's report, *The Health Consequences of Smoking*, found sufficient evidence that smoking contributes to the cause of cancers of the bladder, cervix, esophagus, kidney, larynx, lung, oral cavity and pharynx, pancreas, and stomach, as well as acute myeloid leukemia.[5] More Americans die from smoking each year than from AIDS, alcohol, other drugs, motor vehicle accidents, homicide, and suicide combined. Smoking will cost the nation $167 billion and 438,000 premature deaths each year.[6] Overall, smoking is responsible for more than 13,000 deaths annually in New Jersey alone.[7] Smokers generate $2.48 billion in direct medical costs and $2.2 billion in lost productivity costs each year in New Jersey due to tobacco-related illnesses.[8]

While tobacco is the leading cause of lung cancer, and tobacco cessation is the most effective method for reducing lung cancer morbidity and mortality, there do exist other factors that contribute to the lung cancer burden in New Jersey and the U.S. These other risk factors include environmental and occupational exposures including secondhand smoke, radon, asbestos, arsenic, and some organic chemicals (such as benzene), as well as radiation exposure, air pollution, and tuberculosis. Most importantly, however, there is an interaction between cigarette smoking and exposure to radon or asbestos, resulting in a significantly greater risk of lung cancer than would be attributed to either of the exposures alone.[1] There also may be a genetic, or inherited, component placing some individuals at an increased risk of developing lung cancer.

Prevention and early detection are necessary to decrease mortality from lung cancer. Currently, however, there is no recommended screening or early detection method for lung cancer. While the use of computed tomographic (CT) scans have shown promise in detecting lung cancers early, the impact of such methods on lung cancer mortality has yet to be proven.[9]

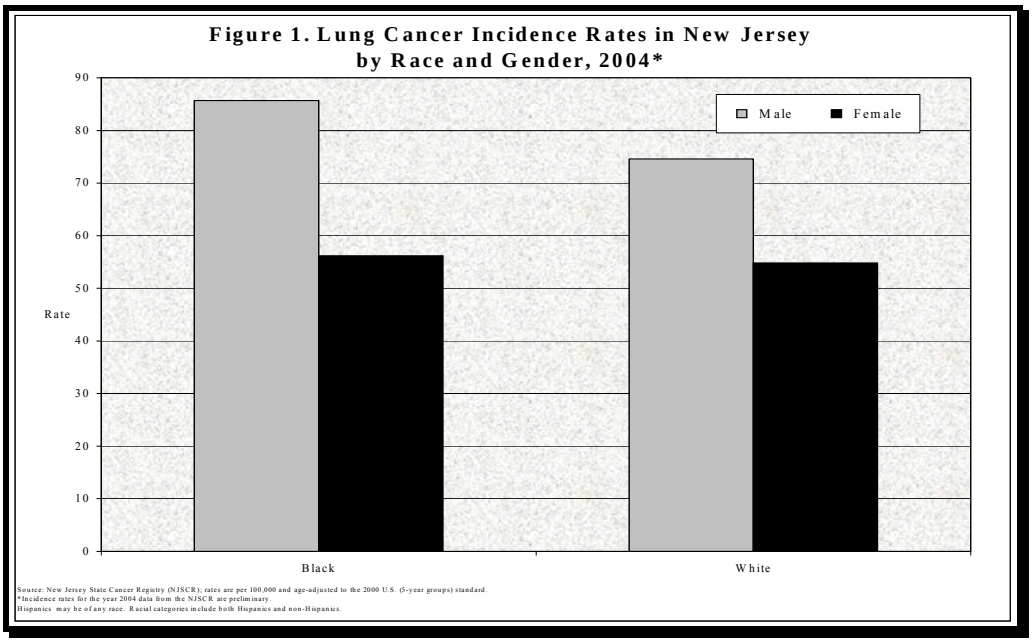
Nationally, unexplained cancer-related health disparities remain among population subgroups (e.g., blacks and individuals with low socioeconomic status have the highest overall rates for both incidence and mortality).[10,11] New Jersey must also address existing lung cancer morbidity and mortality disparities by race and gender, especially for black men, through funded research.

LUNG CANCER IN NEW JERSEY

In this section we discuss the status of lung cancer in New Jersey, including incidence, mortality, prevalence, and survival.

Incidence. According to the American Cancer Society, in 2007, lung cancer was projected to be the second most common cancer in the U.S. and in New Jersey, accounting for about 13% of all cancer diagnoses.[1] Reflecting the national trend of decreasing lung cancer incidence among white men, New Jersey has seen a decreasing trend in incidence since the late 1980s. Female lung cancer incidence rates were rising in New Jersey and the U.S. but have now reached a plateau. While lung cancer incidence rates for white females in New Jersey are similar to those among black females (54.8 versus 56.2 per 100,000**, respectively, in 2004*), the incidence rates for black males in New Jersey are substantially higher than for white males (85.7 versus 74.6 per 100,000**, respectively, in 2004*) (Figure 1).[12] In 2007 the American Cancer Society estimates that 6,310 new lung cancer cases will be diagnosed in New Jersey.[1]

In contrast, the lung cancer incidence rates for Hispanic men and women have risen since 1995. In 1995, the male rate was 58.0 compared to 62.0 per 100,000** in 2004. The female rate was 30.5 in 1995 compared to 37.5 per 100,000** in 2004. Although their rates have increased, Hispanic men and women still have lower incidence rates than non-Hispanic men and women (62.0 versus 75.6 per 100,000** for men and 37.5 versus 55.5 per 100,000** for women in 2004).[12]



* Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Mortality. Lung cancer is the most common cause of cancer death in the U.S. and in New Jersey, accounting for about 28% of all cancer deaths. U.S. mortality rates from the National Center for Health Statistics revealed that lung cancer deaths among men (all races combined) have decreased from 84.4 per 100,000** in 1995 to 71.9 per 100,000** in 2003.[13] For New Jersey females, mortality rates during the same time period remained relatively stable. For the years 1995 through 2003, black males in New Jersey had the highest mortality rate, followed by white males. Mortality rates were lower for females and similar for white and black females in New Jersey during the same years (Figure 2).[14] The American Cancer Society estimates that, in 2007, 4,380 new lung cancer deaths will occur in New Jersey compared to about 4,800 deaths that occurred in 1998, representing an almost 10% decrease.[1] The Hispanic lung cancer mortality rate for males and females is much lower than that for non-Hispanics (32.9 versus 67.9 per 100,000** for men and 13.8 versus 43.1 per 100,000** for women in 2003).[13]

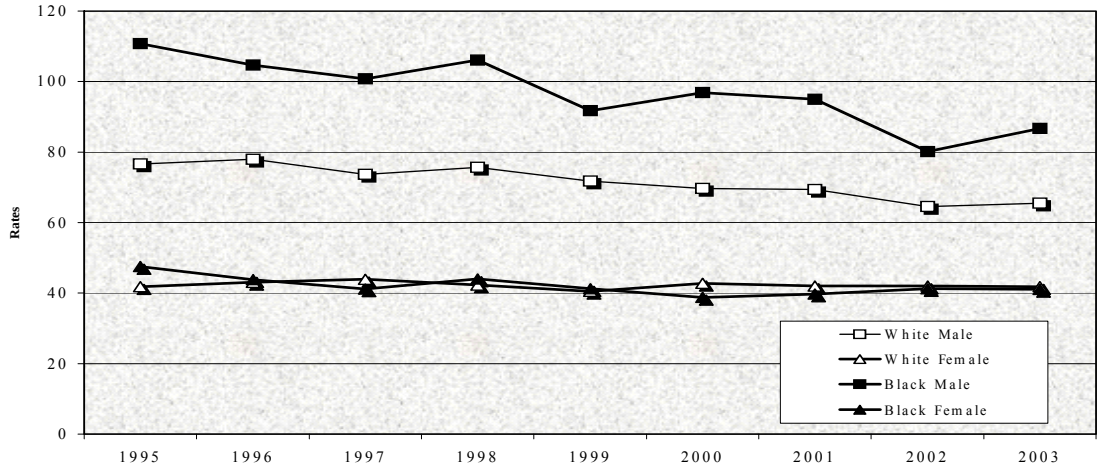
Prevalence. Estimates indicate that on January 1, 2003, there were 11,559 or 0.1% of New Jersey men and women alive who had ever been diagnosed with lung cancer. As with other cancers, the prevalence of lung cancer increases with age and is highest in the 65+ age group (0.7%). The prevalence of lung cancer is the same in whites and blacks (0.1%).[15]

Survival. The five-year survival rate for lung cancer diagnosed in New Jersey from 1994–1997 is 14.5%. This rate is slightly lower than the U.S. rate of 15.2%. Disparities in survival exist between blacks and whites. In New Jersey, as in the U.S., black women have a slightly lower survival rate than white women (14.8% versus 16.3%, respectively), and black men have a lower survival rate than white men (10.0% versus 13.4%, respectively).

Lung cancer survival rates are much higher for cancers diagnosed at the local stage than at the regional or distant stage. For example, in New Jersey from 1994–1997, the five-year survival rate for local-stage lung cancer was 46.2% for men and 49.5% for women, whereas that for regional-stage lung cancer was 13.7% and 16.8% for men and women, respectively, and that for distant-stage was 1.9% and 2.6% for men and women, respectively. Unfortunately, fewer than 20% of lung cancer cases are diagnosed in the early stage.[1,2,16]

**Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Figure 2. Lung Cancer Mortality in New Jersey by Race and Gender, 1995–2003



Source: National Center for Health Statistics; rates are per 100,000 and age-adjusted to the 2000 U.S. Standard Population.

HEALTHY NEW JERSEY 2010 GOALS

Healthy New Jersey Goal 1	Reduce the age-adjusted death rate from lung cancer per 100,000 standard population to target below, by 2010.

Table 1. Age-adjusted death rate from lung cancer, New Jersey, 1999–2002 and Healthy New Jersey 2010 projected target rates.[17]

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
Total	52.9	53.4	52.7	50.4	43.0	38.0
White	53.3	53.8	53.1	51.0	43.0	38.0
Black	60.9	61.1	61.4	56.2	43.0	38.0
Hispanic*	15.6	23.7	20.5	19.6	**	**
Asian/Pacific Islander*	15.7	16.5	18.1	18.7	**	**
Male	72.1	71.1	70.4	64.7	45.0	38.0
Female	39.8	41.6	40.7	40.8	38.0	38.0
Persons 65+	299.7	303.3	301.6	292.0	276.0	256.0

Source: New Jersey Department of Health and Senior Services, Center for Health Statistics, Healthy New Jersey 2010: Update 2005
* *The number of Hispanic and Asian/Pacific Islander deaths is known to be understated.*
** *A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander include Hispanics and non-Hispanics.

GOALS, OBJECTIVES, AND STRATEGIES

In support of the Healthy New Jersey 2010 goal for lung cancer, the recommendations of the Lung Cancer Workgroup are summarized below in the following focal areas:

- Tobacco control
- Provider education
- Screening and early detection
- Public awareness and education
- Research and surveillance

TOBACCO CONTROL

The major intervention in the prevention of lung cancer is tobacco control. The most effective approach to tobacco control is to enact public policies that reduce tobacco use. Proven strategies include increasing tobacco taxes, making tobacco-dependence resources available, and restricting tobacco use in public places.[7,18] Policies that restrict the use of tobacco in public places have been shown to increase the social unacceptability of tobacco use, leading to a reduction in overall smoking prevalence.[19] In 2006 the Surgeon General released a new report on the health effects of secondhand smoke. The report concluded that secondhand smoke causes premature death and disease among adults and children and recommends the elimination of smoking in indoor spaces as the only way to fully protect nonsmokers from exposure to secondhand smoke.[20]

In 2005, the Lung Cancer Workgroup, together with the Task Force and the New Jersey Comprehensive Tobacco Control Program (NJCTCP), was instrumental in the passage of the New Jersey Smoke-Free Air Act (P.L. 2005, c.383), which prohibits smoking inside public buildings, representing a major step in increasing social unacceptability of tobacco use in the state. New Jersey has also implemented an increase in the age of sale for tobacco products (from 18 to 19 years old), as well as an increase in the state tobacco tax that makes it the highest state tobacco excise tax in the nation. Tobacco control programs in New Jersey should continue to build on the existing efforts of the NJCTCP[21–23] in order to further reduce tobacco use among state residents.

Other issues surrounding tobacco control include:

- Addressing racial, gender, and cultural disparities through targeted interventions
- Reducing exposure to Environmental Tobacco Smoke (ETS)
- Educating healthcare providers and insurers
- Expanding access to and funding for smoking cessation
- Promoting public information/support
- Engaging in active advocacy for smoke-free environments
- Implementing countermarketing in response to tobacco industry marketing and promotional activities[21]

For each of these issues, the Comprehensive Tobacco Control Program has identified specific challenges and strategies for overcoming them. The Lung Cancer Workgroup recommends collaborating with the NJCTCP to overcome implementation barriers and facilitate provider actions to achieve desired outcomes.

GOAL LU-1	To adopt the goals already formulated by the New Jersey Comprehensive Tobacco Control Program, namely to: • Decrease the acceptability of tobacco use among all populations • Decrease the initiation of tobacco use by youth under 18 years of age and youth 18 to 24 years of age • Increase the number of youth and adult tobacco users who initiate treatment • Decrease exposure to environmental tobacco smoke • Reduce disparities related to tobacco use and its effects among different population groups[23]

Objective LU-1.1

To support the long-term goals of the New Jersey Comprehensive Tobacco Control Program and its comprehensive components by increasing funding to the levels recommended by the Centers for Disease Control and Prevention.

Strategies

LU-1.1.1 Broaden the number and scope of advocates for tobacco control by identifying new advocates and advocacy groups that will advocate for tobacco control.

LU-1.1.2 Increase the cost of tobacco products through such measures as an increase in the tobacco excise tax or tobacco retailer licensing fee.

LU-1.1.3 Advocate for the revenue generated through the tobacco tax and tobacco retailer licensing fees to be designated for state-sponsored tobacco and cancer programs.

LU-1.1.4 Increase the awareness and use of state-sponsored tobacco treatment resources in communities.

LU-1.1.5 Increase the awareness and improve utilization of the University of Medicine and Dentistry of New Jersey, School of Public Health Certified Tobacco Treatment Specialist training program.

PROVIDER EDUCATION

In 2000, the U.S. Department of Health and Human Services updated the Public Health Service (PHS) *Guidelines for Treating Tobacco Use and Dependence* (henceforth referred to as the PHS Guidelines).[24] The PHS Guidelines provide clinicians with excellent strategies to help their patients abstain from tobacco. However, the guidelines are rendered useless if providers are unaware of them and are unable to execute them effectively. Since publication of the PHS Guidelines, the challenge of tobacco control advocates has been to persuade healthcare providers to implement the recommendations in their respective practices.

The importance of enlisting healthcare providers in tobacco-related treatment is undeniable.[25–27] It is reported that 70% of smokers visit a healthcare provider each year,[28] and smokers visit their doctor on average six times per year,[29] thus allowing for considerable patient/provider contact. Despite the commonly accepted knowledge of the adverse health effects of smoking, a significant number of smokers are still unclear about the full scope of the dangers they are risking.[30] Patients view their healthcare provider as an important and credible source of medical information and, therefore, providers must be up to date on tobacco-related issues. Patients report that a strong quit message from a provider is a very important motivating factor in the quitting process.[31] Reviews show that minimal-duration (less than 3 minutes) counseling by a clinician can increase smoking cessation by 2.5%.[25,26] While this may not seem like a significant difference, it is far from negligible when considered in light of the 1.2 million smokers in the state. Moreover, simple advice to quit has a cumulative effect, and the patient can interpret omitting the advice as a rationalization that quitting is not as important as some say and that the clinician does not care. Providers also have the opportunity to intervene in circumstances beyond the direct patient's habit. This would include pediatricians addressing environmental tobacco smoke in the household of smokers and obstetricians addressing smoking during pregnancy and the fetal effects that ensue.

The PHS Guidelines also make clear that, although brief interventions by clinicians can have an impact, more intense interventions have even greater effect. Interventions have been shown to operate in a dose-response fashion; the more intensive the intervention and the more resources utilized, the higher the rates of success.[24] This effect applies to any smoker willing to participate, not simply those unable to achieve abstinence on their own or with the help of their primary care provider. Luckily, excellent resources exist in New Jersey for specialized treatment. These include the Quitline, Quitnet, and Quitcenter. In addition, the NJQuit2Win website (http://www.njquit2win.com) provides valuable smoking cessation tools and information for physicians, employers, smokers, and their families.

The National Cancer Institute's *5 A's: Ask, Advise, Assess, Assist, Arrange* strategy for smoking intervention, advocated in the PHS Guidelines, has been abbreviated into a 30-second intervention: *Ask, Advise, Refer,* encouraging physicians to **Ask** patients if they smoke, **Advise** them to quit, and **Refer** them to the New Jersey Quit Services and other resources available at the NJQuit2Win website. This new "2 A's + R" campaign represents an innovative strategy for engaging all healthcare professionals in smoking cessation counseling.

The PHS Guidelines recommend that each clinical site designate a tobacco-dependence treatment coordinator, responsible for instructing patients on the effective use of treatments (e.g., pharmacotherapy, telephone calls to and from prospective quitters, and scheduled follow-up visits, especially in the immediate post-quit period).[24] The University of Medicine and Dentistry of New Jersey, School of Public Health has developed a training program to prepare professionals to provide

intensive specialized treatment services for tobacco dependence. The program provides knowledge of evidence-based treatment methods and offers participants the skills and tools needed to assess and treat smokers in multiple settings.[32]

Unfortunately, despite the availability of the PHS Guidelines and specialized resources, smoking cessation counseling by healthcare providers is not occurring as it should. Barriers to physician engagement in smoking cessation include a perceived lack of efficacy, lack of time with the patient, patient sensitivity, perceived lack of patient motivation, and lack of skills or effective strategies for counseling.[26]

There is good evidence that healthcare providers are not fully aware of the tools at their disposal. In New Jersey, while more than 85% of smokers reported being asked their smoking status by their clinician, less than 75% reported being advised to quit. Less than 30% reported being advised on how to quit. While the percent of smokers referred to New Jersey quit services (Quitline, Quitnet, and Quitcenters) is low, it increased from 17.3% in 2002 to 25.1% in 2005.[21]

Despite the increase, providers are not meeting the recommended levels of tobacco treatment. A concerted effort must be made to inform providers of the resources available for specialty referral and improve their utilization.

Healthy People 2010 includes an objective to "increase insurance coverage of evidence-based treatment for nicotine dependency."[33] In order for this objective to be met, a strong advocacy effort must be undertaken to convince third-party insurers that efforts to increase cessation are cost effective in both the short and the long term. If reimbursement is increased to the Healthy People 2010 goals, a major barrier to tobacco-dependency treatment as reported by providers will be reduced.

GOAL LU-2	To increase the proportion of providers in New Jersey who properly and effectively implement the Public Health Service Guidelines regarding tobacco-dependency treatment.

Objective LU-2.1

To increase provider knowledge regarding standard of care for tobacco-dependency treatment in the State of New Jersey.

Strategies

LU-2.1.1 Support the assessment of providers' current knowledge regarding the Public Health Service Guidelines for tobacco-dependency treatment via a provider survey.

LU-2.1.2 Support the development and/or promotion of educational programs to increase the awareness of the Public Health Service Guidelines for tobacco-dependency treatment. These interventions will target stakeholders of provider organizations.

Objective LU-2.2

To increase provider knowledge regarding available resources for tobacco-dependency treatment in New Jersey (Quitline, Quitnet, and Quitcenters).

Strategies

LU-2.2.1 Support the assessment of providers' current awareness of New Jersey's efforts in tobacco control via a statewide providers' survey.

LU-2.2.2 Support promotional programs to increase the awareness of tobacco-dependency treatment in New Jersey (Quitline, Quitnet, and Quitcenters).

Objective LU-2.3

To reduce the barriers for insurance providers in implementing the Public Health Service Guidelines for tobacco-dependency treatment.

Strategies

LU-2.3.1 Advocate for third-party payer reimbursement of tobacco-dependency treatment.

LU-2.3.2 Advocate for third-party payer reimbursement of certified tobacco specialists.

Screening and Early Detection

According to 2007 estimates, lung cancer remains the primary cause of cancer-related death in men and women in the nation. The overall long-term (five-year) survival for lung cancer only increased from 12% in 1974 to 15% in 2001.[2] Despite poor survival in general, five-year survival for cancers diagnosed in the early, localized stage is 50%, although only 16% of lung cancers are localized at the time of diagnosis. Lung cancer accounts for more cancer deaths in the U.S. than the combination of the next three most common causes of cancer death: colorectal, breast, and prostate cancers. However, lung cancer is the only one of these cancers for which there are no screening recommendations.[1,2]

The goal of a screening program is to detect cancers at an early stage when they are small and asymptomatic and when treatment leads to a higher cure rate.[34,35] Several recent studies have sought to demonstrate an effective screening mechanism. During the 1970s, the National Cancer Institute sponsored the Cooperative Early Lung Cancer Detection program, and more recent 20-year follow-up data from the Mayo Lung Project confirmed that early detection of lung cancer with chest x-ray at frequent intervals does not decrease mortality from lung cancer. Although there was a greater surgical

resectability rate in the screened patients and survival time was increased, there was no effect on overall mortality rates. As a result of these and similar trials, no national recommendations for lung cancer screening were made.[9,36–38]

Recent technological advances and development of new tools for screening have led to renewed trials of methods for detection of early-stage lung cancers. The most promising of these is the low-radiation-dose spiral computer topography (LDCT) scan.[9,39] LDCT requires less than 20 seconds of scanning time, does not require intravenous contrast, and is much less expensive than a standard chest CT. The cost is only slightly higher than the cost of a chest radiograph, and the radiation exposure is about equal.[9,40]

Results of lung cancer screening trials have been varied. While studies have established the ability of the LDCT to detect lung cancer at an earlier stage, there is as yet little evidence that screening decreased mortality. In addition, there is a great deal of concern over the potential for harm due to the possibility of a high number of false positive tests.[9,38]

GOAL LU-3 To increase the detection of lung cancer at earlier stages.

Objective LU-3.1

To monitor low-dose spiral CT as an effective screening method to decrease lung cancer mortality.

Strategies

LU-3.1.1 Monitor and support the National Cancer Institute's progress in defining the value of spiral CT and other effective methods as a recommended screening method for lung cancer.

LU-3.1.2 Educate New Jersey healthcare providers about state-of-the-art lung cancer screening, especially if a national lung cancer screening recommendation as defined by a large controlled randomized study is issued.

LU-3.1.3 Educate New Jersey residents about state-of-the-art lung cancer screening, especially if a national lung cancer screening recommendation as defined by a large controlled randomized study is issued.

LU-3.1.4 Promote efforts to have the screening tests covered by health insurers and third-party payers, especially if a national lung cancer screening recommendation as defined by a large controlled randomized study is issued.

Objective LU-3.2

To promote research on early detection of lung cancer and precancerous lesions.

Strategies

LU-3.2.1 Assess results of current studies in the area of early detection of lung cancer and precancerous lesions.

LU-3.2.2 Support existing research projects and additional pilot projects for early detection of lung cancer and precancerous lesions.

Public Awareness and Education

It is important to note that not all lung cancers occur among current smokers. Former smokers and never-smokers should be aware of the factors that may put them at risk for developing lung cancer. While some of the risk factors for lung cancer, such as heredity, cannot be controlled or prevented, raising awareness will ultimately help New Jersey residents to avoid environmental and occupational exposures that may increase their risk of developing lung cancer. For those who are at increased risk due to heredity or past exposures, raising awareness of lung cancer risk and symptoms can lead to earlier detection.

The symptoms of lung cancer may include persistent cough, sputum streaked with blood, chest pain, and recurring pneumonia or bronchitis.[1] In the absence of sufficient evidence to recommend broad, population-based lung cancer screening of asymptomatic individuals, it is important to educate the public about not only the risk factors of lung cancer, but also the signs and symptoms of the disease to facilitate early diagnosis and treatment.

GOAL LU-4	To heighten public awareness and knowledge of lung cancer, its risk factors, symptoms, treatment, and the potential for early detection.

Objective LU-4.1

To implement an awareness campaign to educate New Jersey residents about lung cancer, its risk factors, symptoms, treatment, and the potential for early detection.

Strategies

LU-4.1.1 Work with other organizations to secure funding for a lung cancer awareness campaign.

LU-4.1.2 Identify, and develop where needed, appropriate lung cancer educational materials.

LU-4.1.3 Collaborate with the county cancer Coalitions and other community-based organizations to disseminate educational materials.

RESEARCH AND SURVEILLANCE

Lung cancer is the leading cause of cancer death in the United States. Its major cause is cigarette smoking. Lung cancer is usually detected at the late stage, making treatment more difficult. Therefore, tobacco control and early detection are the two most important strategies for the reduction of lung cancer incidence and mortality. However, continued research is needed to develop more effective measures for tobacco control and early detection.

As discussed previously, many early detection methods are still in the research stage. New Jersey residents should be encouraged to participate in early lung cancer detection trials. Recent advances in cancer biology suggest the potential for developing molecular markers, such as P16 gene hypermethylation and p53 gene mutation, for the detection of early stages of lung cancer or even precancerous lesions. Research in this area is highly promising and should be encouraged in New Jersey.

The American College of Surgeons (ACoS) requires that all ACoS-certified oncology programs enroll at least 2% of their patients in clinical trials.[41] Although it is outside the scope of this plan, the Lung Cancer Workgroup recommends that this requirement be increased, especially concerning lung cancer early detection trials.

As discussed previously in this chapter, the majority of lung cancer cases are diagnosed in late-stage disease, when curative treatment is rarely successful, or even possible. Currently, the goal of standard therapy for late-stage lung cancer is palliative—that is, to provide relief from symptoms and prolongation of survival and comfort, not cure. Enrolling patients in clinical protocols to trial new treatments and investigational agents may lead to improved outcomes and perhaps decreased mortality.

Actions that should be taken in New Jersey with regard to lung cancer research include:

- Advocate for increased funding for lung cancer research.
- Promote research on effective means for tobacco control.
- Promote research on effective means for detecting lung cancer at early stages and precancerous lesions.
- Promote research on the treatment of lung cancers at early and later stages.
- Promote research funding for effective interventions to palliate or relieve the common symptoms associated with lung cancer, including pain, dyspnea/cough, and anorexia.[42]

GOAL LU-5	To increase accrual and broaden access to lung cancer clinical trials for early detection, treatment, and supportive care for patients and physicians in New Jersey.

Objective LU-5.1

To support the National Cancer Institute's Clinical Trial Implementation Committee Goals for Clinical Trials for lung cancer.

Strategies

LU-5.1.1 Develop educational programs to promote participation in and enhance public visibility and understanding of important lung cancer clinical trials.

LU-5.1.2 Publicize the existence of a clinical trials website, particularly New Jersey Cancer Trials Connect (www.njctc.org), via the county cancer Coalitions and other avenues.

GOAL LU-6	To ensure that New Jersey residents and physicians remain up to date on the most currently available lung cancer technologies and resources.

Objective LU-6.1

To continue to monitor and disseminate current advances in lung cancer prevention, screening, diagnosis, treatment, and supportive care.

Strategies

LU-6.1.1 Conduct periodic literature reviews to determine the state of the science in lung cancer research and to identify potentially promising new technologies.

LU-6.1.2 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through CME offerings.

Objective LU-6.2

To continue to monitor trends in lung cancer incidence, mortality, and survival.

Strategy

LU-6.2.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

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CHAPTER 9. Melanoma

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MELANOMA

IMPORTANCE OF MELANOMA CANCER FOR CANCER PREVENTION AND CONTROL

Skin cancer is the most common cancer in the United States, affecting some 1 million Americans every year. There are three main types of skin cancer: basal cell, the most prevalent; squamous cell; and malignant melanoma. Basal and squamous cell cancers have an excellent prognosis, but are at greater likelihood of recurring.[1] Melanoma of the skin[§] or cutaneous malignant melanoma, the rarest but most lethal form of skin cancer, is responsible for about three-fourths of all deaths from skin cancer and is, therefore, the focus of this report.[1] It should be noted that nonmelanoma skin cancers are also important and should not be neglected. Many recommendations offered in this chapter will apply to malignant melanoma of the skin, as well as to nonmelanoma skin cancers and other types of malignant melanoma (e.g., ocular).

Incidence of cutaneous malignant melanoma is increasing approximately 3% per year.[1] In the United States alone, the lifetime risk for developing cutaneous melanoma is approximately 1 in 80 persons. Persons born prior to 1930 have experienced the sharpest increases.[2] In the U.S., about one-fourth of melanoma patients are diagnosed before age 40.[3] Thus, the years of life lost from cutaneous melanoma are higher than for most other forms of cancer. In 2007, it is estimated that 33,910 new cases of cutaneous malignant melanoma will be diagnosed in males and 26,030 in females.[1] Approximately 8,110 people will die from cutaneous melanoma in 2007.[1] In recent years, melanoma is one of the cancer sites showing the most marked increases nationally.[4] The American Cancer Society estimates that, in 2007, melanoma of the skin will be the sixth leading new cancer site in the U.S. for both men and women, accounting for about 6% and 4% of all cancers, respectively.[1]

Exposure to solar ultraviolet radiation (UVR) is well established as a major risk factor for melanoma.[5–7] Increasingly, evidence has shown that artificial UVR exposure, such as that experienced in tanning beds and booths, significantly increases the risk of developing melanoma and other skin cancers.[8–11] Other risk factors include genetics,[7] skin coloring,[7,12] geographic location of residence,[6] sunburn history,[5,6,12] and melanocytic nevi (moles).[6,7] Cutaneous melanoma prevention begins with avoidance of exposure to the sun, especially during midday. Those who cannot avoid the sun should limit direct sun exposure using broad-brimmed hats, long-sleeved shirts, pants, sun-resistant fabrics, or sunscreen.

MELANOMA IN NEW JERSEY

In this section we discuss the status of melanoma in New Jersey, including incidence, mortality, prevalence, survival, and risk factors.

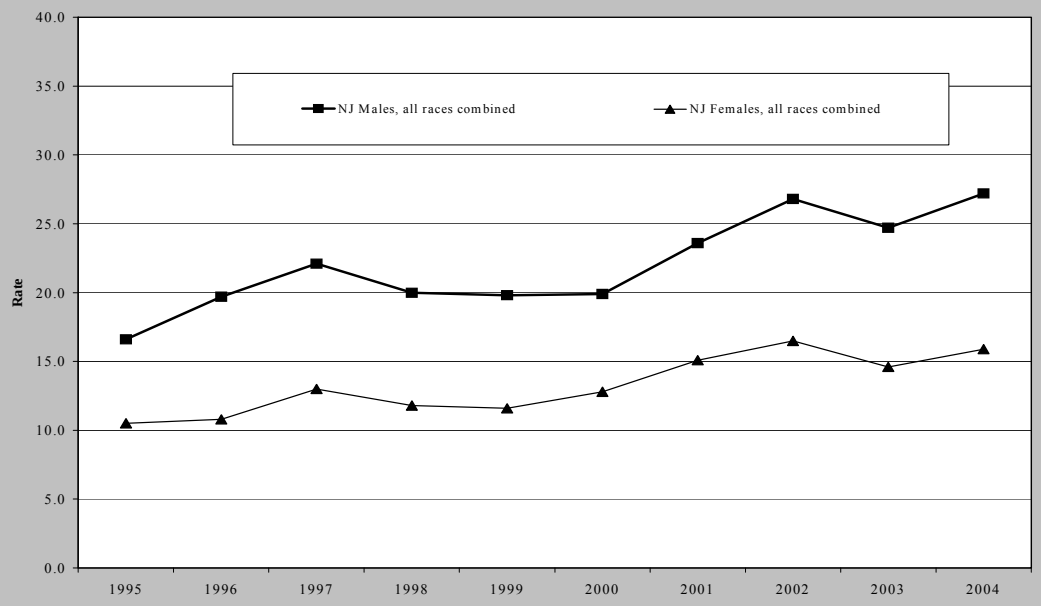
Incidence. New Jersey's cutaneous melanoma incidence rates reflect the national trend of increasing incidence.[4] The stage at which melanoma is being diagnosed in New Jersey is improving. In 2004, 88%

[§]The New Jersey State Cancer Registry data reflect cutaneous malignant melanoma of the skin and do not include basal and squamous cell skin cancers. The American Cancer Society data reflect melanoma of the skin and do not include basal and squamous cell skin cancers.

of melanomas were diagnosed in the early stages (in situ and local) compared to 70% in 1995. Data from the New Jersey State Cancer Registry reveal that the incidence rate of melanoma in New Jersey men (all races combined) increased from 1979 to 2004 (Figure 1). Although melanoma can occur in the black population, the incidence rate is significantly higher in whites (1.2 for black males and females combined versus 23.6 per 100,000** for white males and females combined in 2004). The incidence rate is lower for Hispanics than non-Hispanics (6.5 versus 22.2 per 100,000** for males and females combined in 2004).[13]

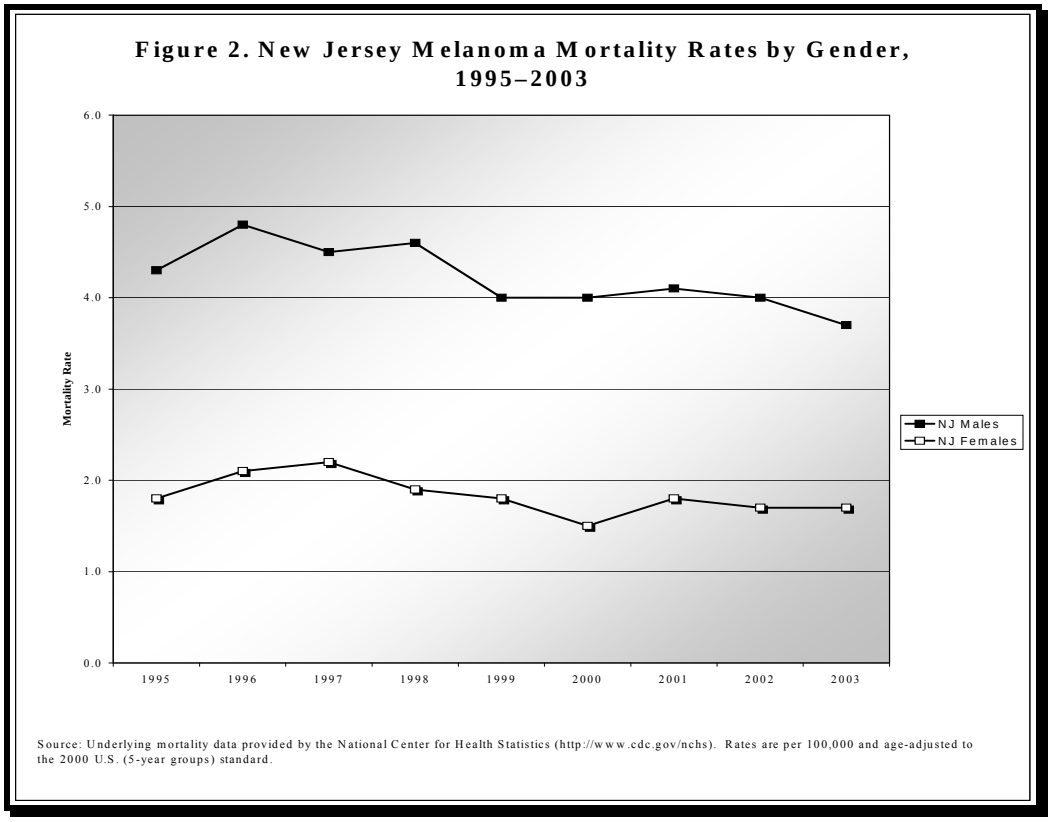
The American Cancer Society estimates that, in 2007, 2,210 new melanoma cases will be diagnosed in New Jersey.[1] Melanoma incidence rates increase as age increases. The highest rates of melanoma in New Jersey are in males aged 80–84 (incidence rate = 112.0 per 100,000** for the years 1995–2004 combined).[13]

Figure 1. Melanoma Incidence Rates for New Jersey by Gender, 1995–2004*



Source: New Jersey State Cancer Registry (NJSCR) and SEER ; rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) standard; *incidence rates for the year 2004 data from the NJSCR are preliminary.

** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.



Mortality. Data from the National Center for Health Statistics reveal that cutaneous melanoma mortality rates for New Jersey males declined slightly between 1995 and 2003 and remained relatively stable for females (4.3 in 1995 versus 3.7 per 100,000** in 2003 for males and 1.8 in 1995 versus 1.7 per 100,000** in 2003 for females)[14] (Figure 2). The U.S. rates for males and females remained relatively stable between 1995 and 2003 (3.9 per 100,000** in 1995 and 2003 for males and 1.8 in 1995 versus 1.7 per 100,000** in 2003 for females).[15] The mortality rate for whites is higher than that for blacks (3.2 versus 0.3 per 100,000** for males and females combined for the period 1995–2003). The mortality rate is lower for Hispanics than for non-Hispanics (0.6 versus 3.0 per 100,000** for males and females combined for the period 1995–2003).[14]

Prevalence. Estimates indicate that on January 1, 2003, there were 15,486 or 0.2% of New Jersey men and women alive who had ever been diagnosed with melanoma of the skin. As with other cancers, the prevalence of melanoma increases with age and is highest in the 65+ age group (0.7%). The prevalence of melanoma is higher in whites than blacks (0.2% versus less than 0.05%, respectively).[16]

Survival. The five-year relative survival rate for melanoma of the skin diagnosed in New Jersey (all races combined) from 1994–1997 is 84.2%. This rate is lower than the U.S. rate of 90.5%. Disparities in survival exist between blacks and whites. In New Jersey, black men have a lower survival rate than white men (57.1% versus 82.6%, respectively) for the period 1994–1997. The white female survival rate for the same time period is 86.9%. The black female survival rate is not available due to a small number of cases.

** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Survival rates are much higher for melanoma diagnosed at the local stage than at the regional or distant stage. In New Jersey from 1994–1997, the five-year survival rate for local-stage melanoma was 91.2% for men and 92.1% for women, whereas that for regional-stage melanoma was 46.9% and 55.8% for men and women, respectively, and that for distant-stage was 14.5% and 31.9% for men and women, respectively.[17]

Risk factors. According to estimates from the 2004 New Jersey Behavioral Risk Factor Survey, more males than females (33.4 % compared to 25.9%) answered 'yes' to the question 'Did you have a sunburn in the past 12 months?'. When broken down by age, the subgroup of 18- to 34-year-olds had the highest percentage of sunburns within the past year (38.7 %).[18]

Cutaneous melanoma is a serious threat in New Jersey in particular, where the number of new melanoma cases is the seventh highest in the nation.[1] New Jersey has a very active coastal community, where tourists visit the beaches and other outdoor attractions every summer. Many opportunities exist to prevent cutaneous malignant melanoma through these recreational activities and facilities.

HEALTHY NEW JERSEY 2010 GOALS

Healthy New Jersey Goal	Reduce the age-adjusted incidence rate of invasive melanoma per 100,000 to 12.0 for the total population, 14.0 for whites, and 0.4 for blacks.

Table 1. Age-adjusted incidence rate of invasive melanoma, New Jersey, 1999–2002, and Healthy New Jersey 2010 projected target rates.

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
Total	14.9	15.4	18.1	20.6	12.0	10.0
White	17.5	18.2	21.4	23.9	14.0	12.0
Black	0.8	0.8	0.9	0.8	0.4	0.3
Hispanic	2.9	3.3	3.7	3.4	**	**
Asian/Pacific Islander*	*	*	*	*	**	**

Source: New Jersey Department of Health and Senior Services, Center for Health Statistics, Healthy New Jersey 2010: Update 2005.
** The number of Asian/Pacific Islander cases is known to be understated.*
*** A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander include Hispanics and non-Hispanics.

GOALS, OBJECTIVES, AND STRATEGIES

In support of the Healthy New Jersey 2010 goal for melanoma, the recommendations of the Melanoma Workgroup are summarized below in the following focal areas:

- Awareness
- Education
- Treatment
- Research and surveillance

AWARENESS

As demonstrated earlier in this chapter, protection from UV rays is the easiest way to eliminate the most common risk factor for cutaneous melanoma. However, according to the 1998 National Health Interview Survey, only 27% of adults sought out shade, only 23% wore protective clothing when exposed to sunlight, and only 30% routinely used sunscreen.[19] Consequently, in 2000 an estimated 36% of U.S. adults experienced one or more sunburns.[20] These data clearly demonstrate the need to make the public more aware of UV exposure as a risk factor for cutaneous melanoma.

Under the auspices of the first edition of this *Plan*, New Jersey implemented the Centers for Disease Control and Prevention's (CDC) "Choose Your Cover" campaign to increase awareness about skin cancer, while also influencing social norms regarding sun protection and tanned skin.

Additionally, CDC has established the National Council on Skin Cancer Prevention and the Federal Council on Skin Cancer Prevention (www.skincancerprevention.org), as well as launching public awareness campaigns such as Pool Cool; Sunwise Stampede; the National Coalition for Skin Cancer Prevention in Health, Physical Education, Recreation and Youth Sports; and the Coalition for Skin Cancer Prevention in Maryland.

The most common public awareness message is that of the "ABCDE's of Melanoma,"[21] which describes suspicious lesions as those that are **A**symmetrical, have an irregular **B**order, have **C**olor variegation, have a **D**iameter greater than 6 millimeters, and **E**volve or change over time.

Awareness campaigns are most prevalent in the form of educational materials for display in dermatologist offices. However, this type of campaign only targets those who have already taken the initiative to visit the dermatologist; those who do not visit the dermatologist or a primary care physician are being missed. Although the basic message of the program is correct, people are only encouraged to look for advanced signs of disease rather than early warning signs.

Despite these state and national efforts, New Jersey is still estimated to rank seventh in the nation for cutaneous melanoma incidence for 2007.[1] Yes, as stated in the introduction to this chapter, while diagnosis in the early stages is increasing, data from the New Jersey State Cancer Registry show that the diagnosis of cutaneous melanoma in the late stages (regional and distant) has decreased slightly from 1995 to 2004 (8% to 7%, respectively).

Reducing the public's exposure to artificial UVR is an important step in reducing the disease burden of melanoma. The annual revenue of the indoor tanning industry was estimated at $5 billion in 2005,

increased from $1 billion in 1992. Each day, over 1 million people are exposed to UVR in tanning salons throughout the United States.[9] The most frequent users of indoor UV tanning are white adolescent girls.[9,11,22] Given the risk of melanoma and other skin cancers associated with the use of tanning beds and booths, the Melanoma Workgroup strongly recommends increasing awareness among New Jersey residents of the risks associated with indoor UVR exposure.

A recent study suggests that tanning salons, through the provision and advertising of pricing policies that allow unlimited use of tanning beds and booths at a discounted rate, encourage frequent tanning, which exceeds U.S. Food and Drug Administration (FDA) guidelines.[23,24]

The fact that melanoma is a life-threatening disease must continue to be communicated effectively to the public and to healthcare professionals in order to increase the proportion of melanomas diagnosed in the early stages when the disease is most treatable. The Melanoma Workgroup recommends continued implementation of awareness campaigns that target early diagnosis. Awareness issues must be addressed on five levels. First, the public at all age levels must be made aware of the gravity of the disease and the need for preventive measures. Second, screening must be promoted to those at risk. Third, patients must be made aware of the treatment regimens that are available immediately after diagnosis. Fourth, medical professionals must be made aware of state-of-the-art diagnosis and treatment programs, as well as the quality-of-life issues that accompany these treatments. Fifth, the public and professionals must be aware of the facilities in New Jersey that offer state-of-the-art diagnosis and treatment for melanoma of the skin.

GOAL ME-1	To decrease the number of melanomas diagnosed in late stages and increase the percent of melanomas being diagnosed in early stages.

Objective ME-1.1

To promote state-of-the-art diagnosis and treatment for melanoma in facilities available for the citizens of New Jersey.

Strategies

ME-1.1.1 Develop continuing education programs to educate New Jersey healthcare providers about state-of-the-art early diagnosis and treatment techniques for melanoma.

ME-1.1.2 Develop and distribute a resource guide specific to melanoma to promote awareness of state-of-the-art diagnosis and treatment. Using this tool, patients will be able to locate providers in their area for melanoma prevention, detection, treatment, and referral.

ME-1.1.3 Develop an awareness campaign targeted to New Jersey residents regarding state-of-the-art treatment and diagnosis of melanoma.

Objective ME-1.2

To develop an alliance with businesses and organizations to develop skin cancer media campaigns promoting public awareness and knowledge.

Strategies

ME-1.2.1 Develop and disseminate educational materials and programs in collaboration with other healthcare organizations.

ME-1.2.2 Collaborate with pharmaceutical companies that make sunscreen to launch a skin cancer awareness campaign piggybacked on their product marketing.

ME-1.2.3 Partner with cosmetic companies and other industries to launch a skin cancer awareness campaign piggybacked on their product marketing.

GOAL ME-2

To decrease the exposure of New Jersey residents to UVR from the use of tanning beds and booths.

Objective ME-2.1

To increase awareness among the public and healthcare professionals of the risk of melanoma associated with UVR exposure from the use of tanning beds and booths.

Strategies

ME-2.1.1 Partner with other organizations to develop and disseminate an awareness campaign emphasizing the risks associated with UVR exposure from the use of tanning beds and booths.

ME-2.1.2 Advocate for legislation mandating the provision and posting of Task-Force-approved educational materials at all licensed tanning salons emphasizing the risks associated with UVR exposure from the use of tanning beds and booths.

ME-2.1.3 Advocate for legislation mandating that all commercial tanning salon print, radio, and television advertisements include a Task-Force-approved statement of the risks associated with UVR exposure from the use of tanning beds and booths.

Objective ME-2.2

To increase regulations imposed on commercial tanning salons operating in New Jersey.

Strategies

ME-2.2.1 Advocate for licensing fees for tanning salon operators. Recommend that revenue generated from tanning salon licensing fees be utilized to advance melanoma programs and research.

ME-2.2.2 Advocate for the development of a state-sponsored certification program to educate tanning salon employees about proper use of tanning beds and booths, the risks associated with UVR exposure from the use of tanning beds and booths, the signs and symptoms of melanoma, and alternatives to UV tanning. Mandate that all tanning salon employees complete the program within sixty (60) days of hire date.

ME-2.2.3 Advocate for the development and systematic enforcement of regulations limiting the duration, frequency, and intensity of indoor tanning based on Food and Drug Administration guidelines.

ME-2.2.4 Advocate for legislation mandating that all commercial tanning salons maintain written records of parental consent for customers under the age of 18.

EDUCATION

Schools, worksites, and the community present ideal venues for educating the public about issues surrounding melanoma prevention and detection. The Melanoma Workgroup recommends educational initiatives be implemented in all three areas.

School-based education. New Jersey school districts must continue to be committed to the promotion of comprehensive school health education in the form of Kindergarten through 12th-grade health instruction that is planned, documented, sequential, and age appropriate. It is recognized that classroom instruction is not effective unless coordinated with, and reinforced by, policies and programs within other components of the school health program. School personnel need to work together with community representatives to ensure that the health needs of students are met and that the school health program reflects the interests of both school and community.

Awareness of the increasing rate of melanoma incidence must be presented to school health educators to impress upon them the seriousness of the problem in our state. The incidence rates can be lowered, and the behaviors of the student-aged population can be modified with assistance from these school health professionals.

Schools can promote sun safety in two ways: through educational interventions and policy changes. Education on prevention meets one need as evidenced by the rate of incidence statistics for the state of

New Jersey. Outcomes resulting from school health education on the prevention, detection, and screening of melanoma will not have immediate impact on the incidence rates but will rather provide a foundation of support for long-term sun-safe programs and policies within the school setting. Sun-safe community promotion can augment existing sun-safe messages, if present, or encourage the school administration to review existing instruction and policies relating to sun safety.

Secondly, schools can promote sun safety through updated policies and by providing environmental support. School policies may address such issues as scheduling outdoor activities before or after those times of day when the sun's rays are most intense and by encouraging all participants in outdoor activities to wear sun-safe clothing, hats, and sunscreen. Providing environmental support by increasing the amount of shade on the school campus is an important way schools can decrease student exposure to the sun. Increasing shade may include planting additional trees in open spaces, erecting temporary and permanent shade structures in such places as lunch areas and playgrounds, and making indoor space available to students for days and/or times when the sun's rays are especially intense.

Community education. Strong evidence exists that melanoma is being detected earlier than previously, particularly after community educational campaigns.[25] Community education efforts include spreading awareness of the damaging effects of natural and artificial UVR, the importance of practicing sun-safe behaviors, and the need to perform self-screening and how to recognize potentially malignant changes.

Worksite education. Employers can have a significant impact on employee behavior by providing employees with education on prevention, detection, and screening for melanoma. The Melanoma Workgroup recommends encouraging employers statewide, particularly those whose employees spend time outdoors, to provide melanoma education to all employees.

GOAL ME-3	To increase the practice of prevention behaviors among youth by instructing students in all New Jersey public school districts on prevention, detection, and screening for melanoma and other skin cancers.

Objective ME-3.1

To include in the curriculum of all public schools, and enhance where necessary, instruction on prevention, detection, and screening for melanoma and other skin cancers. This is supported by New Jersey Statutes Titles 18A:40-32 Cancer Awareness Week and 18A:40-33 Cancer Awareness Program for School-Aged Children.

Strategies

ME-3.1.1 Train representatives from school districts about melanoma and skin cancer prevention, detection, and screening.

ME-3.1.2 Implement incentives for training by providing professional development hours or continuing education credits relating to skin cancer.

ME-3.1.3 Partner with other healthcare organizations to train appropriate professionals in school districts on proven skin cancer prevention programs, e.g., Sun Safe Communities.

ME-3.1.4 Educate parents at PTO/PTA meetings regarding prevention, detection, and screening for melanoma and other skin cancers.

ME-3.1.5 Implement an awareness project via the school district's internal media capabilities to educate students about prevention, detection, and screening for melanoma and other skin cancers by providing interactive information about melanoma and other skin cancers. Websites must be approved and listed by the school.

ME-3.1.6 Develop a partnership with a pharmaceutical company to launch a school-based skin cancer awareness campaign in conjunction with the company sunscreen product.

GOAL ME-4	To increase the proportion of school districts that provide structural sun protection and have sun-safe environmental policies.

Objective ME-4.1

To survey and evaluate the facilities and policies of all school districts to determine which schools have structural sun protection and sun-safe environmental policies.

Strategy

ME-4.1.1 Establish a baseline of school districts that have sun-safe policies and encourage improvement of their sun-safe policies where necessary.

GOAL ME-5	To promote worksite education by employers to employees on prevention, detection, and screening for melanoma and other skin cancers.

Objective ME-5.1

To partner with employers in providing employee education on prevention, detection, and screening for melanoma and other skin cancers.

Strategies

ME-5.1.1 Create and track an awareness campaign encouraging employers statewide to provide employee education on prevention, detection, and screening for melanoma and other skin cancers.

ME-5.1.2 Pilot and implement presentations to employers, emphasizing those industries with "sun-exposed" employees, e.g., agricultural, construction, childcare, recreation, etc. and then roll out to other industries.

GOAL ME-6	To educate the community on prevention, detection, and screening for melanoma and other skin cancers.

Objective ME-6.1

To provide public health educational opportunities relating to skin cancer to the citizens of New Jersey at the local level.

Strategies

ME-6.1.1 Develop, implement, and track community public health education programs on prevention, detection, and screening for melanoma and other skin cancers.

ME-6.1.2 Use public service announcements and media campaigns to educate the public on prevention, detection, and screening for melanoma and other skin cancers.

TREATMENT

Surgery remains the most effective treatment for melanoma. Radiation and chemotherapy have proven ineffective. Until 1998, interferon was the only FDA-approved treatment for melanoma; however, it was generally used as an adjuvant therapy to surgery. In 1998, the FDA approved interleukin-2 for the treatment of metastatic melanoma.

Any lesion considered suspicious should be removed for pathologic examination. Excision with removal of the entire lesion with a narrow margin of normal skin is the preferred method of biopsy.[26] Incisional or punch biopsy is acceptable when it is not feasible to remove the entire lesion because of anatomic or cosmetic concerns. In these circumstances, the blackest area of a flat lesion and the thickest portion of a raised nevus should be sampled. Shave biopsies are not recommended when melanoma is suspected.

Clinical trials that have shown the most promise over the last decade have centered on immunotherapy and biotherapy.[27–38] Both have shown measurable success. In 1998 the FDA approved the use of high-dose interleukin-2 (IL-2) for the treatment of metastatic melanoma. Autologous, polyvalent, and peptide

vaccines have shown promise at different disease stages and are being tested in clinical trials throughout the world.[39–43]

Many melanoma clinical trials are available to residents of New Jersey. The Eastern Cooperative Oncology Group, for example, conducts trials in many sites around New Jersey. Investigator-initiated trials are also available at medical facilities such as The Cancer Institute of New Jersey and its affiliates.

Research has minimized the size of the excision required at the primary site. The introduction of the Sentinel Node Biopsy (SNB) has reduced the need for node resections, and the SNB has proven to be a very accurate predictor of metastatic disease.[26] Recent testing of the TA90 glycoprotein antigen has also shown diagnostic promise. Dendritic Cell vaccinations in different combinations have been positive in early testing. Photographic Mole Mapping has become popular with high-risk patients as a monitoring device.

The critical issue, nevertheless, is that the overall cure rate for melanoma is low, and current research is resulting in treatment evolution at a rapid pace. As many clinical trials as possible should be made available in New Jersey to facilitate state-of-the-art treatment for all New Jerseyans. Information on the evolution of available treatment must be continually updated for medical professionals and patients alike.

GOAL ME-7	To ensure that all persons diagnosed with melanoma receive care from New Jersey hospitals and healthcare professionals with demonstrated proficiency in the diagnosis and treatment of melanoma.

Objective ME-7.1

To develop resource material discussing melanoma treatment options and clinical trial information for patients.

Strategies

ME-7.1.1 Promulgate current treatment options as essential considerations in the treatment of melanoma, such as sentinel node biopsy, interferon alpha-2b.

ME-7.1.2 Encourage participation in clinical trials for melanoma, e.g., vaccine therapy.

Research and Surveillance

Mutations in the *p16* gene have been shown to increase the risk of developing melanoma. The *p16* gene, when functioning normally, acts as a tumor suppressor, preventing the abnormal proliferation of cells. When the gene is damaged, however, cells grow unimpeded, leading to tumor development. Approximately 20% of families with hereditary melanoma have the *p16* genetic mutation.[7]

A newly developed test is able to detect mutations in the *p16* gene in order to identify high-risk individuals. This recent advance will allow physicians not only to identify high-risk individuals, but also to target screening and early intervention toward those most at risk.

Research is ongoing into the development of new mechanisms for melanoma prevention, early detection, diagnosis, and treatment. Recent advances in genetics have yielded promising new technologies that may very soon significantly boost the fight against melanoma. The Melanoma Workgroup will closely monitor new and emerging research in melanoma and partner with organizations to ensure that both patients and physicians remain up to date on the most currently available technologies and resources.

GOAL ME-8	To ensure that New Jersey residents and physicians remain up to date on the most currently available melanoma technologies and resources.

Objective ME-8.1

To continue to monitor and disseminate current information on advances in melanoma prevention, screening, diagnosis, and treatment.

Strategies

ME-8.1.1 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through CME offerings.

ME-8.1.2 Conduct periodic literature reviews to determine the state of the science in melanoma research and to identify potentially promising new technologies.

Objective ME-8.2

To continue to monitor current melanoma incidence, mortality, and survival data in New Jersey.

Strategy

ME-8.2.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

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CHAPTER 10. Oral and Oropharyngeal Cancer

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ORAL AND OROPHARYNGEAL CANCER

IMPORTANCE OF ORAL AND OROPHARYNGEAL CANCER FOR CANCER PREVENTION AND CONTROL

At the first meeting of the New Jersey Task Force on Cancer Prevention, Early Detection and Treatment, members voted to create a separate workgroup on oral and oropharyngeal cancer, although not mandated to do so in the Executive Order. Task Force members reasoned that oral and oropharyngeal cancer requires special attention. The public is less aware of cancers in this body region than of cancer in other sites. Initial detection of early lesions primarily involves dentists and dental auxiliaries rather than medical personnel. Furthermore, the anatomical location and adjacent structures present unique treatment options.

Oral and oropharyngeal cancer include cancer of the lip, tongue, floor of the mouth, palate, gingiva and alveolar mucosa, buccal mucosa, and oropharynx, as well as the pharyngeal tonsils and salivary glands. It is estimated that in 2007 oral and oropharyngeal cancer will account for up to 34,360 new cancer cases and 7,550 deaths[1,2] representing 2.4% of all new cancer cases and 1.3% of all cancer deaths.[1,2] Males are approximately twice as likely as females to be diagnosed with and to die from oral and oropharyngeal cancer.[1]

As in the case of many cancers, blacks bear a disproportionate disease burden compared to whites. From 1998 to 2002, the incidence rate of oral and oropharyngeal cancers was 20% higher in black males than white males. There was a smaller difference in incidence rates between white and black females. During the same time period, oral and oropharyngeal cancer mortality rates were 82% higher among black males than white males, with a smaller disparity observed among black and white females. Five-year relative survival rates were also higher for whites than for blacks. These disparities are suspected to be attributable, at least in part, to differences in alcohol and tobacco use, known risk factors for developing oral and oropharyngeal cancers.[3,4]

The majority of oral and oropharyngeal cancer cases occur among persons over 45 years of age, and the average age of diagnosis is 64 years for whites and 57 years for blacks.[3] In the United States, oral and oropharyngeal cancers are the sixth most common cancers among white males and the fourth most common among black males.[5,6] From 1975 through 2002, trends in five-year relative cancer survival rates increased from 55% to 62% for whites and from 36% to 40% for blacks.[2]

More than 90% of oral cancers are squamous cell carcinoma. The remaining oral cancers are salivary gland malignancies, melanomas, sarcomas, and lymphomas.[7] Therefore, the primary focus of a cancer control program for oral and oropharyngeal cancers should be squamous cell carcinoma, the predominant type. National efforts to reduce morbidity and mortality associated with oral and oropharyngeal cancer center on two areas: primary prevention and early detection.

The most significant known risk factors for oral and oropharyngeal squamous cell carcinoma are long-term tobacco use and excessive alcohol consumption.[3–6,8–11] Alcohol increases the absorption of carcinogens by the tissues of the oral cavity and oropharynx. Furthermore, research shows that alcohol is also, by itself, a risk factor for oral and oropharyngeal cancer.[12–14] A study of individuals who had never smoked demonstrated that alcohol could more than double the risk of developing oral and oropharyngeal cancer.[12,13] Evidence further suggests that the combined use of both alcohol and tobacco increases an

individual's risk more than the sum of their independent effects.[3] While some studies have shown that the use of the betel (areca) quid, popular in the Asian population, independently increases the risk of developing oral and oropharyngeal cancers, there is a body of evidence showing that the combined effects of chewing betel quid and smoking have more serious consequences for oral cancer risk.[15] Immunosuppression[16] and, in the case of lip cancer, long-term sun exposure[5,9] are also identified risk factors. There is increasing evidence to suggest that the consumption of fruits and vegetables may be associated with a reduction in the risk of oral and oropharyngeal cancers.[17,18] Immunosuppressed patients, particularly those diagnosed with HIV/AIDS, are at increased risk for many types of cancer that may present in the oral cavity and pharynx, including squamous cell carcinoma, Kaposi sarcoma, and non-Hodgkin's lymphoma.

Evidence is also growing to support previous reports that infection with human papillomavirus (HPV), particularly genotype 16, is an independent risk factor for squamous cell carcinoma of the oral cavity and oropharynx.[19] One study found HPV 16 DNA in 50% of oropharyngeal cancers and 36% of oral cavity cancers. It appears that HPV-related oral cancers are associated with an improved prognosis.[19,20] The availability and use of the recently approved HPV vaccines, which have been proven effective in preventing HPV 16 and HPV 18 infections, may result in an eventual decline in HPV-related oral cancers, especially if the vaccine is provided to both men and women.

The most significant indicator in predicting survival is the stage of disease at time of diagnosis. Cases diagnosed in the early (localized) stages have a five-year survival rate of more than 82%, while cases diagnosed in the late (advanced) stages have a poor five-year survival rate, less than 25%.[21] According to the National Cancer Institute (NCI), only one-third of cases are diagnosed in the early stages, whereas two-thirds have already spread regionally or have metastasized.[21] For blacks, the statistics are far worse than for the population as a whole—75% of oral and oropharyngeal cancers in this segment of the population have regional or distant spread at the time of diagnosis.[21]

In a recent study, approximately 86% of dentists and 79% of dental hygienists reported that they routinely provide oral cancer examinations to their patients 40 years of age or older at their initial appointment; and 80% and 76%, respectively, indicated they provide this examination at recall appointments.[4] However, very few dentists were found to be routinely offering alcohol abuse and tobacco cessation counseling.[4] While oral cancer screening has become a seemingly routine practice among dental health professionals, these services reach only those individuals who are able to seek oral health services. Due to lack of access to oral healthcare, many people are not offered oral cancer screenings.

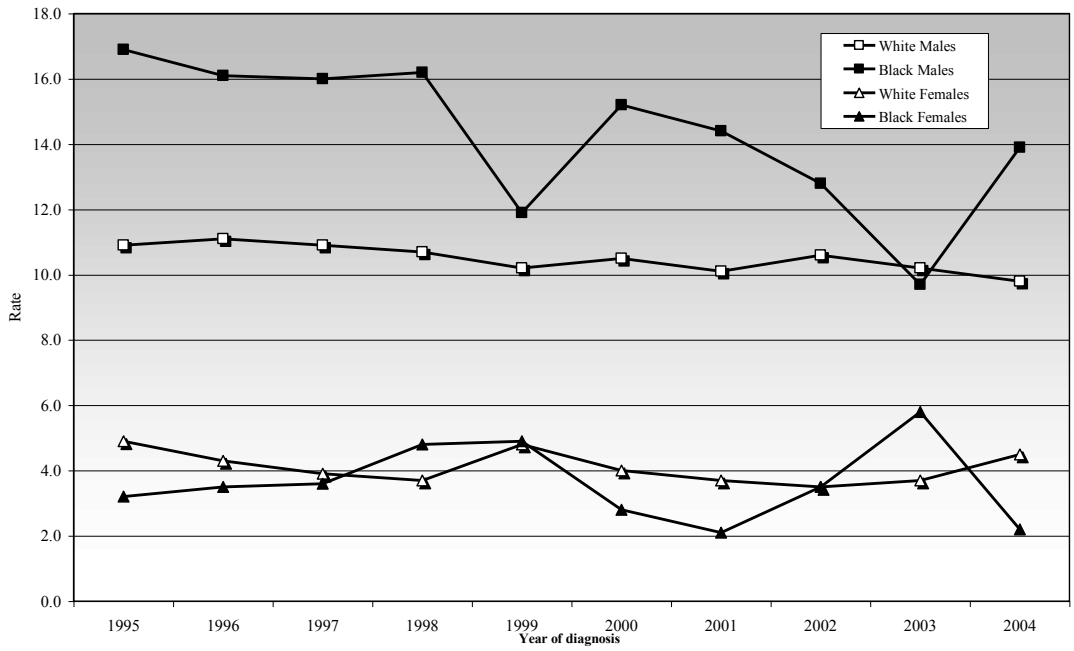
In 1996, the National Institute of Dental Research of the National Institutes of Health and the American Dental Association held the Oral Cancer Strategic Planning Conference to begin addressing oral and oropharyngeal cancer.[8] The national group convened for this conference determined that each state should develop a state model to address oral cancer education, prevention, and early detection. The goals, objectives, and strategies in this *Plan* are based on those developed by the national oral cancer group.[22]

ORAL AND OROPHARYNGEAL CANCER IN NEW JERSEY

In this section we discuss the status of oral and oropharyngeal cancer in New Jersey, including incidence, mortality, prevalence, survival, and risk factors.

Incidence. New Jersey mirrors the national falling trend for oral and oropharyngeal cancer incidence. Since the mid-1980s, New Jersey and U.S. incidence rates for oropharyngeal cancer have been declining.[23] For New Jersey males, incidence rates are higher among blacks than whites. In 2004*, the incidence rate for black males was 13.9 per 100,000** compared to 9.8 per 100,000** for white males. Males have traditionally had higher incidence rates than females in New Jersey (Figure 1). The incidence for females in New Jersey has generally been similar among races. In 2004*, black females had an incidence rate of 2.2 per 100,000** compared to 4.5 per 100,000** for white females (Figure 1).[24]

Figure 1. New Jersey Incidence Rates for Oropharyngeal Cancer by Gender and Race, 1995–2004*



Source: New Jersey State Cancer Registry (NJSCR); rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) standard; rates are for squamous cell only and exclude hypopharynx and nasopharynx.
* Incidence rates for the year 2004 data from the NJSCR are preliminary.

*Incidence rates for year 2004 data from the New Jersey State Cancer Registry are preliminary.
**Rates are per 100,000 and age-adjusted to the 2000 U.S. standard. Rates are for squamous cell only and exclude hypopharynx and nasopharynx.

In a study of New Jersey patients with AIDS, approximately 6% also had a cancer. Of these, 50% had Kaposi sarcoma; 33% had non-Hodgkin's lymphoma; and 17% had lung, oral, and other cancers. This subgroup requires special consideration with regard to diagnosis and management and is discussed separately in the chapter on Emerging Issues.

Mortality. Overall, oral and oropharyngeal cancer deaths in New Jersey mirror the decrease seen in the U.S.[23] In 2003, New Jersey males (all races combined) had a mortality rate of 3.4 per 100,000**, and New Jersey females had a mortality rate of 1.2 per 100,000**. Mortality rates differ by race, with black males generally having higher rates than white males. However, rates for both groups have declined over the years. Mortality rates for New Jersey black males declined from 5.3 per 100,000** in 1995 to 4.2 per 100,000** in 2003; mortality rates for white males declined from 4.0 per 100,000** in 1995 to 3.4 per 100,000** in 2003 (Figure 2). The mortality rates for females in New Jersey remained relatively stable between 1995 and 2003 (Figure 2).[24]

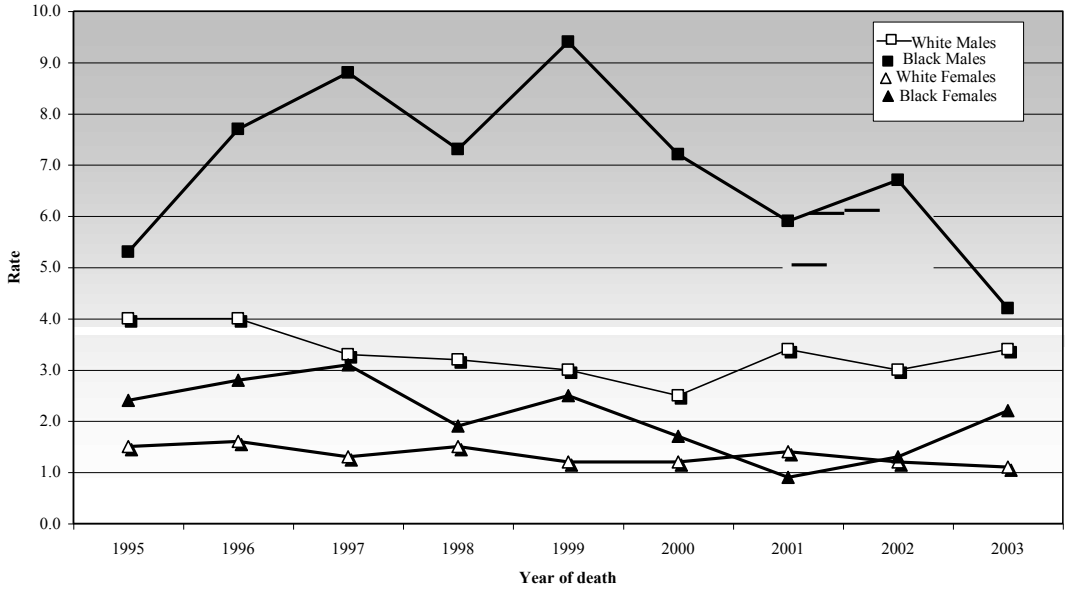
Prevalence. Estimates indicate that on January 1, 2003, there were 6,160 or 0.1% of New Jersey men and women alive who had ever been diagnosed with oral cancer. As with other cancers, the prevalence of oral cancer increases with age and is highest in the 65+ age group (0.3%). The percent prevalence of oral cancer is the same for white males and black males (0.1%). However, the percent prevalence is higher for white females than black females (0.1% versus less than 0.05%, respectively).[25]

Survival. The five-year relative survival rate for oral and oropharyngeal cancer diagnosed in New Jersey (all races combined) from 1994–1997 is 51.1%. This rate is lower than the U.S. rate of 59.0%. Disparities in survival exist between blacks and whites. In New Jersey, black men have a much lower survival rate than white men (29.0% versus 55.2%, respectively) for the period 1994–1997. Black females also have a much lower survival rate than white females (37.8% versus 57.4%, respectively).[26]

With early detection, survival rates are considerably higher. The five-year survival rate for oral and oropharyngeal cancer diagnosed with localized disease is 81%.[27] In 2004, only 32% of those with oral and oropharyngeal cancer in New Jersey were diagnosed in the early stages, and 62% were diagnosed in late stages.[24] Through the use of oral cancer screenings, dentists and primary care physicians can recognize abnormal tissue changes and detect cancer at earlier stages during regular checkups, thereby increasing survival rates.

** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Figure 2. New Jersey Mortality Rates for Oropharyngeal Cancer by Race and Gender, 1995–2003

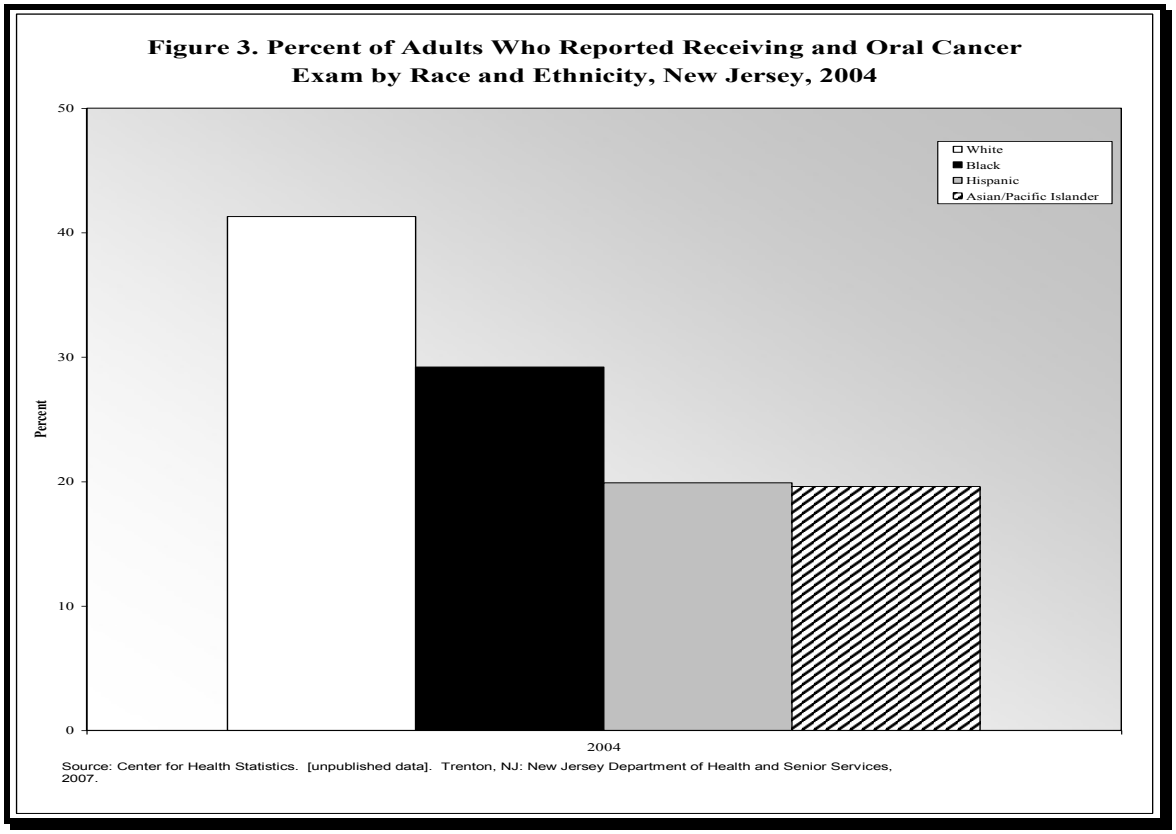


Source: National Center for Health Statistics; rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

Risk factors. According to the 2004 Behavioral Risk Factor Surveillance System (BRFSS), 75.8% of New Jersey residents visited a dentist or dental clinic within the preceding year. Since a majority of residents are already visiting dentists, an opportunity exists to increase the number of routine oral cancer examinations in this setting. Little or no difference is observed for gender or age, and dental visits are positively associated with education and income level. When these data are analyzed by race and ethnicity, a disparity in dental care in New Jersey becomes evident. While this disparity has lessened in recent years for whites and Hispanics, it has not improved among the black population. In 2004, 20.2% of whites surveyed responded that they had not visited a dentist or dental clinic in the past year, compared to 32.2% of blacks and 33.4% of Hispanics. Comparatively, in 1999, 24.4% of whites, 29.9% of blacks, and 41.1% of Hispanics responded negatively to the same question. The racial and ethnic disparities in dental care persist among the black population.[28]

In order to measure public awareness of oral cancer in New Jersey, the Oral Cancer Workgroup requested that state-added questions be included in the 2004 New Jersey Behavioral Risk Factor Survey. According to 2004 data, almost 85% of residents indicated that they had heard of oral cancer. The response was highest in whites (92.0%), followed by Asian/Pacific Islanders (79.4%), blacks (76.7%), and Hispanics (54.5%). Awareness of oral cancer is similar for males and females of all races and ethnicities. Data from the 2004 survey indicate that those who have heard of oral cancer are not very aware of the early signs of the disease. The following percentages of adults who had heard of oral cancer were aware of these early signs: white or red patches in the mouth (9.8%), sores or ulcers in the mouth that do not heal (69.4%), swelling that does not go away (2.3%), and bleeding in the mouth (5.8%). Almost 95% of respondents who had heard of oral cancer were aware that tobacco increases the risk of the disease, but only about 30% were aware that alcohol and sun exposure also increase the risk of oral cancer. In order to estimate the percent of New Jersey residents that receives oral cancer exams, a

question regarding oral cancer exams was also added to the New Jersey Behavior Risk Factor Survey. In 2005, 34.9% of respondents (all races and ethnicities) responded that they had ever had an oral cancer exam. Responses were similar for men and women (35.1% and 34.7%, respectively), but highest in whites (41.3%), followed by blacks (29.2%), Hispanics (19.9%), and Asian/Pacific Islanders (19.6%) (Figure 3).[29] Based on these data, public education on oral cancer is greatly needed to increase awareness of this disease and the availability of screening.



Conclusions. To target oral and oropharyngeal cancer in New Jersey and the surrounding region, the Oral Cancer Consortium was formed in 1998 by a group of professional and public health organizations and agencies united by a common mission. The Oral Cancer Consortium is dedicated to the prevention, early detection, and discovery of the biological basis and treatment of oral and oropharyngeal cancer among the citizens they serve and society at large. To educate healthcare professionals and the public about the importance of comprehensive oral and oropharyngeal examinations, the Consortium emphasizes the following: community outreach to increase public awareness, prevention to change habits and environmental factors, early detection to effect the highest cure rates, clinical trials to develop best-treatment practices, research into the biological basis for disease to prevent occurrence, and application of outcomes in treatment to cure the disease in affected populations.

HEALTHY NEW JERSEY 2010 GOALS

Healthy New Jersey Goal	Reduce the percentage of oral and oropharyngeal cancer diagnosed in the late (regional and distant) stages of disease to 40.0 % for all males and 35.0% for all females by 2010.

Table 1. Percentage of oral cancers diagnosed in late stages, New Jersey, 1999–2002, and Healthy New Jersey 2010 projected target rates.

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
White males	58.1	56.8	60.1	62.2	40.0	20.0
Black males	68.1	75.5	65.9	67.9	40.0	20.0
White females	43.8	48.0	41.1	48.4	35.0	15.0
Black females	52.3	61.5	72.0	75.7	35.0	15.0

Source: New Jersey Department of Health and Senior Services, Center for Health Statistics, Healthy New Jersey 2010: Update 2005.

GOALS, OBJECTIVES, AND STRATEGIES

In support of the Healthy New Jersey 2010 goal for oral and oropharyngeal cancer, the recommendations of the Oral and Oropharyngeal Cancer Workgroup are summarized below for the following focal areas:

- Public awareness
- Public access
- Professional awareness and education
- Research and surveillance

PUBLIC AWARENESS

The Oral and Oropharyngeal Cancer Workgroup defined public awareness and education as the highest priority in oral and oropharyngeal cancer control in New Jersey. Early detection and treatment methods are the most successful mechanisms for reducing morbidity and mortality from oral and oropharyngeal cancer.[30,31] It is therefore essential to raise public awareness about lifestyle behaviors that put one at increased risk. The public must also be informed about the signs and symptoms of oral and oropharyngeal cancer. Finally, the public needs to know about professionals and facilities that employ proven, state-of-the-art early detection and treatment methods.

Despite the success achieved under the first edition of this *Plan*, increasing awareness of oropharyngeal cancer, its risk factors, early signs and symptoms, and the need for screening remains a top priority. The workgroup recognizes a lack of resources to measure public awareness of the issues surrounding oral and oropharyngeal cancer as a barrier to implementation.

Although the overall level of knowledge about risk factors for oral and oropharyngeal cancer is low, adults who have a higher level of knowledge of risk factors for oral and oropharyngeal cancer are more likely to have an oral and oropharyngeal cancer examination.[32] These findings are consistent with trends seen for other cancers, including cervical, breast, and colorectal, suggesting that conducting comprehensive educational interventions might increase the number of oral and oropharyngeal cancer examinations being conducted.[33]

Currently in New Jersey, additional public awareness and education efforts for oral and oropharyngeal cancer are needed to enhance those already under way. The Oral Cancer Consortium, whose mission includes raising awareness in the general public, conducts an annual screening that is widely advertised. The New Jersey Department of Health and Senior Services Children's Oral Health Education Program provides oral health education to school-aged children throughout the state's 21 counties. The age-appropriate programs, employing a variety of teaching methods, address smoking and spit tobacco cessation, good oral hygiene practices, and oral cancer awareness. The New Jersey Dental Association's statewide programs for Children's Dental Health Week expose New Jersey children to important information about tobacco and proper diet, as well as care of teeth and gingiva. The mission of the New Jersey Breathes Tobacco Control Coalition, a 47-member statewide agency, is to alter the social norm of tobacco acceptance fostered by the tobacco industry. Through awareness and education, New Jersey Breathes has been instrumental in providing support for tobacco control policies, increased tobacco taxes, and increased access to nicotine treatment, with the ultimate goal of reducing tobacco

consumption, thus improving the health of New Jersey residents. Data from the New Jersey Comprehensive Tobacco Control Program indicate that the percentage of New Jersey adults who were current smokers significantly declined from 19.8% in 2000 to 17.4% in 2005. Any new tobacco control and oral health programs should build on existing activities, such as those of the New Jersey Comprehensive Tobacco Control Program.[34–37] However, existing activities are insufficient, as oral and oropharyngeal cancer incidence and mortality have remained fairly steady for most groups over the past several years (Figures 1 and 2).

The Oral and Oropharyngeal Cancer Workgroup recognizes the importance of enhancing public awareness efforts already under way in New Jersey. Although cognizant of the fact that this is only the beginning of a continuous, dynamic process, the workgroup proposes two areas in which funds and resources can be dedicated to begin work. First, the workgroup suggests concentrating education and awareness efforts on the population at highest risk. Research has shown that this type of health promotion is necessary to enhance oral and oropharyngeal cancer prevention and early detection.[38] Targeting high-risk segments of the population for educational programs can be accomplished by first determining areas of the state where pockets of at-risk individuals reside and then reviewing and improving existing educational materials for use with this population. To enhance work being done during Children's Dental Health Week, scholastic education about oral and oropharyngeal cancer should be a component of the standard curriculum. Most importantly, it is essential to collaborate with national and local organizations that have made oral and oropharyngeal cancer education and awareness part of their mission, such as the Oral Cancer Consortium, the American Dental Association, the American Academy of Oral Medicine, the University of Medicine and Dentistry of New Jersey (UMDNJ) New Jersey Dental School, and New Jersey Breathes. Through collaboration, media campaigns can be implemented and high-risk populations can be well targeted.

Secondly, the Oral and Oropharyngeal Cancer Workgroup proposes continuing to work on strengthening laws and regulations concerning tobacco and alcohol, the two primary risk factors for oral and oropharyngeal cancer. Under the first edition of this *Plan*, the Oral and Oropharyngeal Workgroup worked closely with the Lung Cancer Workgroup and Advocacy Ad Hoc Committee to ensure passage of the New Jersey Smoke-Free Air Act (prohibiting smoking inside public buildings), as well as to increase the tobacco tax, making it the highest state tobacco excise tax in the nation. These represented significant steps in limiting tobacco exposure; however, more steps are needed to protect New Jersey residents from tobacco exposure.

Alcohol, as well, is an important risk factor for oral and oropharyngeal cancer, both independently and in combination with tobacco use. Studies have shown that, even among individuals who have never smoked, heavy alcohol consumption is significantly associated with increased risk of oral and oropharyngeal cancers.[12–14]

As a result of the 1996 Oral Cancer National Strategic Planning Conference, the Centers for Disease Control and Prevention issued public health policy recommendations regarding the prevention and control of tobacco and alcohol use as a strategy for reducing oral cancer incidence. These include:

- Increase excise taxes on tobacco and alcohol products to provide targeted funding for oral cancer prevention programs.
- Strengthen and enforce laws regarding youth access to tobacco and alcohol.
- Add strong statements to tobacco and alcohol warning labels about the risk of oral cancer.[8]

Without accurate and appropriate information about oral and oropharyngeal cancer, New Jersey residents, regardless of age, race, or ethnicity, cannot make informed decisions about their own health, including the need to seek out an oral and oropharyngeal cancer examination.[39] By improving the knowledge of the general public about the risk factors, signs, and symptoms of oral and oropharyngeal cancer, all populations will be positively influenced. It is nevertheless critical that education efforts be designed to reach those identified as least likely to receive oral and oropharyngeal cancer examinations. Thus, the Oral and Oropharyngeal Cancer Workgroup proposes the following goal, objectives, and strategies.

GOAL OR-1	To heighten public awareness and knowledge of oral and oropharyngeal cancer and the need for early detection in New Jersey.

Objective OR 1.1

To increase direct public education to groups at high risk for oral and oropharyngeal cancer.

Strategies

OR-1.1.1 Collaborate with the Oral Cancer Consortium and other agencies to coordinate and support national oral and oropharyngeal cancer awareness and education campaigns.

OR-1.1.2 Conduct continual review of the limited number of oral and oropharyngeal cancer educational materials currently available for specific target groups and assess their accuracy, comprehensiveness, reading level, and acceptability.

OR-1.1.3 Encourage addition of comprehensive oral and oropharyngeal cancer education as an essential component to elementary and secondary school health curricula across New Jersey.

OR-1.1.4 Work with the American Dental Association and other professional groups and associations in their endeavors to create a media campaign to increase awareness of oral and oropharyngeal cancer in the general public.

OR-1.1.5 Work with the addictions treatment programs surrounding tobacco, alcohol, and other drugs to increase awareness of oral and oropharyngeal cancer in these high-risk populations.

OR-1.1.6 Maintain representation from the Oral and Oropharyngeal Cancer Workgroup on New Jersey Breathes in order to collaborate with leading tobacco control advocates and to support oral health funding from a larger collaborative.

OR-1.1.7 Maintain an Oral Cancer Workgroup Speakers Bureau.

Objective OR 1.2

To strengthen tobacco and alcohol laws and regulations.

Strategies

OR-1.2.1 Work with New Jersey Breathes to promote tobacco control standards that include oral and oropharyngeal cancer.

OR-1.2.2 Encourage warning labels on tobacco and alcohol products to include oral and oropharyngeal cancer risk factors.

OR-1.2.3 Reinforce no-smoking laws and encourage more comprehensive regulation of tobacco products.

OR-1.2.4 Advocate for expanding legislation promoting indoor and outdoor smoke-free environments.

OR-1.2.5 Support the reduction of youth access to tobacco through Tobacco Age of Sale Enforcement (TASE) Operations and alcohol through the "We Check 21" Program.

OR-1.2.6 Support the increase of tobacco and alcohol taxes.

Public Access

The Access and Resources chapter of the first edition of this *Plan* clearly demonstrated the need for better access and resources for cancer screening, early detection, and treatment in New Jersey. These issues continue to present barriers to New Jersey residents. Since oral and oropharyngeal cancer is one of the most preventable and treatable cancers, improving access and resources is essential to decreasing morbidity and mortality from oral and oropharyngeal cancer. Even if public awareness can be heightened and even if dentists and physicians can be better educated and motivated, access issues are likely to persist as obstacles to early detection of oral and oropharyngeal cancer.[40]

The incidence and mortality data presented earlier in this chapter demonstrate that racial and gender disparities continue to persist. Given the stark differences between oral and oropharyngeal cancer stage at diagnosis and survival data between the nation's black and white populations, as well as the relationship between socioeconomic level and oral and oropharyngeal cancer survival, access issues must be addressed.

The lack of availability of dental health professionals and the inadequate ratio of dentists to specific residents is a major barrier to access to dental care.[41] In New Jersey, as in the U.S., too few dentists are serving the high-risk population. A number of specific urban and rural areas throughout New Jersey have been designated as Dental Health Professional Shortage Areas by the U.S. Department of Health and Human Services due to the lack of availability of dentists.[42,43]

The Oral Cancer Consortium, described earlier in this chapter, has recognized these problems as well. Currently, the member organizations of the Oral Cancer Consortium, along with the Oral and Oropharyngeal Workgroup, have been conducting and promoting free oral and oropharyngeal cancer screening events throughout New Jersey to improve access to care. The Consortium strives to increase the number of patients being screened, increase the number of facilities offering free screening, and improve access to screening for populations at high risk. Additionally, the Consortium is offering public and professional educational programs in early detection of oral and oropharyngeal cancer. However, without a secure source of ongoing funding, the Consortium will not be able to reach the entire dental community, and efforts to educate the general public will be limited.

To complement the work being done by the Oral Cancer Consortium, the Oral and Oropharyngeal Cancer Workgroup proposes the following. First, the Oral and Oropharyngeal Cancer Workgroup and the Oral Cancer Consortium must continue to partner to begin centralizing the oral and oropharyngeal cancer efforts within New Jersey.

Second, the workgroup proposes that hospitals be used as access points to provide at-risk patients with oral and oropharyngeal cancer screening. The Oral and Oropharyngeal Cancer Workgroup recognizes that population segments at highest risk for oral and oropharyngeal cancer may overlap significantly with groups of individuals unlikely to voluntarily seek screening and unlikely to visit a primary care physician and/or dentist routinely. Individuals who may not seek routine medical and dental examinations may become patients at hospitals as a result of illness or accidents. Admission to the hospital may provide the opportunity to screen these patients, particularly those at increased risk for oral and oropharyngeal squamous cell carcinoma. To target populations that might otherwise utilize oral and oropharyngeal cancer screening, but are not doing so because of barriers, the Oral and Oropharyngeal Cancer Workgroup proposes that examinations and screenings be offered in conjunction with other existing services, such as screening for other types of cancer and at meetings for addicted populations.

Third, the Oral and Oropharyngeal Cancer Workgroup recommends that general dental residency programs in New Jersey, particularly those serving urban populations, be supported. Currently, residency programs are supported by aid from the federal government from Medicare reimbursement. Direct medical education aid (DME) and indirect medical education aid (IME) support residency positions. Hospitals support the programs to a certain extent as well. Saint Joseph's Regional Medical Center found that DME and IME offset much of the hospital's expense, and residents can easily justify their existence financially, even in hospitals where most patients are on New Jersey Charity Care or Medicaid.

However, additional dental residency slots in urban hospitals are needed to develop screening programs for all hospital-admitted patients. This approach to more widespread oral cancer screening also requires a multi-disciplinary protocol involving the Emergency Department and the medical and surgical services at these hospitals. Therefore, funding is needed to increase the number of residents and to provide essential professional human resources for the delivery of diagnostic care and treatment to this underserved segment. This early experience will also better prepare young dentists to assume leadership roles in cancer prevention, detection, and care throughout their professional careers.

New Jersey must improve access to oral and oropharyngeal cancer screening and must outreach to all segments of the population. Existing data are inadequate to quantify the relative contributions made by risk factors and barriers to care (e.g., access to prompt and accurate diagnosis and appropriate care,

nutrition and general health, genetics, use of alcohol and tobacco, etc.). The differences noted between black and white New Jersey residents in oral and oropharyngeal cancer incidence and mortality must be further investigated in order to improve access to care for all populations. The following goal, objective, and strategies are offered to begin the process of improving access and resources for oral and oropharyngeal cancer care.

GOAL OR-2	To increase access to oral and oropharyngeal cancer screening and the ability to reach all segments of the population.

Objective OR 2.1

To increase community outreach for oral and oropharyngeal cancer screening.

Strategies

OR-2.1.1 Partner with the Oral Cancer Consortium to determine areas in which collaboration on screening can be effective.

OR-2.1.2 Use the hospital as an access point and develop protocols in these institutions for the oral and oropharyngeal examination of every at-risk patient admitted, beginning with those hospitals with dental residency programs. Additionally, appropriate protocols should be adapted and spread to hospitals that do not have dental residency programs.

OR-2.1.3 Piggy-back oral and oropharyngeal cancer examinations onto existing outreach programs with appropriately equipped facilities to increase screening without creating substantial cost fluctuation, by using the following venues: mobile units; outpatient facilities run by medical centers, nursing homes, and assisted-living facilities; free oral and oropharyngeal cancer screenings in major urban hubs; free oral and oropharyngeal cancer screenings in remote and underserved areas; and free oral and oropharyngeal cancer screenings at meetings for those with addictions, as well as meetings for other high-risk groups.

OR-2.1.4 Partner with New Jersey Department of Human Services Division of Addiction Services and addictions providers to disseminate oral and oropharyngeal cancer education to "12 Step" groups for those with addictions as well as for other high-risk groups.

Professional Awareness and Education

Mortality from oral and oropharyngeal cancer has remained high and, while survival has increased significantly for whites, blacks have experienced very little increase, despite significant advances in cancer treatment.[1,2] It is generally acknowledged that only primary prevention and early detection offer significant opportunities for improving survival statistics and the quality of life of survivors.[30] (The role of healthcare providers in primary prevention is dealt with earlier in this report.) Of the many

obstacles to early detection of oral and oropharyngeal cancer, one that can be overcome is the current inadequacy of education and training among healthcare providers. There is strong evidence that professional awareness, education, training, and motivation fall below desirable levels.[4] Studies have shown that dental health professionals are not as knowledgeable about oral cancer prevention and early detection as they could be and that they recognize these deficiencies.[4,9] As noted earlier, many dentists do not provide annual oral cancer examinations, even though they recognize their importance.[4,5] Furthermore, an insufficient proportion of dental healthcare providers counsel patients on tobacco and alcohol use, the primary risk factors for oral and oropharyngeal cancer. In a recent study, 61% of dentists reported discussing tobacco cessation, and 33% reported discussing alcohol use. The proportion of dental hygienists discussing these risk factors with patients was even lower.[4]

While organized dentistry is beginning to acknowledge this responsibility, there appears to be no strong incentive for any group of clinicians to make oral and oropharyngeal cancer prevention and early detection a priority in the way that dermatologists have for skin cancer detection. As dentistry is beginning to take ownership of this issue, the upgrading of awareness, education, training, and motivation should be applied across many disciplines, including family practice and internal medicine.

The Oral and Oropharyngeal Cancer Workgroup offers three goals by which the involvement of dentists, hygienists, physicians, and nurses in the prevention and early detection of oral and oropharyngeal cancer can be upgraded to have a significant impact on mortality and quality of life for survivors. First, we propose that professional development about oral and oropharyngeal cancer begin with young professionals in medical and dental schools in New Jersey. Second, practicing clinicians should be educated and re-educated about comprehensive oral and oropharyngeal cancer examinations through continuing medical education classes. Third, to ensure that practicing clinicians are receiving training for oral and oropharyngeal cancer, the workgroup recommends that this type of professional education be added to the licensure requirements.

As stated in the public awareness section of this chapter, it is essential that high-risk populations be targeted. One method to reach specific populations is to educate professionals about the high-risk populations and make them more aware of the need to outreach to special populations.

The Oral and Oropharyngeal Cancer Workgroup offers the following goal, objectives, and strategies to address needs in professional awareness and education relating to oral and oropharyngeal cancer.

GOAL OR-3	To upgrade involvement of all dentists and hygienists and those physicians in appropriate specialties in the prevention and early detection of oral and oropharyngeal cancer by increasing the current level of awareness, education, training, and motivation among oral and oropharyngeal healthcare providers.

Objective OR 3.1

To provide appropriate education on oral and oropharyngeal cancer to physicians, dentists, and hygienists in training.

Strategy

OR-3.1.1 Encourage the continuing provision of resources to appropriate educational facilities to incorporate oral cancer screening education.

Objective OR 3.2

To update and upgrade the knowledge and awareness of New Jersey's practicing clinicians in the area of oral and oropharyngeal cancer.

Strategy

OR-3.2.1 Coordinate existing continuing education program for dentists, hygienists, and interested physicians on the primary prevention and early detection of oral and oropharyngeal cancer.

Objective OR 3.3

To assure the citizens of New Jersey that all licensed dentists in the state have adequate baseline knowledge of oral and oropharyngeal cancer prevention and early detection.

Strategy

OR-3.3.1 Recommend to the New Jersey Board of Dentistry that oral and oropharyngeal cancer education become part of the 40-hour requirement for license renewal every two years.

Research and Surveillance

Research is needed on key public health issues, as well as on basic biomedical mechanisms relating to oral and oropharyngeal cancer. Public health research should include both studies to better understand the epidemiology of this disease and outcomes assessments of the effect of early detection and intervention on survival. On the biomedical side, a better understanding of basic biological processes underscoring the natural history of this disease and development of novel treatment strategies are critical.

New Jersey, while experiencing a slightly lower incidence of the disease than the nation as a whole, nevertheless has higher mortality, with cases being diagnosed at later stages. Epidemiological research will identify those populations at higher risk and will help identify susceptible populations for early

detection and intervention. Research into the effectiveness and efficacy of risk-reduction interventions and early detection in oral and oropharyngeal cancer will guide development of policy for broader application.

The histologic type of oral and oropharyngeal cancer is predominantly squamous cell carcinoma, comprising greater than 90% of cases. Prior to the development of frank carcinoma, premalignant lesions may be clinically evident and identified on biopsy as mild, moderate, or severe dysplasia or as carcinoma in situ. Considerable investigation is ongoing into the genetic events leading to the development of squamous cell carcinoma. The basic biological processes of initiation and progression of this malignancy are being addressed, and reliable biomarkers for prognosis and response to treatment are being explored.

The workgroup's recommendation is, therefore, to encourage and support research on the epidemiology of oral and oropharyngeal cancer, the impact of early detection and intervention on oral and oropharyngeal cancer, the pathogenesis of progression or regression of dysplastic lesions in oral and oropharyngeal cancer, chemoprevention of oral and oropharyngeal cancer, and the development of improved technologies for identifying and characterizing oral and oropharyngeal cancer.

GOAL OR-4	To identify high-risk groups in order to maximize interventional and educational impact while permitting evaluation of cost-effectiveness.

Objective OR 4.1

To assess knowledge of oral and oropharyngeal cancer and screening in the public and professional sectors.

Strategies

OR-4.1.1 Survey a random sample of the New Jersey population to measure knowledge of oral and oropharyngeal cancer risks, signs, and recollection of oral and oropharyngeal cancer examinations. The survey will include demographic and geographic variables to assess bias in the sampling procedure.

OR-4.1.2 Survey healthcare practitioners in New Jersey to measure knowledge of oral and oropharyngeal cancer risks, signs, and screening guidelines for oral and oropharyngeal cancer examinations.

Objective OR 4.2

To document prevalence of risk factors for oral and oropharyngeal cancer in New Jersey.

Strategy

OR-4.2.1 Use BRFSS and other data sources (such as the National Health and Nutrition Examination Survey) to analyze the prevalence of tobacco and alcohol use, as well as nutritional habits, in New Jersey populations.

GOAL OR-5	To ensure that New Jersey residents and physicians remain up to date on the most currently available oral and oropharyngeal cancer technologies and resources.

Objective OR 5.1

To continue to monitor and disseminate current advances in oral and oropharyngeal cancer prevention, screening, diagnosis, and treatment and its impact on incidence and mortality.

Strategies

OR-5.1.1 Conduct periodic literature reviews to determine the state of the science in oral and oropharyngeal cancer research and to identify potentially promising new technologies.

OR-5.1.2 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through CME offerings.

Objective OR 5.2

To continue to monitor trends in oral and oropharyngeal cancer incidence, mortality, and survival, especially trends in racial, ethnic, and gender disparities.

Strategy

OR-5.2.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

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CHAPTER 11. Prostate Cancer

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PROSTATE CANCER

IMPORTANCE OF PROSTATE CANCER FOR CANCER PREVENTION AND CONTROL

Prostate cancer is the most common cancer in U.S. men, accounting for about 29% of all newly diagnosed cancers, and the second leading cause of cancer deaths in U.S. men. One in six men will develop prostate cancer over the course of his life.[1] The American Cancer Society estimates that 218,890 cases of prostate cancer will be newly diagnosed in 2007 in the U.S.[1,2]

Risk factors that predispose men to prostate cancer are older age, black race, and a family history of prostate cancer (a history of having an affected first-degree relative at least doubles the risk).[3] Despite increasing research on the subject, the relationship between diet and obesity and risk of developing prostate cancer is as yet unclear. However, obesity and other related conditions, such as diabetes, have been associated with poorer post-surgical outcomes and increased mortality from prostate cancer.[4]

According to the American Cancer Society, more than 65% of all men with prostate cancer are 65 years of age or older.[2] Because prostate cancer usually occurs at an age when conditions such as heart disease and stroke cause death, many men die *with* prostate cancer rather than *from* it. Fewer than 10% of men with prostate cancer die of the disease within five years of diagnosis.[1] However, survival varies by stage at diagnosis and the characteristics of each individual case. Without treatment, men diagnosed with aggressive, or high-grade, prostate cancer have a significantly higher mortality than those with low-grade tumors, regardless of stage at diagnosis.[5] Black men develop prostate cancer at a higher rate than men in any other racial or ethnic group, but the reasons for the higher rate remain unknown. Black men are also far more likely than other men to die of this disease. In the years 1999–2003, 65 of every 100,000 black men died of prostate cancer compared with 27 of every 100,000 white men, 22 of every 100,000 Hispanic men, 18 of every 100,000 American Indian men, and 12 of every 100,000 Asian/Pacific Islander men.[1]

Although the risk factors for prostate cancer are inherent and therefore not preventable, certain tests can be performed for early diagnosis and screening. In 1986, the U.S. Food and Drug Administration approved the prostate-specific antigen (PSA) test as a method to monitor prostate cancer progression. The PSA test permitted the detection of latent and preclinical cancers that cannot be detected by clinical means. As a result, a large number of prostate cancers have been diagnosed that would never have been detected clinically (latent) or were detected earlier than clinical detection would have allowed (preclinical).[6] The prevalence of latent prostate cancers diagnosed at autopsy has decreased significantly with the advent of screening, especially in men over 70 years of age.[7] This suggests that prostate cancers that, in the past, went undiagnosed are now being diagnosed during the patient's lifetime.

Scientific consensus has not yet been reached on the effectiveness of prostate cancer screening in reducing deaths, and effective measures to prevent prostate cancer have not yet been determined. Prostate cancer screening by PSA or digital rectal exam (DRE) may, in fact, lead to the over-treatment of cancers that, if left undetected, would pose no threat to the health of the patient.[8]

Many physicians recommend screening to their patients, and in recent years a substantial proportion of men in the United States have been screened for prostate cancer with PSA, DRE, or both. Although screening detects some prostate cancers early in their growth, it is not yet known whether prostate screening saves lives or whether treatment reduces disability and death from this disease. A recent study conducted in Austria found a 19% reduction in mortality among men who received free PSA screening

compared to men who did not. Ongoing randomized trials in the United States and Europe will better evaluate the survival benefit of prostate cancer screening with PSA.[9]

Guidelines for prostate cancer are controversial primarily because of lack of evidence from randomized trials that early detection and aggressive treatment of prostate cancer can reduce mortality.[2,10,11] Other controversies exist because PSA testing frequently detects prostate cancer in older men, who may well die of other causes long before they are affected by the slow-growing prostate tumor that might otherwise have gone undetected. Additionally, as with other screening mechanisms, patients must contend with the possibility of false positives, anxiety over false positives, drawbacks to aggressive treatment, and the burden of dealing with a cancer that might never have been discovered or affected the patient during his natural life.[3,8]

A recent study published by the American College of Physicians recommends that all men begin prostate cancer screening at age 40 to establish a baseline PSA. PSA levels should be carefully monitored to identify rapid increases. The study also supports screening men older than 70 due to increasing life expectancy. All patients, regardless of age, should be counseled about the risks and benefits of undergoing prostate cancer screening and should discuss their options with a physician.[11]

The Centers for Disease Control and Prevention do not recommend prostate cancer screening but do recommend that men be provided with up-to-date information about screening, including the potential harms and benefits. Several organizations—including the American Cancer Society, the American Urological Association, the National Cancer Institute, and the U.S. Preventive Services Task Force—recommend offering information about the potential harms and benefits of screening in order that men, their physicians, and their families can make informed decisions about screening.[10,12]

For all of these reasons, it is important to educate the public and healthcare professionals about these issues concerning prostate cancer. Then, individuals should be able to make informed decisions about their prostate health in consultation with their doctors and families.

PROSTATE CANCER IN NEW JERSEY

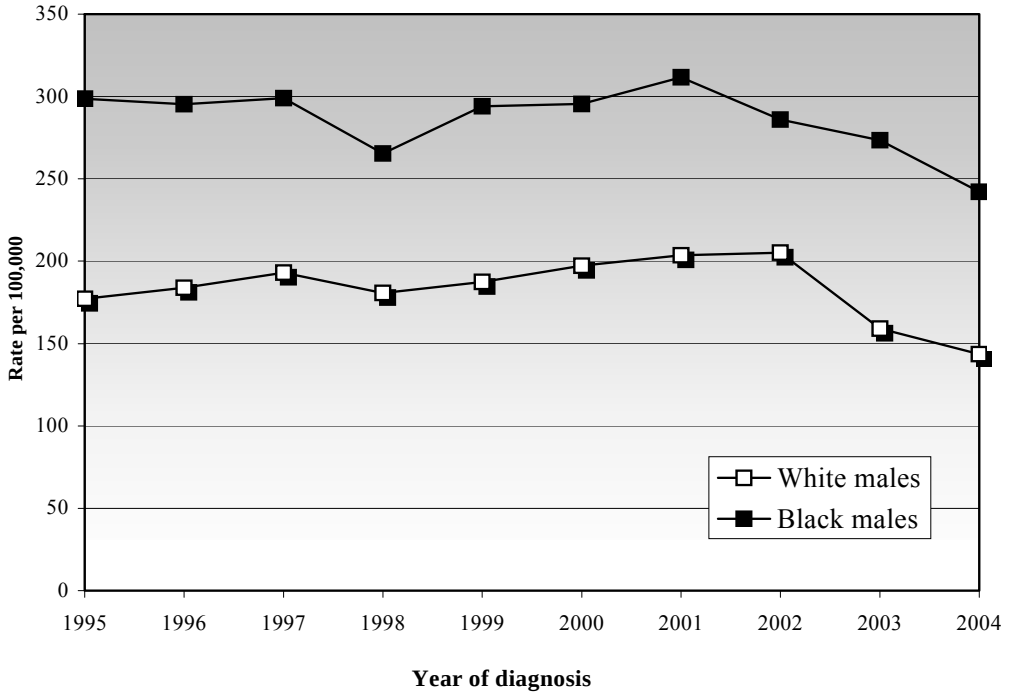
In this section we discuss the status of prostate cancer in New Jersey, including incidence, mortality, prevalence, survival, and screening.

Incidence. Among New Jersey men, about 8,070 cases of prostate cancer will be diagnosed in 2007.[1] In 2004*, 157.7 men per 100,000** were diagnosed with prostate cancer in New Jersey; the rate was 143.6** among white men, 242.2** among black men**, and 157.7** among Hispanic men.[13] Black males have consistently had a higher incidence rate than white males in New Jersey, as well as in the nation (Figure 1).

* Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

A significant decline in the number of deaths from prostate cancer has occurred since 1996, while the number of new cases has declined slowly. However, the burden is not equal. Among black men the toll of prostate cancer is particularly high, with a disease incidence approximately 50% higher than among white men. In addition, black men tend to experience the disease at an earlier age than white men, are diagnosed at more advanced stages of the disease, and die at a rate twice that of white men.[1] Men of all races with close relatives with prostate cancer are also at high risk for the disease. Between 1995 and 2004*, the annual proportion of cases diagnosed in the early stages of the disease (either in situ or localized) increased from about 61% in 1995 to about 85% in 2004*.[13,14,15]

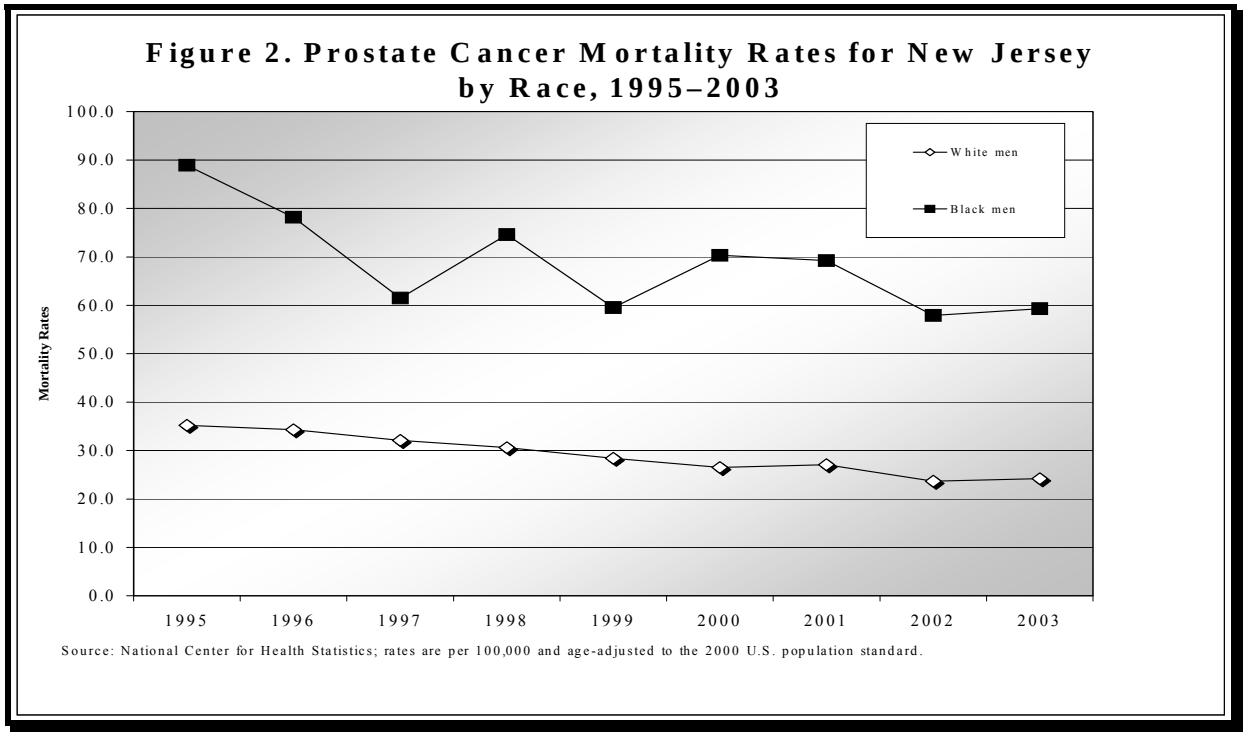
Figure 1. New Jersey Prostate Cancer Incidence Rates by Race, 1995–2004*



Source: New Jersey State Cancer Registry (NJSCR); *rates for the year 2004 data from the NJSCR are preliminary; rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) Standard Population.

Mortality. The American Cancer Society estimates that about 27,050 deaths due to prostate cancer will occur among men in the U.S. in 2007.[1] In New Jersey about 750 men will die of prostate cancer in 2007.[1] Prostate cancer mortality rates have decreased from 1995 to 2003. In whites in 1995 the New Jersey mortality rate was 35.2 per 100,000** compared to 24.2 per 100,000 in 2003; for blacks the rate was 88.9 per 100,000 in 1995 compared to 59.3 per 100,000** in 2003. The mortality rate for Hispanics has also decreased from 1995 to 2003. In 1995, the mortality rate for Hispanics was 26.4 per 100,000** compared to 20.1 per 100,000** in 2003 (Figure 2).[13] This is similar to decreases seen in the U.S. as a whole.[16]

* Incidence rates for the year 2004 data from the New Jersey State Cancer Registry are preliminary.
** Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.



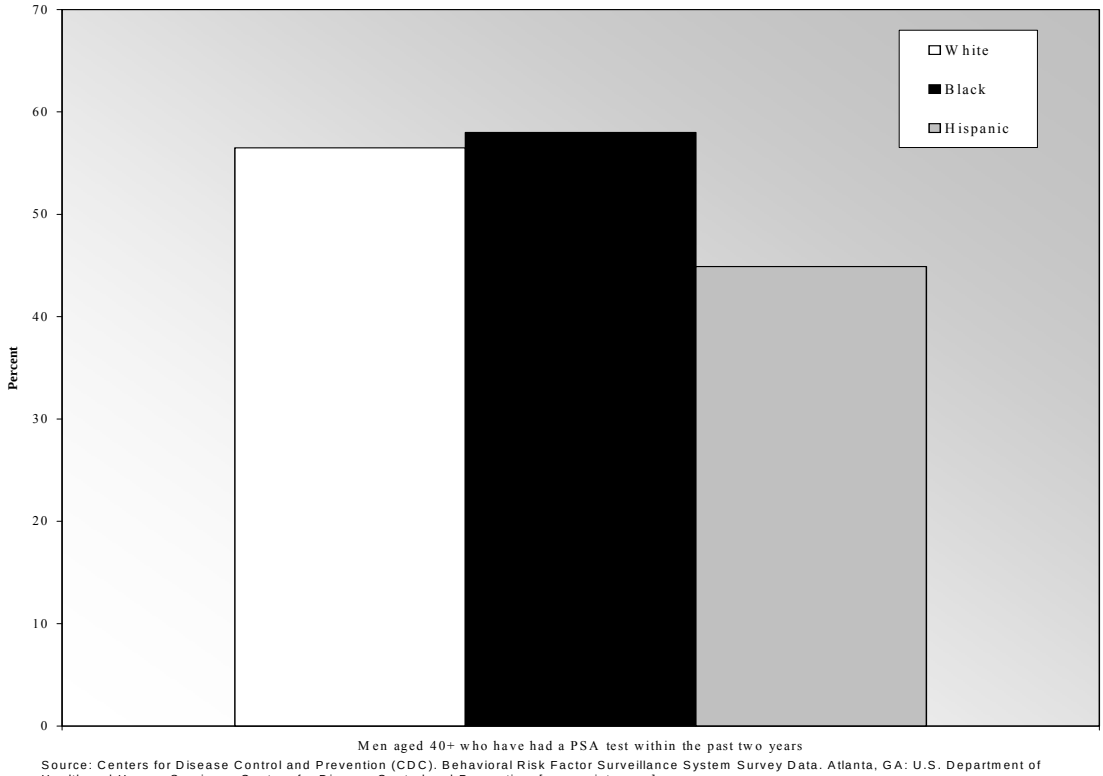
Prevalence. Estimates indicate that on January 1, 2003, there were 61,483 or 1.5% of New Jersey men alive who had ever been diagnosed with prostate cancer. As with other cancers, the prevalence of prostate cancer increases with age and is highest in the 65+ age group (11.0%). The prevalence of prostate cancer is higher in whites than blacks (1.6% versus 1.2%, respectively).[17]

Survival. Similar to the U.S., the five-year relative survival rate for prostate cancer diagnosed in New Jersey (all races combined) from 1994–1997 is very high at 98.4%. Disparities in survival, however, exist between blacks and whites. In New Jersey, black men have a lower overall five-year survival rate than do white men (93.8% versus 99.2%, respectively) for the period 1994–1997 due to a higher proportion of black men being diagnosed at late stage.

Prostate cancer survival rates are much higher for cancers diagnosed at the local and regional stages than at the distant stage. In New Jersey from 1994–1997, the five-year relative survival rate for local- and regional-stage prostate cancer was almost 100%, whereas that for distant-stage prostate cancer was only 28.6%. From 1984–1997 prostate cancer diagnosed at the local stage has increased from 58% to 71% for white men and from 53% to 70% for black men. The five-year survival rate for black men and white men is the same for local disease (100%). However, the survival rate for regional and distant disease is slightly higher for black men than white men (100% versus 97.5% for regional disease and 30.1% versus 27.8% for distant disease, respectively).[18]

Screening. According to 2004 data from the New Jersey Behavioral Risk Factor Survey, approximately one-half of men aged 40 years and older reported having had a PSA test within the past two years. The number of men who reported having had a PSA test increased with age; 27.4% for the 40- to 49-year-old age group, 61.8% for the 50- to 59-year-old age group, 78.2% for the 60- to 64-year-old age group, and 77.5% for men 65 years of age and older. The rate of screening in New Jersey is highest in the black population; 58.0% of blacks reported PSA testing within the previous two years, followed by 56.5% of whites, and 44.9% of Hispanics (Figure 3).[19]

Figure 3. 2004 NJ Behavioral Risk Factor Survey,
Percent of Men aged 40+ who have had a PSA test within the past two years



Source: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [appropriate year]

HEALTHY NEW JERSEY 2010 GOALS

Healthy New Jersey Goal	Reduce the age-adjusted death rate of males from prostate cancer per 100,000 to 23.0 for total males, 23.0 for white males, and 46.0 for black males, ensuring that all efforts are appropriate culturally, linguistically, and at the proper literacy level, by 2010.

Table 1. Age-adjusted death rate from prostate cancer, New Jersey, 1999–2002 and Healthy New Jersey 2010 projected target rates.[20]

Population	1999	2000	2001	2002	Target	Preferred 2010 Endpoint
Total	30.4	29.6	30.0	25.9	23.0	14.0
White	28.4	26.7	27.1	23.8	23.0	13.0
Black	58.4	69.1	68.3	57.5	46.0	25.0
Hispanic	17.5	21.4	14.8	27.1	***	***
Asian/Pacific Islander*	**	**	**	**	***	***

* *The number of Hispanic and Asian/Pacific Islander deaths is known to be understated.*
** *Figure does not meet standard of reliability or precision; based on fewer than 20 cases in numerator.*
*** *A target was not set because the baseline data for this subpopulation were statistically unreliable.*
Note: Data for white, black, and Asian/Pacific Islander include Hispanics and non-Hispanics.

GOALS, OBJECTIVES, AND STRATEGIES

Prostate Cancer Summits were held—most recently in April 2001—to gather New Jersey physicians, researchers, health professionals, patients, advocates, and various organizations to address the serious healthcare crisis in prostate cancer. Four areas for action were identified for New Jersey: public education and awareness, patient/client education for screening and follow-up, access to care, and research and surveillance. Therefore, the Prostate Cancer Workgroup has used these four areas as a basis for addressing prostate cancer in this report.

In support of the Healthy New Jersey 2010 goal for prostate cancer, the recommendations of the Prostate Cancer Workgroup are summarized below for the following focal areas:

- Public awareness and education
- Patient/client education for screening and follow-up
- Access to care
- Research and surveillance

PUBLIC AWARENESS AND EDUCATION

As described earlier in this chapter, scientific consensus has not been reached on the effectiveness of prostate cancer screening in reducing deaths, and effective measures to prevent prostate cancer have not yet been determined. Education and early detection, therefore, represent the two prongs of our approach to addressing prostate cancer in New Jersey. Because there is no consensus on screening for this disease, the public must be educated on the risk factors for prostate cancer, the screening methods, and the options for treatment if cancer is found. The public should be educated about the pros and cons of prostate cancer screening to facilitate informed decision-making.

New Jersey is fortunate in that the New Jersey Cancer Education and Early Detection Program (NJCEED) has a state appropriation of 5.4 million, $900,000 of which is allocated to provide prostate cancer education, outreach, and screening to medically underserved men (Appendix B). If an individual consents to being screened, he is given the PSA and DRE screening tests. If a screening test result is found to be suspicious, the patient is then referred for further examination and work-up. It is hoped that such education and access to screening and treatment services will be instrumental in fighting prostate cancer in New Jersey.

However, the NJCEED program targets only those individuals living at or below 250% of the Federal Poverty Level. Dissemination of prostate cancer information should be broadened to reach all New Jersey residents in order to more widely influence knowledge, attitudes, and practice related to adherence to prostate-healthy behaviors, prevention, and early detection.

Educational and community-based programs can play an integral role in contributing to the improvement of health outcomes related to prostate cancer, specifically in high-risk populations. These programs, when developed to reach those outside of traditional healthcare settings, can be critical to enhancing health promotion and quality of life for New Jersey residents. Interventions that will elicit and ensure participation from populations at high risk for prostate cancer should be a high priority.

One such intervention that has been successfully implemented in New Jersey under the first edition of this *Plan* is the Prostate Net's *Going to the Barbershop to Fight Prostate Cancer* initiative. With the support of the Prostate Cancer Workgroup, the Prostate Net brought this innovative national initiative to New Jersey in 2004. The objectives of the Barbershop Initiative are to:

- Address the situation of racial health disparity prevalent within minority communities through education on disease risk leading to informed disease screening.
- Establish a network of barbershops, medical centers, and other concerned stakeholders (**The Barbershop**) for providing to those at greatest risk consistent, ongoing healthcare communication and motivation to participate in the healthcare system.
- Establish and validate a credible peer educator/communicator (**The Barbershop**) to facilitate delivery of the healthcare messages and to motivate the audience to participate in the healthcare system.
- Address other medical conditions with a negative impact on these communities.

To date, the Barbershop Initiative in New Jersey encompasses 73 barbers and 16 healthcare centers.

In 2005 and 2006, the Prostate Net awarded the Prostate Cancer Workgroup and the Task Force an Honorable Mention at the first annual "In the Know" Awards for Eliminating Health Disparities for its work in implementing the Prostate Cancer chapter of the *Plan*.

The Prostate Cancer Workgroup recommends the continued implementation of such public awareness and education interventions.

GOAL PR-1	To promote a public health message regarding prostate cancer screening and the benefits and risks of early detection, symptoms, and follow-up for normal and abnormal screening and treatment.

Objective PR-1.1

To increase public knowledge among **all** people about the risk factors associated with prostate cancer and the benefits of early detection, especially for men aged 40 years and older who are at high risk, men of African descent, and men with a family history of prostate cancer.

Strategies

PR-1.1.1 Promote educational programs that comprehensively describe prostate cancer screening, the risks involved in screening, symptoms, follow-up, and treatment for all men, including participation in clinical trials.

PR-1.1.2 Monitor to ensure that the educational materials list the pros and cons of prostate cancer screening.

PR-1.1.3 Promote educational programs that describe the issues related to barriers, myths, access, funding for prostate cancer screening, follow-up, and treatment for high-risk individuals throughout the age continuum, especially men of African descent. Promote the provision of these educational programs by partnering with national, local, and statewide organizations.

PR-1.1.4 Identify and partner with community-based organizations for prostate cancer educational programs to further implementation.

PR-1.1.5 Develop and distribute a prostate cancer resource guide for New Jersey residents, as well as a communication plan for public education on prostate cancer.

PATIENT/CLIENT EDUCATION FOR SCREENING AND FOLLOW-UP

Although PSA levels alone do not supply doctors with sufficient information to distinguish between benign prostate conditions and cancer, the doctor will take the result of this test into account in deciding whether to check further for signs of prostate cancer. While there is no definitive PSA level above which the test is considered diagnostic, PSA velocity (the rate at which a patient's annual PSA level increases) and PSA doubling time (the length of time it takes for a patient's PSA level to double) can be used as an indicator to recommend further testing. For this reason, it is important that a baseline PSA be established and followed for any change.[11] Men should discuss PSA or DRE results with their doctors, especially since it is not clear that all men need to be treated immediately for prostate cancer. Men should receive information regarding possible risks and benefits of detecting and treating prostate cancer early. Men who ask their doctors should receive education and information about testing.

According to the American Cancer Society, many factors may cause an individual to refrain from seeking out available screening and educational programs. Personal beliefs and practices, fear, lack of physician recommendation, and lack of access to medical care have all been identified as barriers to cancer screening. Low cancer-screening prevalence is found particularly among adults who have little or no access to medical care, are uninsured or underinsured, have lower education levels, live in rural areas, have language barriers, are members of ethnic minorities, or lack referrals from their physicians. Additionally, people with unhealthy lifestyle practices, such as smoking, are less likely to seek out cancer screening than those with healthy lifestyles.[10]

Currently, men in New Jersey who are eligible can be screened for prostate cancer through the NJCEED program (Appendix B). Yet additional efforts will be required to increase the number of men who seek out screenings. These efforts will demand improved collaboration among government agencies, private companies, non-profit organizations, healthcare providers, policy-makers, insurance companies, survivors, and the general public. No formal state mechanism currently exists to ensure downstream care if prostate cancer is diagnosed through the NJCEED program.

Providing education is the first step to increasing the number of New Jersey residents accessing prostate cancer screening. Increasing knowledge, improving physician recommendations, and creating access to affordable cancer screening tests are important ways to lower barriers to cancer screening. For example,

when offices and/or insurance companies use methods such as computerized reminders for screening appointments, screening rates tend to increase.

GOAL PR-2	To improve client/patient education about prostate cancer screening, risk factors, symptoms, follow-up, and treatment.

Objective PR-2.1

To increase knowledge among men with normal screening results about the need to annually discuss prostate cancer screening, using nationally recognized screening guidelines, with a medical professional.

Strategies

PR-2.1.1 Promote educational materials and resources that provide information on prostate health and screening.

PR-2.1.2 Ensure that distributed materials on prostate health and screening are up to date.

PR-2.1.3 Develop a communication plan for client/patient education on prostate cancer.

Objective PR-2.2

To increase knowledge among men with screening abnormalities about the benefits and risks associated with nationally recognized prostate cancer diagnostic and treatment procedures by providing information and resources.

Strategies

PR-2.2.1 Investigate available prostate cancer educational materials and resources that explain in detail the next steps to be taken following an abnormal screening, the available procedures, and the benefits and risks of each procedure. Develop these materials if needed.

PR-2.2.2 Distribute the above-mentioned materials to men with abnormal screening results for prostate cancer.

ACCESS TO CARE

One of the major barriers to cancer prevention and early detection is lack of access to proper screening. Although screening programs are available, access to care is a problem in medically underserved areas. Studies have shown that those with less than optimal access to care are generally ethnic minorities, unemployed, and have lower levels of education and income, usually below the poverty line.[21]

In New Jersey, challenges within the healthcare delivery system have been identified as a major access issue, along with language and transportation barriers.[21]

A variety of community-based organizations, especially faith-based organizations, specifically design their programs for underserved populations. Local, state, and federal agencies also need to expand their programs to underserved populations.

Partnerships with healthcare providers are essential to facilitate prevention, and selected healthcare providers based on their location should target underserved populations. Establishment of a public announcement system available throughout the state that includes sites, times, availability of transportation, networking system, etc. is also essential.

Currently, eligible men and women have access to screening for breast, cervical, colorectal, and prostate cancers through the NJCEED program. If diagnosed through the program, women may be eligible to receive Medicaid coverage of treatment for breast and cervical cancer. However, there is no program currently in place to provide treatment for those diagnosed with prostate or colorectal cancer. It is essential that funds be allocated to provide treatment to these individuals.

To improve access to care for prostate cancer, the Prostate Cancer Workgroup proposes the following goal, objectives, and strategies.

GOAL PR-3	To increase access to prostate cancer services for all New Jersey men, including education, screening, treatment, and palliative care.

Objective PR-3.1

To increase the number of contacts, e.g., prostate cancer screenings, education, support groups, etc. made available by healthcare practitioners and advocates for targeted populations.

Strategies

PR-3.1.1 Partner with community leaders/community-based organizations, including faith-based organizations, on prostate cancer education and screening programs to create incentives that attract underserved populations.

PR-3.1.2 Identify underserved populations in need of prostate cancer education and screening using credible data available through local, state, and federal agencies.

PR-3.1.3 Identify prostate cancer education and screening services in convenient sites or areas within communities.

PR-3.1.4 Develop strategies to empower significant others to encourage males to seek prostate cancer education and screening services.

PR-3.1.5 Provide advocacy services to help clients with prostate cancer navigate the healthcare system.

PR-3.1.6 Develop strategies to encourage payers to support community-based prostate cancer prevention services since early detection may be more cost effective.

PR-3.1.7 Partner with community-based organizations to address language, education, literacy, cultural, and economic barriers to receipt of prostate cancer education and screening services.

PR-3.1.8 Partner with community-based organizations to develop and offer culturally relevant programs located within easily accessible community sites, e.g., take prostate cancer education and screening programs to community events, bring programs to the people.

PR-3.1.9 Evaluate funding sources through government agencies, insurance and pharmaceutical companies, and foundations to assist in finding ways to increase access to prostate cancer education and screening services.

Objective PR-3.2

To ensure that all men diagnosed with prostate cancer through the NJCEED program have access to follow-up and treatment services.

Strategy

PR-3.2.1 Advocate for funding to be allocated to provide treatment for all men diagnosed with prostate cancer through the NJCEED program.

Research and Surveillance

Prostate cancer is characterized by a wide range of treatment options depending on a patient's age, overall health, status of the cancer, and personal choice. In addition, knowledge about the disease, its

detection, and its treatment is constantly evolving. Physicians, particularly primary care doctors, may find it difficult to remain apprised of new developments and subsequently advise or treat individual patients in an efficient and comprehensive manner.

The Prostate Cancer Workgroup will closely monitor new and emerging research in prostate cancer and partner with organizations to ensure that both patients and physicians remain up to date on currently available technologies and resources.

New research into prostate cancer prevention, early detection, and treatment is ongoing. In order to ensure that research outcomes are applicable to diverse populations, it is important to recruit racial and ethnic minorities to participate in clinical trials. However, significant barriers have been identified that lead to under-representation of minorities in clinical research. A recent study identified barriers to research participation among Latinos and blacks. These included fear of experimentation/harm, lack of transportation, lack of financial resources, time conflicts, mistrust of the healthcare system and medical research, fear of deportation, poor communication, and language barriers. Several factors were also found to motivate minorities to participate in research, including having medical staff from the same racial/ethnic group and having childcare and transportation provided.[22]

Strategies to improve minorities' participation in clinical research should include: (1) effective communication and interaction between research teams and the community; (2) developing culturally sensitive research teams to build trust; (3) planning to eliminate the burden of cost associated with transportation, childcare, and time off from work; (4) improve effective communication regarding the business of research and the benefits to the participant and the community; (5) improve the participant-research team relationship by creating a research environment in which the patient feels valued and respected.[23] Addressing these barriers and providing appropriate motivation is an important step in increasing minority representation in clinical research studies.

GOAL PR-4	To expand a research agenda specific to prostate cancer issues in New Jersey.

Objective PR-4.1

To develop a plan to incorporate men, in demographic groups that are underrepresented, in prostate cancer screening and clinical trials.

Strategies

PR-4.1.1 Identify and develop community leaders as intermediaries between organized medicine and the individual client concerned about prostate cancer.

PR-4.1.2 Develop outreach programs with community leaders to improve client participation in screening and clinical trials.

PR-4.1.3 Increase the quality and the amount of information patients receive to facilitate making informed decisions to seek prostate cancer screening.

PR-4.1.4 Partner with the New Jersey Commission on Cancer Research to encourage researchers to seek out grants in prostate cancer research.

Objective PR-4.2

To facilitate collaboration between institutions providing prostate cancer clinical trials and underrepresented populations.

Strategies

PR-4.2.1 Encourage the physicians of underrepresented populations to refer their prostate cancer patients to clinical trials in New Jersey.

PR-4.2.2 Encourage the physicians of underrepresented populations to participate directly in clinical trials for prostate cancer in New Jersey.

PR-4.2.3 Educate physicians about clinical trials for prostate cancer so that this information can be disseminated to men who may be eligible to participate.

GOAL PR-5

To ensure that New Jersey residents and physicians remain up to date on currently available prostate cancer technologies and resources.

Objective PR-5.1

To continue to monitor and disseminate current advances in prostate cancer prevention, screening, diagnosis, and treatment.

Strategies

PR-5.1.1 Conduct periodic literature reviews to determine the state of the science in prostate cancer research and to identify potentially promising new technologies.

PR-5.1.2 Work with stakeholders to disseminate, as they become available, evidence-based advances to healthcare providers through CME offerings.

Objective PR-5.2

To continue to monitor trends in prostate cancer incidence, mortality, and survival.

Strategy

PR-5.2.1 Request appropriate data, as needed, from the New Jersey State Cancer Registry and other applicable sources.

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Section III
The Future of Cancer Control and Prevention in New Jersey

Chapter 12. Implementation
Chapter 13. Evaluation
Chapter 14. Emerging Trends

CHAPTER 12. Implementation

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IMPLEMENTATION

The Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey, its standing committees, workgroups, and county cancer coalitions (Coalitions) jointly implemented the first *New Jersey Comprehensive Cancer Control Plan* during the period 2003 to 2007. Major accomplishments during this period include: (1) conducting the first-ever statewide capacity and needs assessment in 21 counties, (2) maintaining and expanding funding for cancer prevention and control efforts in the state, and (3) coordinating and documenting the results of collaboration among contributing partners. Achievements in each of these focal areas are described in further detail below.

ASSESSMENT

In 2003, the Task Force conducted the first-ever statewide capacity and needs assessment (C/NA) encompassing all cancer-related activities and resources in each of New Jersey's 21 counties. The C/NA assisted the Task Force and its partners in mapping county-level resources and identifying critical target areas for cancer prevention and control activities. The C/NA also served as a mechanism for assessing gaps, a means to engage additional stakeholders, and a baseline against which to measure future progress. Tangible products of the C/NA include county-based C/NA Report Summaries and companion Fact Sheets, which have been posted on the Office of Cancer Control and Prevention (OCCP) website and distributed throughout the state via the Coalitions. In addition to the Report Summaries and Fact Sheets, an interactive, geocoded website of cancer resources is being finalized as a further way to disseminate the valuable information collected during the C/NA.

The results of the C/NA Report Summaries have been utilized by the 21 Coalitions, which are charged with implementing the *Plan* at the community level. The Report Summaries provide the evidence needed to identify priority cancers in each county, along with specific recommendations for action to effectively reduce the cancer burden. To the extent possible recommendations were coordinated with those in the state-level *Plan*. Further dissemination of the information in the Report Summaries and Fact Sheets is accomplished by the Coalitions as they recruit and retain participants and educate the public on findings pertinent to their community.

The information gathered in the C/NA, kept current through periodic updating, will guide the Task Force, its standing committees, workgroups, and Coalitions in prioritizing evidence-based implementation activities, while also offering the most up-to-date and accurate information to the public via the OCCP website (http://www.njcancer.gov). The New Jersey State Cancer Registry further serves as a valuable aid in helping to prioritize activities to improve the delivery of effective and appropriate interventions to targeted populations.

The activities of the Coalitions, as well as those of the Task Force standing committees and workgroups dedicated to implementing the *Plan*, are captured in an Internal Monitoring Program (IMP) and reported to the Task Force Evaluation Committee bi-annually. The data collected by IMP are a primary data source for the Evaluation Committee in monitoring the progress of the implementation process.

FUNDING

Identifying and attracting funding sources is critical to successful cancer control implementation. Since 2003, the State of New Jersey has demonstrated continued support through annual appropriations. With New Jersey's recognition as a comprehensive cancer control state, cooperative agreements and grant monies have also been received from the Centers for Disease Control and Prevention (CDC). In addition, foundations and non-profit organizations have provided not only financial but also in-kind support for this "organization of organizations" and its undertakings. However, the ongoing process of mobilizing support involves more than merely securing funding. Rather, what is required is a broad campaign that provides visibility for the initiative, develops political will to institute positive change, and enhances awareness of community leaders who then become advocates for both funding and implementing portions of the *Plan*.[1] Since its inception, the Task Force has adopted just such a broad-based approach to garnering support for its mission. In the coming years, its members will continue to pursue this path as they engage current and new partners in comprehensive cancer control, not only for their considerable expertise, but also for their power as key decision-makers who can advocate persuasively for and deliver on commitments to *Plan* implementation.

COORDINATION

As the dedicated program within the New Jersey Department of Health and Senior Services charged with coordinating development and implementation of the *Plan*, the Office of Cancer Control and Prevention (OCCP) has demonstrated its effectiveness in facilitating the process of consensus-building among the diverse participants and activities involved in New Jersey's cancer control efforts.

In 2006, OCCP conducted a stakeholder assessment to gauge the level of satisfaction among individuals currently involved in the comprehensive cancer control program in New Jersey. The assessment demonstrated that stakeholders were highly satisfied in all seven key areas (membership, climate, communication, leadership, implementation, process, and collaboration).[2] Yet continued involvement and expansion of a broad group of stakeholders is essential to the success of cancer control implementation. To this end, the Task Force in May 2006 held a stakeholder summit aimed at solidifying its partnerships through recruitment, retention, recognition, and recommitment. The day-long meeting was structured to inform attendees about the breadth of activities engaged in by those working to implement the *Plan*. The gathering further served as a forum for sharing accomplishments and success stories and identifying prospects for future collaboration and replication of successful programs. The meeting agenda was designed to:

- Detail the efforts of the Plan.
- Identify ways to impact cancer care.
- Highlight best practices from programs around New Jersey.
- Foster collaboration in order to decrease cancer morbidity and mortality, reduce health disparities, and enhance quality of life.
- Foster networking and joint planning.
- Develop projects for partnerships in cancer control.[3]

Successful implementation will continue through the demonstrated effectiveness of the OCCP in facilitating the consensus-building process among a diverse mix of participants and activities. Enhanced emphasis on communication through establishment of a Task Force standing committee charged to develop a communications plan can only improve the dialogue among collaborators. The Communications Standing Committee will utilize guidelines and tools developed by the CDC in generating this plan. The impact of this committee's efforts will be measured by the Evaluation Committee, as well as through ongoing progress monitoring and furtherance of communication with and among partners about programs, resources, and best practices. Coordination and communication will serve to foster synergy among the stakeholders and will ultimately benefit all the citizens of New Jersey through enhanced cancer prevention and control.

GOALS, OBJECTIVES, AND STRATEGIES

The Task Force on Cancer Prevention, Early Detection and Treatment, its standing committees, workgroups, and Coalitions have developed a culturally sensitive plan for state-level action on cancer prevention and control that encompasses prevention, early detection, treatment, rehabilitation, palliation, and quality-of-life issues and will embrace all New Jersey residents. Drawing on its own experiences and best practices, the Task Force can further the reduction of the cancer burden in New Jersey through implementation of the *Plan* and recognizes that coalition-building, partnerships, and education are essential to its fruition. The Implementation Ad Hoc Committee presents the following goal, objectives, and strategies for implementation.

GOAL IM-1	To implement the *New Jersey Comprehensive Cancer Control Plan.*

Objective IM-1.1

To continue updating the resources identified through the cancer capacity and needs assessment process.

Strategies

IM-1.1.1 Identify and update a database inventory of those organizations and programs that engage in or support cancer-related activities.

IM-1.1.2 Investigate additional resources necessary to update cancer-related activities in an ongoing capacity and needs assessment effort in New Jersey.

IM-1.1.3 Partner with key stakeholders to identify gaps in cancer-related programs and activities.

IM-1.1.4 Disseminate results utilizing multiple media, especially the internet.

Objective IM-1.2

To identify funding streams for implementation of the *New Jersey Comprehensive Cancer Control Plan*.

Strategy

IM-1.2.1 Establish a funded, state-level grant-writing position to pursue funding opportunities for the *New Jersey Comprehensive Cancer Control Plan*.

Objective IM-1.3

To coordinate and mobilize key stakeholders for implementation of the *Plan*.

Strategies

IM-1.3.1 Empower Task Force standing committees, workgroups, and county cancer Coalitions to prioritize items in the *Plan* based on current evidence provided by the New Jersey State Cancer Registry among other recognized data sources.

IM-1.3.2 Develop and implement a stakeholder assessment tool annually to assess partner satisfaction, level of involvement, and barriers or challenges to implementation.

Objective IM-1.4

To develop and implement a communications plan for the *New Jersey Comprehensive Cancer Control Plan*.

Strategies

IM-1.4.1 Establish a Task Force Communications Standing Committee charged with development and implementation of a communications plan.

IM-1.4.2 Continue to internally monitor implementation activities of the Task Force standing committees, workgroups, and county cancer Coalitions through assessment of progress made toward achievement of goals, objectives, and strategies for the *New Jersey Comprehensive Cancer Control Plan*.

IM-1.4.3 Continue to share programs, resources, and best practices through such means as a newsletter, website, and/or annual conference.

IM-1.4.4 Based on evaluation of implementation activities, provide for review and revisions and initiate the next planning cycle.

Objective IM-1.5

To plan and coordinate a rollout campaign for the *New Jersey Comprehensive Cancer Control Plan*.

Strategy

IM-1.5.1 Work with the Office of the Governor and the Office of Communications in the New Jersey Department of Health and Senior Services on a statewide rollout campaign to include plan presentation, recognition of participants, and public acknowledgement of the commitment of participants.

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CHAPTER 13. Evaluation

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EVALUATION

Evaluation is critical to ongoing success and utility of the *New Jersey Comprehensive Cancer Control Plan* (the *Plan*). Charged by Executive Order 114 and mandated by P.L. 2005, c.280, the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey is responsible for reporting its progress to the Governor via biennial reports.[1,2] Recognizing the importance of obtaining data on implementation progress over time for the biennial reports to the Governor, the Task Force charged its Evaluation Committee, one of its standing committees, with development of this Evaluation Chapter for the 2008–2012 *Plan*.

An ad hoc committee had reviewed best practices in developing the 2003–2007 *Plan.* In particular, that committee was guided by the comprehensive cancer control model of the Centers for Disease Control and Prevention (CDC) and the successful state-level models developed by Kentucky, Maine, Michigan, and North Carolina. The Committee also considered recommendations from the Battelle Centers for Public Health Research and Evaluation, a consultant to the Task Force throughout the planning process.

A conceptual model developed by Battelle for CDC's Division of Cancer Prevention and Control involves an outcomes-based planning and implementation process.[3] The long-range goal of that process is to achieve significant reductions in the incidence, morbidity, and mortality of cancer. In this model, evaluation is one of the six key "building blocks" in comprehensive cancer control. Evaluation is needed to monitor progress and record results for accountability purposes, but also to identify problems and facilitate ongoing program improvement. Following this model, New Jersey built evaluation into its first comprehensive cancer control plan to assist Task Force members in assessing and documenting success over time. Thus, evaluation has been part of New Jersey's planning process from the outset. An example of this ongoing commitment to evaluation is the fact that evaluation activities are regularly conducted after each Task Force, workgroup/committee, and county cancer Coalition meeting to benchmark participant satisfaction and to guide "continuous quality improvement" of processes.

Comprehensive cancer control is a highly complex and dynamic program, and many of its outcomes are relatively intangible and difficult to measure, such as improved working relationships among partners.[3] Assessing some health outcomes prematurely (such as changes in morbidity and mortality or in disparities) can be misleading; there is a need to maintain a long-term perspective as the anticipated health improvements are expected to take time to become evident and measurable. While improved health outcomes remain always in view as the ultimate goals desired, they will not be achieved until some years hence. Task Force efforts during the first *Plan* concentrated on building an infrastructure able to implement the statewide cancer *Plan* that New Jersey cancer experts believe will lead to the desired health outcomes.

The Task Force delegated to the Evaluation Committee the preparation of an evaluation plan to be utilized during the 2003–2007 period of the *Plan*. This evaluation plan[4] included an overview of the timeframe and reporting for activities related to evaluation of the *Plan*, a description of the evaluation components, and delineation of the primary data to be utilized in evaluation.

Materials were developed for evaluation by the New Jersey Department of Health and Senior Services (NJDHSS) Office of Cancer Control and Prevention (OCCP) and the Evaluation Team (based in the Department of Preventive Medicine and Community Health at the University of Medicine and Dentistry of New Jersey [UMDNJ] New Jersey Medical School), and these were reviewed and endorsed by the

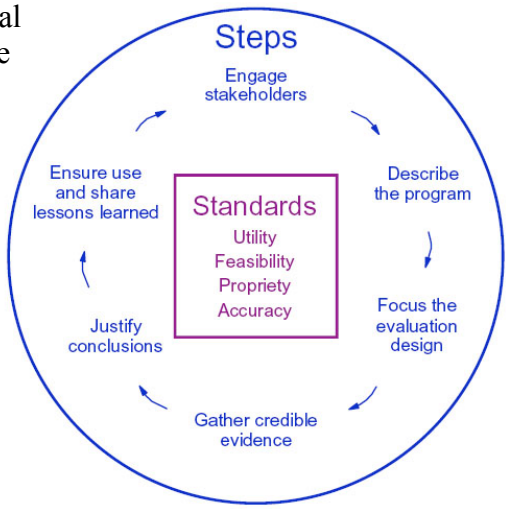
Evaluation Committee. Outside consultants were utilized at the discretion of the OCCP, the Evaluation Team, and/or the Evaluation Committee to enhance breadth of experience.

The 2004 biennial *New Jersey Comprehensive Cancer Control: Status Report to the Governor (*the *2004 Status Report)* identified issues that were not addressed in the *Plan*. These included assessing cancers that were not among the original seven priority cancers (but may be on the rise or were identified as emerging trends) and addressing evolving matters concerning the priority cancers.[5] The OCCP accepted responsibility for addressing these issues and distributed the recommendations to the appropriate workgroups for further consideration. The *2004 Status Report* further documented many successes and described systems that were being established to measure long-term health outcomes.

As part of the initial implementation of the *Plan*, a thorough and structured comprehensive capacity and needs assessment (C/NA) process was conducted.[5] This county-based effort established a well-documented baseline status that will assist eventually in measuring long-term health outcomes. A systematized compendium of recommendations from these C/NA reports was developed by the Evaluation Team.[6]

The cancer control community recognizes that availability of adequate evaluation data is critical for effective implementation of comprehensive cancer control plans, as well as for development of future plans.[7] While the Evaluation Committee realizes that improvements in incidence and mortality are the critical long-term goals, measurement of the ongoing process to achieve those changes is also essential. Thus, one component of evaluation is assessment of the entire comprehensive cancer control program, as an ongoing process. Such program evaluation has the dual goals of showing that a program works and of further improving the program.[8] Figure 1 below depicts CDC's recommended framework for program evaluation in public health.[9]

Figure 1. Steps in CDC's Framework for Program Evaluation in Public Health



Understanding how the program functions, examining the internal and external factors that influence the program, and assessing the impact of the program on participants, organizations, and the community provides stakeholders with necessary information to improve the program. The evaluation plan,[4] effective through December 2007 for the first five-year implementation period, was developed using the framework recommended in the W.K. Kellogg Foundation *Logic Model Development Guide*.[10] It uses the three-tiered evaluation design outlined below. Integration of these three different aspects of evaluation is critical to understanding how and why a program is working, monitoring the program, and developing recommendations for improvement as needed.[4,11]

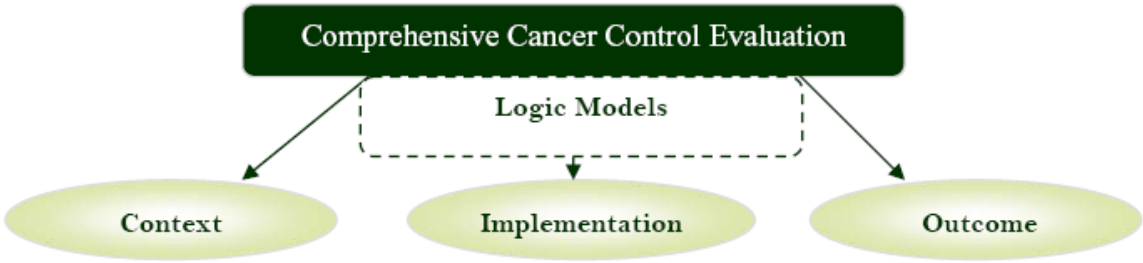
Context evaluation describes how the program functions within its environment and can help identify strengths and weaknesses of the program and the effect of unanticipated and/or external influences on the program.

Implementation evaluation seeks to assess how well the program tasks are being performed relative to their specifications in the *Plan*.

Outcome evaluation addresses progress toward the desired change in individuals, organizations, communities, and/or systems as a result of the program. The effectiveness of the program's activities is assessed.

Reducing the cancer burden is a long-term process. Changes in many types of outcomes generally take years or decades to observe. The tiered evaluation structure described above lends itself specifically to early assessments that are more heavily focused on process, rather than outcomes. Thus, this approach has been particularly appropriate for New Jersey, which is still in the first years of comprehensive cancer control planning. This type of logic model was utilized in developing the 2006 biennial *New Jersey Comprehensive Cancer Control: Status Report to the Governor and Legislature* (the *2006 Status Report*).[11] Figure 2, below, depicts the evaluation logic model used.[12]

Figure 2. Comprehensive Cancer Control Evaluation Logic Models



During the time period 2008–2012 of this second *Plan*, continuing emphasis on process evaluation will be appropriate. In accordance with CDC recommendations, the *Plan* should continue to include explicit clarification of how goals and objectives are linked with strategies and to outcomes. Evaluation of the *Plan* will need to begin to shift toward increased inclusion of assessments of outcomes. Thus, as future evaluation plans are developed, data collection efforts and analysis plans, including specific measures and time frames for their assessment, will need to be continually delineated and refined.

CDC requires reports to include an evaluation component. CDC anticipates, for these annual reports, that assessment of performance will include measurement of state- and local-level policy changes regarding important cancer control outcomes including physical activity, nutrition, tobacco, screening, tanning, insurance coverage, and professional education. CDC recommends that data be gathered from such sources as state population-based central cancer registries, the Behavioral Risk Factor Surveillance System (BRFSS), the Youth Risk Behavior Surveillance System (YRBSS), and vital statistics. The reporting efforts for CDC should be coordinated with the state-mandated biennial status reports for efficiency and continuity.

The Task Force and the OCCP recognize the continuing importance of utilizing an outside agency to develop and implement an Evaluation Plan, based on the success of this approach in evaluating New Jersey's first *Plan* as well as the earlier experiences of the New Jersey Comprehensive Tobacco Control Program. CDC concurs that monitoring progress and measuring outcomes against plan goals, objectives, and strategies may require the services of an outside evaluator.[3] CDC has enthusiastically commended New Jersey for its approach and its thorough evaluation efforts. Two comprehensive reports have been issued thus far,[5,11] and these are available from the OCCP.

GOALS, OBJECTIVES AND STRATEGIES

The goal, objective, and strategies developed by the Task Force's Evaluation Committee to implement ongoing evaluation for New Jersey's comprehensive cancer control process are presented below.

GOAL EV-1	To evaluate the *New Jersey Comprehensive Cancer Control Plan* by: • Assessing the implementation and effectiveness of its strategies • Determining its impact on the knowledge and behavior of the citizens of New Jersey • Measuring resultant changes in health outcomes

Objective EV-1.1

To develop and implement annual Evaluation Plans for the *New Jersey Comprehensive Cancer Control Plan*.

Strategies

EV-1.1.1 Continue to recruit and retain members for the Evaluation Committee.

EV-1.1.2 Continue to identify and secure funding for evaluation of the *Plan*.

EV-1.1.3 Continue to contract with a New Jersey institution to develop and implement annual Evaluation Plans in partnership with the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey.

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CHAPTER 14. Emerging Trends

ACCESS TO CLINICAL TRIALS

Issues pertaining to access to clinical trials have been integrated into site-specific chapters across the *Plan*.

CANCER SURVIVORSHIP

Issues pertaining to cancer survivorship have been integrated into site-specific chapters across the *Plan*.

COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

Issues pertaining to complementary and alternative medicine are now addressed in Chapter 3 Palliation.

ESOPHAGEAL CANCER

Esophageal cancer is a rare cancer in New Jersey and the U.S., although it is common in some areas of the world, including Iran and certain regions in China. Recently, incidence rates of the two main types of esophageal cancer in the U.S. and other western countries have changed dramatically. The incidence of squamous cell carcinoma (SCC) of the esophagus has declined or remained stable in the U.S., while the incidence of esophageal adenocarcinoma increased rapidly, especially among white men.[1] In the U.S., SCC was previously the most common type, accounting for 90% of all esophageal cancer cases, but now accounts for approximately 39% of cases.[2,3] Racial differences in histologic type exist in the U.S. and in New Jersey. The incidence of esophageal adenocarcinoma is highest among white men, while the incidence of esophageal SCC is highest among black men, even though SCC rates in this group have declined during the past 20 years.[1,4]

The different temporal trends in the incidence of esophageal adenocarcinoma and SCC suggest distinct etiologies. Cigarette smoking is a risk factor for both cell types, although the association with SCC appears to be stronger.[1,5] Excessive alcohol consumption increases the risk for esophageal SCC, although it does not appear to increase the risk for esophageal adenocarcinoma.[1,5,6] Low intake of fruits and vegetables is also a risk factor for both types of esophageal cancer, although the association with SCC is more pronounced.[1,7]

Obesity or higher body mass index has consistently been found to increase risk for esophageal adenocarcinoma in epidemiologic studies,[1,6,8,9] but not for esophageal SCC.[1,8] The prevalence of obesity increased steadily in the U.S. over the past 30 years,[10] and this may explain in part the increasing incidence of esophageal adenocarcinoma. One possible mechanism is that obesity may increase pressure in the abdomen, which promotes the reflux of gastric acid into the esophagus and the development of gastroesophageal reflux disease (GERD).[1] The accompanying irritation and damage to esophageal cells in persons with GERD can cause Barrett esophagus, which is a pre-malignant condition that can progress to dysplasia and esophageal adenocarcinoma.[1] Persons with GERD have increased risk for

esophageal cancer, even if they have not been diagnosed with Barrett esophagus.[2] Obesity increases the risk for GERD[11] and may also influence risk for esophageal adenocarcinoma through additional mechanisms.[8] Chow et al. reported an increased risk for esophageal adenocarcinoma among both persons with and without a self-reported history of GERD.[8] An increased risk for esophageal adenocarcinoma associated with obesity was observed in a case-control study conducted in the United Kingdom, after adjusting for a history of GERD.[6] GERD appears to be very common—the American College of Gastroenterology estimates that 60 million persons in the U.S. (20% of the population) experience symptoms of GERD at least once a month.[12] As the prevalence of obesity continues to increase in the U.S. and many other countries, esophageal adenocarcinoma rates may increase further.

Another possible factor in the increasing incidence of esophageal adenocarcinoma is *H. pylori* infection, which has been linked to reduced risk for this type of esophageal cancer.[13–15] Due to improvements in sanitation and increasing use of antibiotics, the prevalence of *H. pylori* infection has declined.[16] Possible mechanisms for a protective effect of *H. pylori* infection against the development of GERD and esophageal adenocarcinoma are discussed below in the section on *H. pylori* under Infection and Cancer. In a population-based case-control study conducted in Sweden, a protective effect associated with *H. pylori* infection was observed for esophageal adenocarcinoma, while infection with the Cag-A positive strains of *H. pylori* was found to increase risk for esophageal SCC.[14]

Survival for esophageal cancer patients is poor and appears to be similar for the two main types.[1] For New Jersey residents diagnosed with esophageal cancer during 1994–1997, the five-year relative survival rate was only 13%.[17] Effective prevention, early detection, and improved treatments are important to reduce mortality.

Since esophageal SCC and adenocarcinoma have different risk factors, prevention of esophageal cancer varies by cell type.[1] Smoking prevention and cessation programs and programs that promote consumption of fruits and vegetables could help to reduce both types of esophageal cancer, especially SCC, in addition to other types of cancer and chronic diseases. Alcohol abuse prevention and treatment programs could help to further reduce esophageal SCC, as well as provide other health benefits. Effective programs to encourage exercise and healthier diets could aid in the prevention of obesity or weight reduction among obese persons, and thus in the prevention of esophageal adenocarcinoma, GERD, and other diseases.

Currently, there are no early detection tests to screen for esophageal cancer in the general population in the U.S. Since esophageal cancer is a rare cancer, it may be more effective to screen patients who are at increased risk. More research is needed to address the question of whether screening patients with Barrett esophagus is effective in reducing esophageal adenocarcinoma mortality.[1] One issue is that many people with Barrett esophagus are unaware of their condition.

Further considerations should include: (1) encouraging participation of New Jersey institutions in studies of the effectiveness of screening Barrett esophagus patients to reduce esophageal adenocarcinoma mortality; (2) supporting any clinical trials designed to assess whether aspirin or non-steroidal anti-inflammatory drugs can prevent esophageal cancer incidence; and (3) supporting any clinical trials to evaluate the effectiveness of treatments for esophageal cancer patients. In addition, more research is needed to identify why esophageal adenocarcinoma is increasing and any modifiable risk factors.

INFECTION AND CANCER

In this section we review the relationship between infection and cancer, including Epstein-Barr Virus (EBV), Human Immunodeficiency Virus (HIV), *helicobacter pylori*, human papillomavirus (HPV), and hepatitis.

Epstein-Barr Virus

Epstein-Barr virus (EBV) is a human herpes virus. It is the etiologic cause of infectious mononucleosis and is associated with several malignancies. EBV has been strongly associated with nasopharynegeal carcinoma (NPC) and Burkitt's lymphoma.[18] In 1997 the International Agency for Research on Cancer (IARC) concluded there was sufficient evidence for the carcinogenicity of EBV in the causation of Burkitt's lymphoma, NPC, Hodgkin's disease, and immunosuppression-related lymphoma.[19] Varying degrees of evidence link EBV to Hodgkin's disease, gastric carcinoma, lung carcinomas, and neoplasms of smooth muscle origin.[20] It has long been suspected that EBV acts in concert with other co-factors in the development of cancer, but those putative co-factors remain unidentified.[18] Age at EBV infection and the host immune response appear to be important in terms of risk for developing EBV-associated cancers.[21] Alternatively, it has been suggested that EBV is reactivated during the course of development of some of these tumors, and thus that EBV may merely be a marker rather than having any etiologic relationship.

Non-keratinizing NPC, especially the undifferentiated type, is closely associated with EBV. While this cancer is common in South East Asia, Alaska (among Eskimos), and North Africa, occurrence is rare in Western countries, with an annual incidence of less than 0.5 cases per 100,000.[20] In geographic regions of high squamous-cell NPC incidence, the proportion linked with EBV is high. In contrast, in low NPC incidence regions, a low proportion is linked with EBV. Another infectious agent, human papillomavirus (HPV), has also been implicated in the pathogenesis of squamous cell NPCs.[20] Proposed risk factors for development of NPCs include exposure to salted fish at an early age and certain tumor-producing compounds, such as nitrosamines, that are found in some food products.[22] Further, smoking has been established as a major risk factor for development of squamous cell NPCs (though not of non-keratinizing NPCs) and may account for up to two-thirds of squamous cell NPCs.[20]

Burkitt's lymphoma (BL), a high-grade lymphoma of B cells, is commonly found in equatorial Africa and New Guinea. However, it occurs sporadically in other areas of the world.[23] Over 95% of BL cases in Africa are associated with EBV, but only 20% to 30% of cases in the U.S. demonstrate an association.[23] Baumforth and others hypothesize that the low percentage of EBV-associated cases in the U.S. is related to a loss of EBV at some point in tumor development.[22]

Approximately 10% of gastric carcinoma cases worldwide (more than 50,000 cases per year) have EBV integrated into the cancer cells. Germany (18%) and the U.S. (16%) have the highest proportions of gastric carcinomas positive for EBV.[24] A study involving a Japanese population reports that the incidence of EBV-positive gastric carcinoma is three times higher in men than in women and is higher for younger men.[24]

The development of Hodgkin's disease, a relatively uncommon cancer in the U.S., has long been thought to be associated with EBV. Compared to persons without a history of infectious mononucleosis, persons with a history of infectious mononucleosis have a two- to five-fold increased risk of developing

Hodgkin's disease.[25] In addition, EBV has been detected in up to 50% of Hodgkin's disease cases in Western nations and in up to 100% of pediatric cases.[26]

EBV may be involved in the pathogenesis of various other cancers as well. EBV is found in cases of non-Hodgkin's lymphoma (NHL) of the peripheral T-cell type. A consistent association has been described between EBV and nasal angiocentric T/NK-cell lymphoma.[26] Lymphoepithelial carcinoma of the salivary gland, a relatively uncommon tumor, is most prevalent in Eskimos and Southern Chinese populations and is associated with EBV. While past cases of Caucasian patients have not demonstrated association with EBV, newer cases have been reportedly associated with EBV.[23] EBV may be involved in the development of oral squamous cell carcinomas, especially given that a proportion of patients with the disease do not smoke or consume alcohol.[23] EBV has been associated with lymphoepithelioma-like carcinoma of the lung in Asian populations but not in Western patients.[27] The first report of an EBV-associated smooth muscle tumor of the kidney occurred in 1998.[28] EBV-associated smooth muscle neoplasms arising at other locations have been reported previously in patients with AIDS and in recipients of organ transplants.[28]

Currently there are no therapies or vaccines available for EBV. Since several anti-herpes agents are presently available, it is likely that EBV-specific agents will be developed at some point.[23]

In the future, if national clinical trials of treatments for EBV-positive gastric carcinoma commence, we should encourage participation in these trials by New Jersey institutions and persons at risk and consider enhancement of support. Additionally, if national clinical trials of a vaccine for EBV commence, we should encourage participation and consider enhancement of support. In addition, research into the use of immunotherapy to treat early-stage EBV-positive Hodgkin's disease and NPC should be encouraged.[21] As smoking appears to further increase the risk from EBV for the development of squamous cell nasopharynegeal carcinoma, smoking cessation efforts should be strongly reinforced.

Cancers Associated with the Human Immunodeficiency Virus (HIV) Epidemic

The acquired immunodeficiency syndrome (AIDS) pandemic has been associated with cancer essentially from the outset.[29–32] The human immunodeficiency virus (HIV) is the etiologic cause of AIDS.[33] HIV has been implicated in the increased incidence of several cancers. In addition, with the advent of more effective anti-retroviral therapies and improved supportive care, many persons are living longer with their HIV infection. Due to lengthening lifespans and the attainment of older ages, at which cancers tend to begin occurring, AIDS patients are now developing malignancies that are not necessarily related to their HIV status. The underlying immunosuppression due to HIV, however, often greatly complicates standard therapeutic cancer approaches. For example, susceptibility to infections is greatly increased, often necessitating reductions in the standard therapeutic doses. Bleeding complications are also more common.

Persons at risk for HIV may also place themselves at increased risk from other environmental exposures. For example, many HIV patients are also injection drug users (IDUs) and often use multiple illicit substances, for which they receive counseling and therapy. Some HIV patients also enter alcohol treatment programs. However, although most IDUs also smoke, this has not generally been perceived to pose a major health threat, so counseling on smoking and smoking cessation components within substance abuse treatment programs are rare. Yet data suggest that smoking tobacco is the drug that in fact increases these individuals' mortality and cancer risk, which raises the issue that smoking cessation programs warrant new emphasis among IDUs.[34] Furthermore, both sexual and parenteral exposures put

persons who are at risk for HIV also at increased risk for infection with other agents associated with specific cancers.

The first tumor recognized in association with AIDS was Kaposi's sarcoma (KS). After the discovery of HIV, epidemiologic data suggested that in addition to HIV, a second infectious agent ("agent K")[32] might be involved.[35] Although a herpes-like virus was linked with Kaposi's as long ago as 1972,[36,37] it was not until the AIDS epidemic that a specific agent, now called both human herpes virus type 8 (HHV-8) and a Kaposi's-associated herpes virus (KS-HV) was discovered.[38,39] Almost all HIV-associated KS in the U.S. (note: this is not true in some African countries and other areas) has occurred among men who have sex with men (MSM). In some areas of Africa where KS was common before the AIDS epidemic, KS incidence has increased 20-fold.[40] However, the evolving epidemiology of HHV-8 has demonstrated evidence of this virus in other risk groups, leaving the puzzle partially unresolved.

Non-Hodgkin's lymphoma, including primary brain lymphomas, also emerged early on as linked with the AIDS epidemic. The Epstein-Barr virus may be involved in the pathogenesis. Although many HIV-infected young adults have been diagnosed with Hodgkin's disease, the high incidence of Hodgkin's lymphoma in young adults has led to uncertainty and controversy as to whether or not it is linked to the HIV epidemic.

In 1993, the Centers for Disease Control and Prevention (CDC) definition of AIDS, for the purposes of U.S. surveillance, newly includes the occurrence of invasive cervical cancer (ICC) in an HIV-infected woman as a sufficient condition.[41] The change was supported by data strongly linking cervical dysplasia with HIV infection,[42] and by the finding by one group in New York City of an association with ICC.[43] Thus, since that time, any woman infected with HIV who has ICC is automatically defined as having AIDS.[44] This led to an increase in the number of women defined as having AIDS, especially in New Jersey.[45] However, later data have raised some questions about the nature of the association.[46,47] Anal carcinoma and squamous dysplasia both appear to have increased among MSM. Both anal carcinoma and cervical carcinoma are strongly associated with certain types of human papillomavirus. It has been difficult to fully untangle the complex relationships, in part because some of the factors placing persons at risk for HPV are also risk factors for HIV acquisition. The role of screening for anal cancer and dysplasia in MSM and others at high risk warrants further clarification.[48,49]

The New Jersey Department of Health and Senior Services recently reviewed the New Jersey experience concerning the occurrence of cancers among persons with AIDS.[47] This report serves as a comprehensive overview of the AIDS-related issues in New Jersey and provides relevant statistics. Data from the University of Medicine and Dentistry of New Jersey University Hospital cancer registry[50,51] indicate increased lung cancers among HIV-infected patients compared to other cancers. Other studies, both from the U.S. and abroad, have also raised the issue of lung cancer and AIDS.[47,52–55]

A prospective cohort study in New Jersey of men and women at high risk for HIV was begun in 1984.[56] The increased risk of lung cancer,[57] when examined in terms of New Jersey yearly incidence data by age, gender, and race for lung cancer,[58] remains: 8.4-fold increased in those HIV+ compared to expected, 2.7-fold increased in those HIV negative. The 3.1-fold higher rate among those HIV+ within the cohort was not attributable to increased smoking of tobacco or other products. These are the first cohort data to suggest an increase in lung cancer among HIV-infected persons, thereby raising the possibility that lung cancer may emerge as a problem as HIV-infected persons age and also survive longer with the therapeutic advances in HIV care.

Human T-cell lymphotropic virus type I (HTLV-I) is causally associated with an aggressive leukemia and lymphoma syndrome,[59–62] as well as with neurologic disease. Both HTLV-I and human T-cell lymphotropic virus type II (HTLV-II) are associated with immunologic abnormalities.[63–66] It remains uncertain whether HTLV-II is linked to an increased risk for cancer.[67] HTLV-I is uncommon in New Jersey except in people born in the Far East and the Caribbean. HTLV-II is common in New Jersey injection drug users.[68,69] Current screening of blood donors has nearly eliminated the former risk of transfusion-related acquisition.

Hepatitis B and C viruses are discussed in a separate section on Hepatitis and Liver Cancer. Human papillomavirus is discussed in further detail in the sections on cervical cancer in Chapter 7 Gynecologic Cancers.

Steps that can be taken in the future to address issues in HIV and cancer include: (1) programs focusing on the primary prevention of HIV infection, such as education programs for young people and drug treatment and needle-exchange programs for IDUs; (2) monitoring cancer incidence trends in New Jersey among persons at increased risk for HIV and among those with HIV-infection; (3) encouraging development of clinical trials that seek to improve survival in HIV-infected persons diagnosed with a malignancy; (4) encouraging recruitment of persons for these trials, in light of the fact that many eligible persons are from groups historically less likely to participate in trials; (5) continuing epidemiologic studies examining the risks for cancer among HIV-at-risk groups, including support for efforts exploring whether there are predictive markers or co-factors; (6) continuing emphasis on providing integrated healthcare services to persons at HIV risk, including the routine provision of gynecologic screening services on site at primary healthcare settings, drug treatment programs, and AIDS clinics[42]; and (7) develop programs targeted to IDUs to reduce excessive use of tobacco products. Highly Active Anti-Retroviral Therapy (HAART) treatment reduces the risk of KS among HIV+ patients and may also reduce the risk for primary central nervous system lymphoma.[40]

Helicobacter Pylori

Helicobacter pylori, a type of bacteria that colonizes human stomachs, has been associated with increased risk for development of peptic ulcer disease and gastric cancers, in particular non-cardia gastric adenocarcinoma and gastric non-Hodgkin's lymphomas of the B-cell type.[16] In 1994, the International Agency for Research on Cancer classified *H. pylori* as a group I carcinogen (e.g., as a definitive human carcinogen) for its role in gastric cancer development.[70] Patients with chronic atrophic gastritis tend to have a particularly high risk of developing gastric carcinomas.[70] There is also evidence of a strong association between *H. pylori* and gastric mucosal-associated lymphoid tissue (MALT) lymphoma. Since eliminating *H. pylori* often leads to MALT lymphoma regression, U.S. and European consensus conferences on *H. pylori* have recommended anti-bacterial treatment in cases of low-grade MALT lymphoma.[70] In contrast, there is no evidence that, once other gastric cancers have developed, treatment of *H. pylori* infection per se changes the natural history of those cancers. Individuals with *H. pylori* colonization, especially by cytotoxin-associated gene-A-positive (CagA+) strains, may also have an increased risk for developing pancreatic cancer.[71]

Meta-analyses have reported that *H. pylori* infection increases risk two-fold for gastric cancer development.[72] More specifically, *H. pylori* infection is associated with a nearly six-fold increased risk of developing non-cardia gastric cancer.[73] However, *H. pylori* infection does not increase the risk for development of cardia gastric cancer. Current topographic codes permit description of the primary localization of the cancer within the stomach, when this can be determined. These data suggest that

coding for the specific topography of gastric cancer in data routinely submitted to the New Jersey State Cancer Registry would be useful, given that *H. pylori* infection is associated with the non-cardia gastric cancers, to assess trends with respect to *H. pylori*-related cancers. While this coding scheme already exists, specific research efforts would be needed to assess the extent to which it is being properly abstracted, coded, and submitted and to assess whether efforts to improve the data quality and/or completeness should be undertaken. It is likely that standard reports from clinicians may not currently enable registrars to attain this degree of specificity with regard to the place of origin within the stomach.

The most highly studied types of *H. pylori* have been Cag+ strains, which account for 40% to 60% of strains in the Western world (i.e., Western Europe, the U.S., and Latin America), and "most" of the strains in East Asia. Cag+ colonization is significantly associated with ulceration, gastritis, and gastric adenocarcinoma in the Western world.[16]

The cohabitation of humans and *H. pylori* for millions of years implies that some type of symbiotic relationship may exist.[16] In recent years, the prevalence of *H. pylori* has been declining. Factors contributing to the decline likely include: (1) lower birth rates (risk factors for colonization include early childhood crowding), (2) increased antibiotic utilization,[16] and (3) improvements in household sanitation and hygiene.[70] The fall in *H. pylori* colonization has been mirrored by a decrease in the incidence of gastric cancers.

In addition, there is evidence from some recent studies that *H. pylori* infection increases the risk for pancreatic cancer.[74,75]

However, there have been increasing rates of various esophageal diseases (i.e., gastro-esophageal reflux or GERD, Barrett's esophagus, and adenocarcinomas of the lower esophagus), as well as gastric cardia adenocarcinomas.[16] Blaser has speculated that there may be potentially protective effects of *H. pylori*, especially of Cag+ strains, and that perhaps the declining prevalence of *H. pylori* and increased rates of GERD and reflux esophagitis are related to *H. pylori* elimination. *H. pylori*-associated gastritis tempers gastric acid secretion; so eradication of the bacteria may lead to localized increased acid production and subsequent reflux esophagitis.[76] Infection with Cag+ strains is significantly associated with a reduced risk for adenocarcinomas of the esophagus and gastric cardia.[13] These results suggest that eradication of *H. pylori* may also produce some harmful effects.

Smoking has been associated with a three-fold increase in the risk of gastric cancer. There is evidence of a much higher risk for non-cardia gastric cancer among smokers with *H. pylori* infection. As compared to uninfected non-smokers, smokers infected with CagA-negative *H. pylori* strains have a 9-fold increased risk of developing non-cardia gastric cancer, while smokers infected with CagA+ *H. pylori* strains have a 17-fold increased risk for non-cardia gastric cancer.[77]

A well-documented risk factor for developing gastric cancer is a family history of this cancer, in the range of 1.5- to 3-fold.[78] In addition, as compared with uninfected individuals with no family history, individuals with positive family history and infection with the CagA+ *H. pylori* may have a 16-fold risk of noncardia gastric carcinoma.[78]

The theory of intrafamilial clustering of *H. pylori* infection is supported by evidence of *H. pylori* colonization in the parents and siblings of infected children.[79] A strong association exists between the *H. pylori*-infection status of parents and preschool-aged children, suggesting that transmission may occur from parent to child. Specifically, as compared to children with uninfected mothers, preschool-aged

children of mothers infected by *H. pylori* have an almost 8-fold risk of being infected. As compared to children with uninfected fathers, children of infected fathers have nearly a 4-fold risk.[80] Further, infected individuals of higher birth order or from larger families may be at increased risk for developing gastric cancer.[81]

While the prevalence of *H. pylori* in children may be less than 10%, more than one-half of children in poor socioeconomic conditions may be infected.[82] Estimates suggest that about 1% of infected children will develop gastric cancer. Thus, the risk for developing gastric cancer in children is limited. The multi-factorial basis of gastric cancer development (e.g., *H. pylori* infection, smoking, family history, vitamin C deficiency, etc.) further complicates the issue of screening and treatment. Generalized population screening has not been shown to be beneficial or cost-effective. Imrie et al. suggest that, once an effective vaccine for *H. pylori* is developed, vaccination might be considered for reducing gastric cancer.[82]

Use of vitamin C has also been suggested as a preventative measure, because it may help to prevent gastric cancer by inhibiting the formation of *N*-nitroso compounds in gastric juice, destroying reactive oxygen metabolites in the stomach and possibly inhibiting *H. pylori* infection.[83] Since data are currently insufficient to support this approach, controlled trials will be needed to assess the positive and negative effects of vitamin C.

H. pylori eradication may be a treatment option, especially among individuals at high risk for developing noncardia gastric cancer. Currently, regimens such as triple antimicrobial therapy—a therapy that may include bismuth, metronidazole, and tetracycline,[84] as well as other equally effective combinations, such as esomeprazole, clarithromycin, and amoxicillin[85]—have been used to effectively treat over 80% of *H. pylori* infections in patients with peptic ulcer disease. However, neither routine screening for *H. pylori* nor empiric treatment in the absence of active disease are currently recommended. Fendrick et al. estimate that *H. pylori* screening may remain cost-effective at rates of cancer risk reduction of less than 30%.[86] However, controlled studies are needed to prospectively confirm, and determine the amount of, noncardia gastric cancer risk reduction associated with *H. pylori* eradication and further to determine whether any reduction in risks differs among age groups. In addition, the benefits of *H. pylori* elimination should be weighed against a loss of its possible protective effects against esophageal disease. Until benefit is clearly established, the issue of cost-benefit remains moot. An indirect strategy for reducing the risk of developing gastric cancer may involve an intervention that prevents the progression from chronic atrophic gastritis to gastric cancer.[86]

Future strategies should include: (1) emphasizing smoking cessation programs; (2) considering support for clinical trials that screen for *H. pylori* among persons at high risk (e.g., smokers and persons with a family history); and (3) if national clinical trials of the efficacy of vitamin C commence, encouraging participation of New Jersey institutions in these trials among persons at risk. Further, (4) funding should be considered for a research study led by cancer epidemiologists in conjunction with local cancer registrars and the New Jersey State Cancer Registry. This study could examine the extent to which gastric cancer subtype information (e.g., cardia versus non-cardia gastric cancer) is being collected, its adequacy, and the feasibility for improvement, as well as to assess its utility for prospective surveillance. This study should be undertaken in the near term, before further advances in therapy or development of a vaccine for *H. pylori*, so that adequate baseline data may be assessed.

Human Papillomavirus (HPV)

Issues pertaining to HPV are now being addressed in Chapter 7 Gynecologic Cancers.

Hepatitis and Liver Cancer

Primary liver cancers are any malignant tumors that arise in the liver itself, as opposed to having metastasized to the liver. The most common types are hepatocellular carcinoma (HCC) and cholangiocarcinoma, which arise from the liver cells and the bile ducts, respectively.[87] Cases are usually rapidly fatal.

Infection with either hepatitis B virus (HBV) or hepatitis C virus (HCV) are important risk factors for development of HCC.[88–90] Infection with HBV early in life appears to be a much stronger risk factor for HCC than acquisition of HBV in adulthood.[87] Studies in China found that 40% of babies born to mothers who carried HBV also became infected with HBV, leading to public health efforts to interrupt the chain.[91] Chronic infection with HBV has been associated with HCC even in the absence of detectable serum HbsAg.[92] Use of a hepatitis B virus vaccine, which provides durable immunity in very young children, will likely prevent most cases of HCC.[93] Vaccination against HBV is currently recommended for all children in the United States.[94,95]

Worldwide, exposure to aflatoxins is also a major risk for HCC.[96] This risk may be modulated by both genetic factors (which may be increased in some ethnic groups) and environmental factors (such as infection with HBV).[96–98]

HCC incidence in the United States has recently been rising,[99] with HCV the suspected cause.[100] Recently reported findings from a prospective cohort study in New Jersey of HCV-infected men and women found an increased risk of 9.7-fold compared to expected (based on New Jersey HCC yearly incidence data, by age, gender, and race).[58] These New Jersey data are believed to be the first prospective data from the United States supporting an increasing risk for HCC and an apparent link with HCV.[58]

HCV is believed to have spread extensively among injection drug users in the United States during the 1970s and early 1980s, with particularly high rates in New Jersey that reach 99% in one statewide cohort.[101] In addition to the HCC risk, HBV and HCV are also associated with substantial morbidity and mortality, with liver failure accounting for 10% of the deaths among IDUs (for both HIV negative and positive persons).[101,102] HBV and HCV are also related to progressive liver disease in persons with blood-product-related acquisition (e.g., hemophiliacs and persons receiving blood products prior to implementation of effective screening).[103,104] In the United States, about 2.7 million persons are chronically infected with HCV.[105] Among U.S. patients undergoing liver transplantation, HCV is currently the leading cause of liver failure. People who use illegal drugs or engage in high-risk sexual behavior account for most of those currently infected with HCV in the United States.[105] However, tattooing and body piercing are risk factors for HBV and HCV,[106] as well as other parenterally transmissible pathogens, such as HIV. HIV infection appears to worsen this natural history of chronic parenterally acquired hepatitis C, leading to an unusually rapid progression to cirrhosis.[107,108]

Studies from Japan have led to estimates that the average time from initial infection with HCV until the development of HCC likely exceeds 20 to 30 years. Thus, the above data from New Jersey are likely the

first harbingers of a forthcoming rapid and significant rise in the number of new HCC cases in our state, as well as globally, over the next one to two decades.

In 1988, the New Jersey Commission on Cancer Research urged primary care physicians to consider the emerging role of prevention strategies in hepatocellular carcinoma.[109] These data reinforce the importance of prevention measures, including the primary prevention approach of vaccination.

Future steps in liver cancer should include: (1) continuing support for vaccination of New Jersey children against HBV in accordance with CDC guidelines; (2) increasing efforts to identify and vaccinate adults at risk for HBV and HCV; (3) support for research in developing a vaccine against HCV; (4) continuing epidemiologic studies examining HCC risk and efforts to explore whether there are predictive markers or co-factors amongst HCV-infected persons; (5) monitoring HCC incidence trends in New Jersey; (6) encouraging clinical trials that seek to improve survival in persons diagnosed with HCC and to develop safe and effective antiviral drugs to treat persons chronically infected with HBV or HCV; (7) considering establishing regulations to reduce HBV, HCV, and retroviral transmission that can occur in establishments engaged in tattooing, body piercing, or similar practices[110,111]; and (8) drug treatment and needle-exchange programs for IDUs to prevent HCV and HBV transmission in this group.

THYROID CANCER

The thyroid gland is located in the base of the throat and is responsible for the regulation of hormones that play a role in regulating heart rate, blood pressure, body temperature, and weight. Though cancer of the thyroid is rare, surveillance data show a marked increase in incidence rates over the last decade. In 2004, there were 268 cases of thyroid cancer diagnosed in New Jersey. Between 1993 and 2004, New Jersey's thyroid cancer incidence rates approximately doubled for men and tripled for women, leaping to 6.3 and 18.8 per 100,000, respectively. The increase is more pronounced in women than men and in whites than blacks. Both New Jersey and the U.S. have experienced similar increases in thyroid cancer incidence rates.[3,4]

While little is known about the risk factors for thyroid cancer, the disease is more common in women than men and occurs most frequently in individuals between the ages of 20 and 60. Inherited conditions, such as familial medullary thyroid carcinoma (FMTC) and other hereditary medical conditions, may increase an individual's risk of developing thyroid cancer. Exposure to radiation during childhood is a proven risk factor for one type of thyroid cancer; and a diet low in iodine may also increase the risk. However, most of those who develop thyroid cancer have no known risk factors for the disease. There is no accepted screening test to diagnose the disease before symptoms occur, although the American Cancer Society recommends that all adults over the age of 20 should have their thyroid examined as part of a routine health examination.[112]

Research is ongoing into the potential causes for the recent increase in thyroid cancer incidence.

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APPENDICES

Appendix A. Mission Statement

Appendix B. The New Jersey Cancer Education and Early Detection (NJCEED) Program

Appendix C. Screening Guidelines and Resources

APPENDIX A

TASK FORCE ON CANCER PREVENTION, EARLY DETECTION AND TREATMENT IN NEW JERSEY

MISSION STATEMENT

"Comprehensive cancer control is a dynamic and ongoing process which can only be achieved through an active and committed partnership. This can be accomplished with public and private sectors working together from the belief that neither entity can do it alone. Our mission is to develop, recommend, advocate, and promote an integrated, collaborative, and multi-disciplinary approach to reducing the incidence, illness, and death from cancer. This will be addressed through a culturally sensitive plan which reflects prevention, early detection, treatment, rehabilitation, palliation, and quality of life issues and will embrace all of the citizens of New Jersey. Coalition building, partnerships, and education are essential to achieving this mission."

APPENDIX B

THE NEW JERSEY CANCER EDUCATION AND EARLY DETECTION PROGRAM (NJCEED)

The New Jersey Cancer Education and Early Detection (NJCEED) Program is part of the New Jersey Department of Health and Senior Services. NJCEED provides comprehensive screening services for breast, cervical, prostate, and colorectal cancer. The services provided include education, outreach, early detection, case management, screening, tracking, and follow-up. Breast, cervical, prostate, and colorectal cancers can be treated more effectively when found early.[1,2] NJCEED services are available in all 21 counties through 23 lead agencies.

Persons eligible for these services must be at or below 250% of the Federal Poverty Level and be uninsured or under-insured.[3,4] To find a program near you, please call **1-800-328-3838**.

This program is supported by both Federal and State funds. The Federal Breast and Cervical Cancer Prevention and Treatment Act of 2000 allows States to expand Medicaid coverage to eligible women who are diagnosed with breast or cervical cancer. As of July 1, 2001, New Jersey adopted this coverage.

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APPENDIX C

SCREENING GUIDELINES AND RESOURCES

SCREENING GUIDELINES

Given differences in recommendations for cancer screening among major U.S. authorities (e.g., National Institutes of Health), non-federal expert panel (e.g., U.S. Preventive Services Task Force), national professional organizations, or national voluntary health organizations, patients are advised to make an informed decision about cancer screening based on his or her provider's recommendations, which are made in accordance with the patient's individual risk factors for the disease. Upon selection of the cancer screening protocol, it will be necessary to determine whether or not this screening protocol is covered by your insurance carrier.

For more information:

American Cancer Society: *www.cancer.org*

National Cancer Institute: *www.nci.nih.gov*

National Guideline Clearinghouse: *www.guideline.gov/NAVBARS/top_home.asp*

U.S. Preventive Services Task Force: *www.ahcpr.gov/clinic/uspstfix.htm*