

# **Comprehensive Cancer Control Plan**

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

**Report to the Governor  
July 2002**

# **DEDICATION**

## ***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 John Slade, M.D., physician, advocate and Plan reviewer. To all, thank you for making a difference and helping to tell New Jersey's story.***

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## ***Acknowledgments***

*The work of the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey was supported by the New Jersey Department of Health and Senior Services. Creation of the Task Force was the result of collaboration between the Governor's Office, the State Legislature, and numerous state agencies.*

*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 over 350 individuals and organizations whose passion is reflected in, and whose names appear with, each respective chapter of the Plan.*

*We also acknowledge various organizations that offered hospitality for the many Task Force workgroup and subcommittee sessions.*

*In addition, the rich resources of sister state agencies 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. We also gratefully acknowledge the work of other states, including Kentucky, Maine, Michigan and North Carolina, who generously shared their best practices with New Jersey.*

## Executive Summary

### HISTORY

According to a recent Eagleton survey, cancer is the leading health concern among New Jersey's citizens. In 1999, a New Jersey Department of Health and Senior Services (NJDHSS) Internal Strategic Cancer Planning Team identified the need for a more systematic and integrated approach to cancer prevention and control and identified priority recommendations as reflected in the *Strategic Plan for Organizing Cancer Control in New Jersey* (1). One recommendation in the strategic plan was that the state develop and implement a comprehensive cancer control plan.

New Jersey has a rich history of cancer planning and public health efforts that provide a foundation for such a plan. The earliest planning efforts in cancer prevention and control involved the development of site- and risk-factor specific programs. Since the 1970s, cancer control stakeholders have made major contributions by establishing cancer awareness programs directed toward various New Jersey populations. These include a coalition to fight tobacco use, The Advisory Committee on Smoking OR Health, and several programs to provide free or low-cost cancer screening to the medically underserved. In 1992, the State Cancer Plan, initiated by a task force composed of approximately 50 representatives from key private and public organizations, outlined a comprehensive approach to reduce cancer mortality. All of the initiatives cited above, along with many other activities led by both public and private agencies, laid the groundwork for addressing the full spectrum of cancer control activities throughout the state in a coordinated and cost-effective manner.

In 2000, former Governor Whitman issued Executive Order 114 establishing the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (henceforth known as the Task Force). The Task Force was charged with addressing the impact of cancer on New Jersey citizens. More specifically, the Task Force was authorized to evaluate historic, current, and emerging trends and produce a document that would become a blueprint for cancer control efforts in the state over the next five years. In conjunction with this process, the NJDHSS, along with the University of Medicine and Dentistry of New Jersey/School of Public Health and the New Jersey Commission on Cancer Research, hosted two educational roundtable programs. These roundtables fostered collaboration among cancer control stakeholders and represented a starting point for developing a new, more comprehensive approach to cancer prevention and control in New Jersey.

New Jersey began the formal process of developing a comprehensive cancer control plan with the appointment of the 16 Task Force members and the establishment of planning support from the NJDHSS Office of Cancer Control and Prevention (OCCP). The Task Force formally began its work with a meeting convened on January 29, 2001. The Task Force's first action was to adopt the Centers for Disease Control and Prevention's (CDC) operational definition of *comprehensive cancer control* as "an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation" (2). The Task Force further developed a mission statement, goals, and objectives based on the parameters of the Executive Order.

Utilizing the comprehensive cancer control framework developed by the CDC, the Task Force designated eight workgroups to undertake background research and strategy formulation for specific areas of the *New Jersey Comprehensive Cancer Control Plan*. Seven workgroups focused individually on specific cancer sites including breast, cervical, prostate, lung, melanoma, colorectal, and oral/oropharyngeal cancers, thus aligning Task Force efforts with the Healthy New Jersey 2010 goals relating to cancer. The Task Force recognized that the Healthy New Jersey 2010 goals were projected for ten years and allowed for further planning beyond the five-year implementation period envisioned for the *Comprehensive Cancer Control Plan*. The eighth workgroup addressed overarching issues that crossed multiple cancer sites and risk factors, such as advocacy, palliation, access to care, childhood cancer, and nutrition and physical activity. Additionally, the Overarching Issues Workgroup explored a number of emerging issues, including access to clinical trials, cancers associated with the Human Immunodeficiency Virus (HIV) pandemic and other infectious diseases, cancer survivorship, and complementary and alternative medicine. The Overarching Issues Workgroup recommended further consideration be given to these issues as additional evidence emerges.

The Task Force workgroups are comprised of decision-makers from medicine and nursing, academia, community health groups, public health representatives, health and human service agencies and organizations, and cancer survivors, all of whom are stakeholders in cancer prevention and control. Operationalizing the CDC's framework for comprehensive cancer control, the workgroups became an "organization of organizations" committed to planning and implementing together, using an evidence-based process. Workgroup members set about developing goals and objectives and prioritizing strategies based on a variety of data sources, including the New Jersey State Cancer Registry, a designated registry of the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program. Epidemiologists dedicated to each workgroup provided planning data and current research, a model which was recommended by the CDC. This active and broad involvement by key stakeholders reflected a multidisciplinary, whole-person, population-based approach to service delivery that represents the core principle of the *New Jersey Comprehensive Cancer Control Plan*. Integral to the process has been the input of cancer survivors, and their wisdom and experiences have been noted throughout the *Plan*.

The planning stage of New Jersey's comprehensive cancer control initiative was complemented and supported by the guidance and counsel of the Battelle Centers for Public Health Research and Evaluation (Battelle) and was marked with a two-day site visit by two Battelle staff members to NJDHSS in May 2001. Their findings, summarized in a case study report, benchmarked the progress that had been made to date in comprehensive cancer control planning in New Jersey and recommended next steps. Battelle – instrumental in the development of the CDC conceptual model for comprehensive cancer control designed with input from six "model planning states" and six CDC implementation grantees<sup>1</sup> – assessed New Jersey's progress in the six core areas of the Conceptual Model. These core areas are (1) assessing/addressing the cancer burden, (2) enhancing infrastructure, (3) mobilizing support, (4) utilizing data/research/evaluation, (5) building partnerships, and (6) institutionalizing the initiative. Battelle found that New Jersey had a well-developed coordinating infrastructure, rich data resources, a high level of existing support

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<sup>1</sup> The six model planning states for comprehensive cancer control were Arkansas, Illinois, Kansas, Kentucky, Maine, and Utah. The six CDC implementation grantees were Colorado, Massachusetts, Michigan, North Carolina, the Northwest Portland Indian Health Board, and Texas.

in terms of both funding and political will, and a firm basis for expert, broad-based planning in the composition of its Task Force. “New Jersey not only has the ingredients for a successful comprehensive cancer control planning effort – with well beyond the minimum needed in each of the core areas – but also has a considerable head start on institutionalization.” “Institutionalization” is the end point of an ideal comprehensive cancer planning process, the point at which comprehensive cancer control becomes a new and widely accepted way of “doing business” and the planning body becomes an expert forum for debating cancer control issues (3).

## TELLING NEW JERSEY’S STORY

The Task Force workgroups began by examining best practices from such states as Kentucky, Maine, Michigan, and North Carolina, who gave generously of their advice and expertise. With a total of nearly 350 volunteers, the various workgroups applied the CDC framework, which consists of four phases of development moving from “setting optimal objectives” to “implementing effective strategies”. The phases are also incorporated into a cycle that allows for continual revisiting of efforts invested in cancer issues. The product of each workgroup, reviewed by external peer reviewers, was then submitted to the Task Force along with priority recommendations. The Task Force included in the *Plan* issues raised by its workgroups and subcommittees, along with their respective goals, objectives, and strategies. However, the Task Force also recognized that for successful implementation, the *Plan* must “start” somewhere. For this reason, the top priorities from each workgroup are presented below.

### **Access and Resources Workgroup – *Identification of Need***

Barriers in New Jersey can restrict residents’ timely access to proper healthcare, thereby limiting their ability to achieve the best outcomes. Determining the unmet cancer care needs and barriers to our state’s population – and the special subpopulations within it – may aid efforts to improve access to care. Community-level needs analyses are essential to guiding the cost-effective and efficient deployment of limited resources.

### **Advocacy Workgroup – *Internal Structure and Funding***

Advocacy has been incorporated as a major strategy for advancing the *Plan*, with the goal of ensuring all citizens access to education, screening, and quality cancer care. By building capacity through recruitment of key stakeholders, advocacy for funding of and support for the *Plan* can be fostered to assure its successful implementation for the benefit of all New Jersey citizens.

### **Childhood Cancer Workgroup – *Adolescent and Young Adult Treatment***

Cancer in adolescents and young adults is more common than in younger children. However, the survival rate for young adults has not kept pace for specific types of cancers seen in both groups. Educating healthcare providers about the availability of existing clinical research protocols and identifying how current psychosocial needs are being met are among the goals for improving care for the 15- to 19-year-old cancer patient.

## **Nutrition and Physical Activity Workgroup – *Cancer Prevention***

Although the body of literature demonstrating the correlation between dietary intake and reduced risk of cancer is large and fairly consistent, many aspects of the relationship between diet and cancer are not completely understood. Evidence for the role of physical activity in reducing cancer risk is also accumulating. Educating all New Jersey residents about healthy eating patterns, healthy weight, and adequate physical activity for cancer prevention through a fully funded comprehensive nutrition program is necessary.

## **Palliation Workgroup – *Education***

Palliative care is likely to become the practice norm in mainstream U.S. healthcare in the coming decade, with the potential for New Jersey cancer patients in need of palliative care services very high. Despite advances, many New Jersey cancer patients still suffer from unmanageable symptoms. Alleviating barriers to effective palliative care by addressing the lack of awareness among healthcare professionals and the public is the first step to improving quality of life for New Jersey cancer patients.

## **Breast Cancer Workgroup – *Awareness and Education***

Approximately 1,400 New Jersey women will die from breast cancer in 2002, and New Jersey data reveal that, while white women have a higher incidence of breast cancer, black women have a higher mortality. In an effort to increase screening, increase early diagnosis, and ultimately decrease breast cancer death rates in New Jersey, education of many constituencies with a consistent message must be undertaken.

## **Cervical Cancer Workgroup – *Access to Care***

Cervical cancer is a preventable and curable disease when detected early. Those populations that are currently not being screened for cervical cancer in New Jersey must be identified. This can be accomplished through studies to develop a more comprehensive database of cervical cancer morbidity and mortality in the state and through analytic work that targets needed service improvements and barrier removal. The *Plan* proposes that populations at high risk for cervical cancer be identified and the reasons for that high risk investigated, thereby providing information needed to develop solutions for barriers to care.

## **Colorectal Cancer Workgroup – *Awareness and Education***

New Jersey has the highest incidence rate of colorectal cancer in the country for males, and the second highest rate for females. Education and enhancing awareness of the public, healthcare professionals, and third-party payers must be encouraged to facilitate dialogue, to increase the utilization of colorectal screening tests and to reduce personal, social, and economic barriers to screening. Only through recognition of colorectal cancer as a major health problem will New Jersey be able to effectively impact incidence and mortality rates from this disease.

### **Lung Cancer Workgroup – Tobacco Control**

Lung cancer accounts for 25% of all cancer deaths in New Jersey and is the most common cause of death; however, both incidence and mortality are declining. In 2002, the American Cancer Society estimates that 4,900 new lung cancer cases will be diagnosed in New Jersey compared to 6,200 diagnosed in 1998. Tobacco control has been recognized as the most effective approach in the prevention of lung cancer. The Lung Cancer Workgroup, recognizing the ongoing efforts of the New Jersey Comprehensive Tobacco Control Program, recommends support of the long-range goals of this successful initiative.

### **Melanoma Workgroup – Awareness**

The top priority of the Melanoma Workgroup is communicating the fact that malignant melanoma is a life-threatening disease through the development of a multi-level, multi-faceted awareness campaign. This awareness campaign, which will also be beneficial to those with non-melanoma skin cancers and other sites for malignant melanoma, is of particular importance to New Jersey with its active coastal community. The development of initiatives that target diagnosis through early detection and screening provide the opportunity to impact the state's rising melanoma incidence rate, which ranks eighth in the nation.

### **Oral and Oropharyngeal Cancer Workgroup – Public Awareness**

Oral and oropharyngeal cancer requires special attention, as the public is only minimally aware of cancers occurring in this body region. Nor is the public aware of lifestyle behaviors that increase risk for these diseases, signs and symptoms of the diseases, and locations where oral cancer screenings may be obtained. Enhancing public awareness in New Jersey through a collaborative effort with local and national organizations will positively impact all populations.

### **Prostate Cancer Workgroup – Public Awareness and Education**

Cancer of the prostate is the most prevalent of all cancers in men because of the slow tumor growth rate and improved survival rate. However, there is no scientific consensus on the effectiveness of prostate cancer screening in reducing deaths, and effective measures to prevent prostate cancer have not yet been determined. Until there is scientific consensus, empowering the public through education about early detection remains the most powerful tool. It is imperative to inform the public regarding the pros and cons of prostate cancer screening so that educated decisions about screening and treatment can be made.

## **WHAT THE FUTURE HOLDS**

In a report prepared for the CDC, entitled *Essential Elements for Developing/Expanding Comprehensive Cancer Control Programs* (4), four elements are cited as essential for planning and implementation:

- State health department leadership and commitment
- Public-private partnerships

- Access to data and scientific expertise
- Resources

NJDHSS has demonstrated its willingness to dedicate staff, resources, and attention to initiating and maintaining comprehensive cancer control planning. The OCCP, on behalf of the Task Force, has coordinated efforts with private partners and state programs. This process has maximized the collaboration of multiple divisions within the NJDHSS, among them the New Jersey State Cancer Registry, Family Health Services, and the New Jersey Commission on Cancer Research. The OCCP has effectively communicated with a wide variety of stakeholders throughout the planning process and will continue as facilitator and coordinator throughout the implementation phase.

However, implementation of the *New Jersey Comprehensive Cancer Control Plan* will require intensive collaboration among 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 nearly 350 volunteers who have already invested their time, energy, and expertise to make this *Plan* happen. As the workgroups transition into implementation teams, they will be networking with existing, successful programs. This will continue to build relationships, broaden membership, and expand cancer control activities to achieve the *Plan*'s goals.

The cornerstone of implementation will be conducting a statewide Cancer Capacity and Needs Assessment that will bring together information on the cancer-related efforts of both public and private agencies into a centralized resource for New Jersey's many constituents. Access to data and scientific expertise is needed to assess needs and identify gaps in cancer programs and services. Community-level prevalence data are especially important to improving delivery of effective and appropriate interventions. Finally, the availability of adequate evaluative information is crucial, not only for effective implementation of the *Plan*, but also for development of future plans.

No discussion of plan implementation would be complete without addressing the need for funding. However, as the CDC points out in its *Guidance Document for Comprehensive Cancer Control Planning*, the ongoing activity of mobilizing support involves more than merely securing funding. It requires a broad campaign that will provide visibility, develop political good will, and enhance awareness of community leaders who can become advocates for both funding and implementing portions of the *Plan* (2). Current and new partners must be engaged in comprehensive cancer control, not only for their expertise, but also as key decision-makers who can advocate persuasively for and deliver on commitments to plan implementation.

The value of the *Comprehensive Cancer Control Plan* is better integration and coordination of cancer control activities among all New Jersey agencies and organizations. This collaborative effort will reduce duplication and improve the delivery of programs at the state and community levels. Ultimately, this will benefit every citizen in New Jersey. Together we can make a difference.

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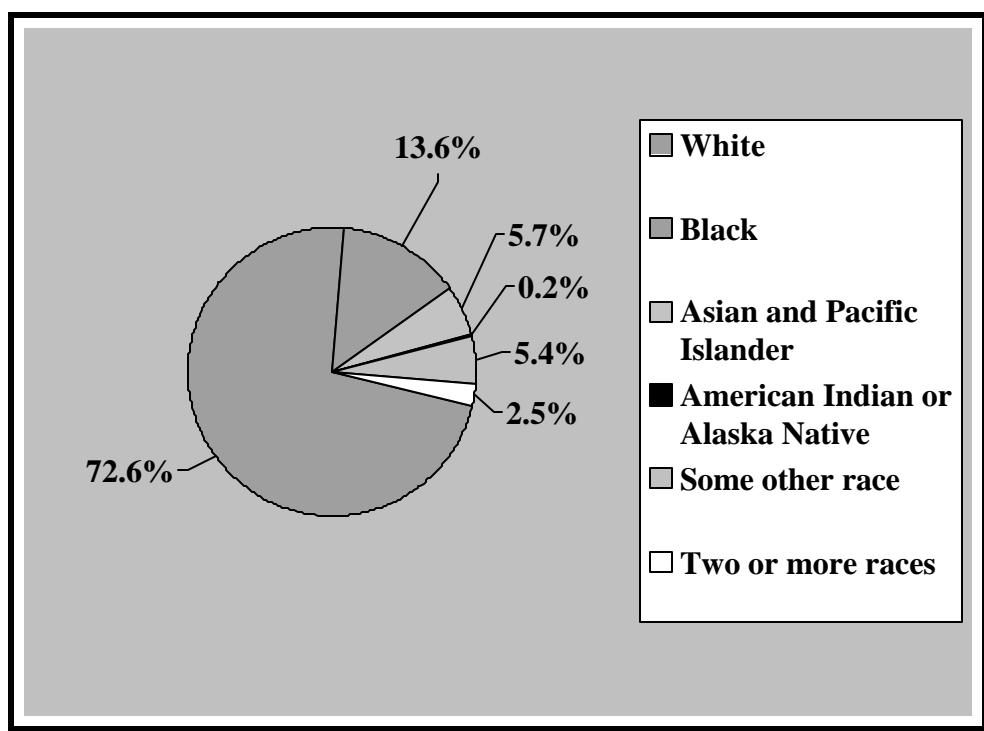
## The Burden of Cancer in New Jersey

### A DEMOGRAPHIC PICTURE OF NEW JERSEY

New Jersey is a geographically small, but heavily populated state. The state's population of over 8.4 million is the ninth highest in the nation. According to the 2000 Census, New Jersey is the most densely populated state, with 1,134 persons per square mile.

Figure 1 demonstrates the racial composition of New Jersey. According to the 2000 Census, though still a majority, the white population in New Jersey is decreasing, while populations for all other races are increasing. Approximately 13.3% of the population were Hispanic of any race, which accounts for 55.4% of New Jersey's total population growth from 1990 through 2000.

**Figure 1: Breakdown of New Jersey population by Race, Based on 2000 Census**



The 2000 Census also revealed that New Jersey's population is also older than the national average, with a median age of 36.7 years as compared to 35.3 years for the nation. The percentage of the population aged 65 and older is 13.3% in New Jersey and 12.4% in the nation as a whole. Similar to the national trend, the oldest age group (85 years and over) is growing at the fastest rate, growing by 43.1% in New Jersey and 38.1% in the nation from 1990 to 1999 (1).

The 2000 Census demonstrated that New Jersey ranks first in the nation for median household income (\$54,149). 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 a 1997 model-based estimate, 9.3% of New Jerseyans had income below the poverty level, compared to 13.3% nationally.

Additionally, adult New Jerseyans exceed national estimates of average educational attainment. For persons 25 years and over, in 1999, 87.4% of state residents 25 and over had completed high school, compared to 83.4% nationally, and 30.5% had completed a bachelor's degree or more compared to 25.2% nationally (2).

## CANCER INCIDENCE IN NEW JERSEY

In 2000\*, the data reported to the New Jersey State Cancer Registry (NJSCR) indicate that 42,525 cases of invasive cancer were diagnosed among New Jersey residents. Males (all races combined) had a rate of 591.4 per 100,000\*\* compared to females (all races combined) who had a rate of 445.2 per 100,000\*\* (Figure 2). The American Cancer Society predicts that in 2002, the incidence rates will be 513.4 per 100,000 males and 377.3 per 100,000 females (3). Since 1995, more cancers are being diagnosed in the early stages (*in situ* and local); however, this number is only 50% (Figure 3). In the paragraphs below, the most striking patterns from the New Jersey State Cancer Registry statistics for age, race, and gender are highlighted, taking into account fluctuations and trends in incidence data for years prior to 1995. Incidence data for years prior to 1995 can be viewed on the New Jersey Department of Health and Senior Services (NJDHSS) website, [www.state.nj.us/health](http://www.state.nj.us/health), and can also be found in previously issued New Jersey State Cancer Registry cancer incidence reports.

**Males.** Data from the New Jersey State Cancer Registry (NJSCR) demonstrate that the overall cancer incidence rate for New Jersey males increased through 1992 and then began to decline. While white males mirrored the overall trend for New Jersey males, black males have seen a continuous decline since 1995. Lung cancer incidence rates (all races combined) were stable from 1994 through 1998 and then a decrease was seen in 1999 and 2000\*. The same trend is seen in black and white males diagnosed with lung cancer, although the incidence rates are slightly higher among black males in New Jersey. Overall, New Jersey prostate cancer rates (all races combined) were 184.8 per 100,000\*\* in 1995 compared to 192.2 per 100,000 in 2000\*. Malignant melanoma of the skin increased from 16.2 per 100,000\*\* in 1995 to 21.6 per 100,000\*\* in 1997 and decreased to 18.5 per 100,000 in 2000\*.

In New Jersey males, cancer incidence increases with age. 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 rates in their 70-74 and 75-79 age groups.

In 2000\*, 50% of the new cancer cases in New Jersey males were diagnosed in the early stages (*in situ* and local), which is an increase from 42% in 1995. Cancers are being diagnosed earlier among white men in New Jersey than black men.

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\*Incidence rates for the year 2000 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 New Jersey State Cancer Registry (NJSCR) demonstrate that during the years 1995 through 2000\*, the overall cancer incidence rate for New Jersey females increased gradually through 1998 and then began to decline. The incidence rates for both white and black females in New Jersey mimic the trends seen in overall cancer incidence rates. Incidence rates of lung cancer appear stable during the years 1995 to 2000\* 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 were 12.0 per 100,000\*\* in 2000\*, compared to 10.2 per 100,000\*\* in 1995.

Similar to 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 2000\*, 48.5% of the new cancer cases in New Jersey females were diagnosed in the early stages (in situ and local), which is an increase from 44% in 1995. Cancers are being diagnosed earlier in white women in New Jersey than black women.

#### **NEW JERSEY COMPARED TO THE NATION, 1995-1999**

**H**istorically, 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 the U.S. during the period 1979 to 1999. 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. Since 1995 the incidence rate for both white and black males in New Jersey is higher than the national incidence rates.

For females, New Jersey had higher incidence rates than the U.S. during the period 1979 through 1999 for total cancers and colorectal cancer. New Jersey's females had higher breast cancer rates than the U.S., although the rates in 98-99 are more similar. Melanoma incidence rates for New Jersey females were lower than U.S. females. Incidence rates among white females in New Jersey have consistently been higher than the U.S. incidence rates for females. Black women in New Jersey have similar incidence rates when compared to U.S. black women.

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\*Incidence rates for the year 2000 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, 1994-1998**

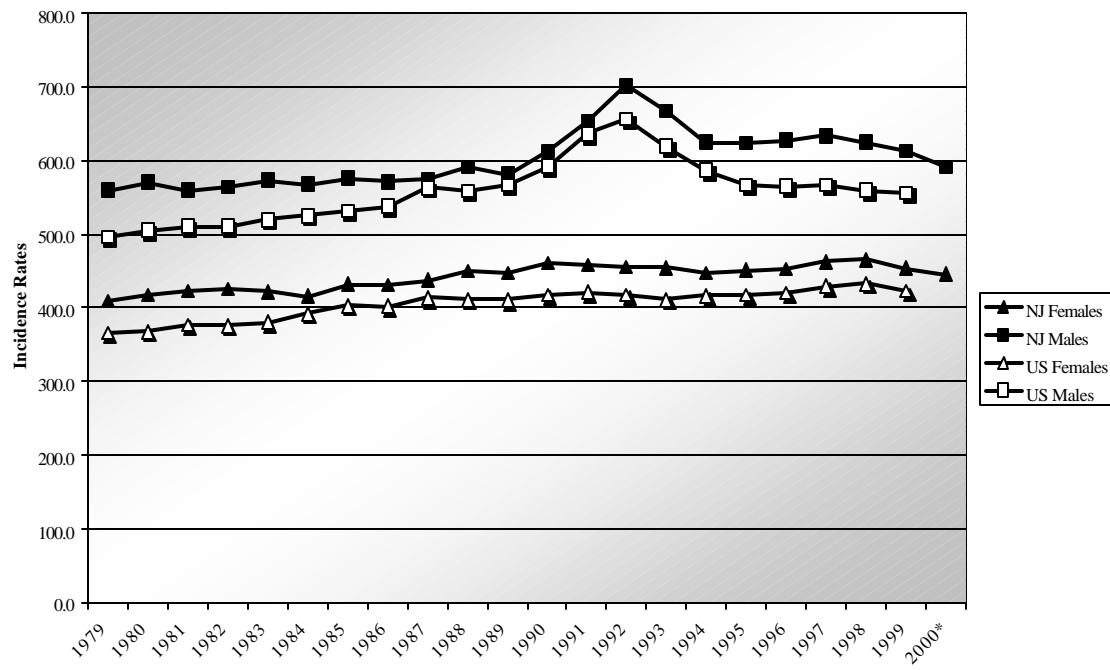
Currently, in New Jersey, about 13.2% or 1.1 million people are aged 65 and older. In New Jersey and nationally, over one-half of all newly diagnosed cancers occur in adults aged 65 and older. In New Jersey alone, 64% of men and 58% of women who are newly diagnosed with cancer are aged 65 and older and, therefore, this age group bears the greatest burden of cancer (4).

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.

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/or pharyngeal cancers. Better screening efforts among older adults and their physicians may increase the detection of these cancers at an earlier stage.

With the rising number and proportion of older adults with cancer in New Jersey over the coming decades, attention should be given to interventions that will decrease the burden of cancer among adults aged 65 and older. Opportunities abound 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.

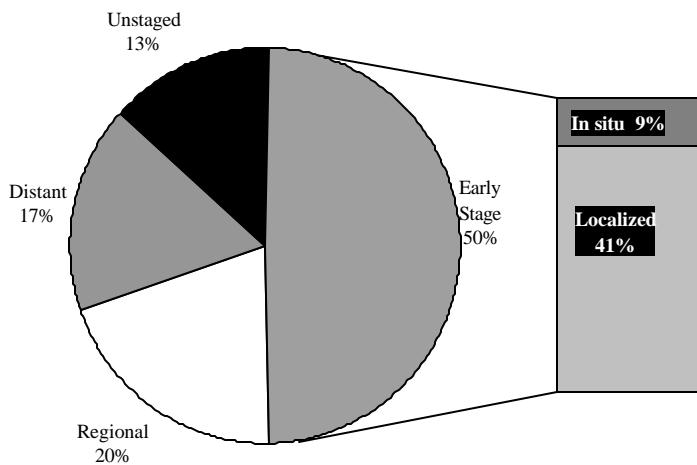
**Figure 2: U.S. and New Jersey Age-Adjusted Incidence Rates, All Cancer Sites, 1979-2000\***



Source: New Jersey State Cancer Registry (NJSCR) and SEER; Rates are per 100,000 and age-adjusted to the 2000 US standard.

\*Incidence rates for the year 2000 data from the NJSCR are preliminary; 2000 data are not available from SEER.

**Figure 3: Stage of Diagnosis for New Cancer Cases in New Jersey Males and Females, 2000\***



Source: NJSCR; \*Incidence rates for the year 2000 data from the NJSCR are preliminary.

## SURVIVAL AFTER CANCER IS DIAGNOSED

Cancer is the second leading cause of death in New Jersey. 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 18,177 deaths in 1999 for which cancer was designated on the death certificates as the underlying cause. The mortality rate for New Jersey was 256.0 per 100,000\*\* for males (all races combined) and 181.5 per 100,000\*\* for females (all races combined) in 1999.

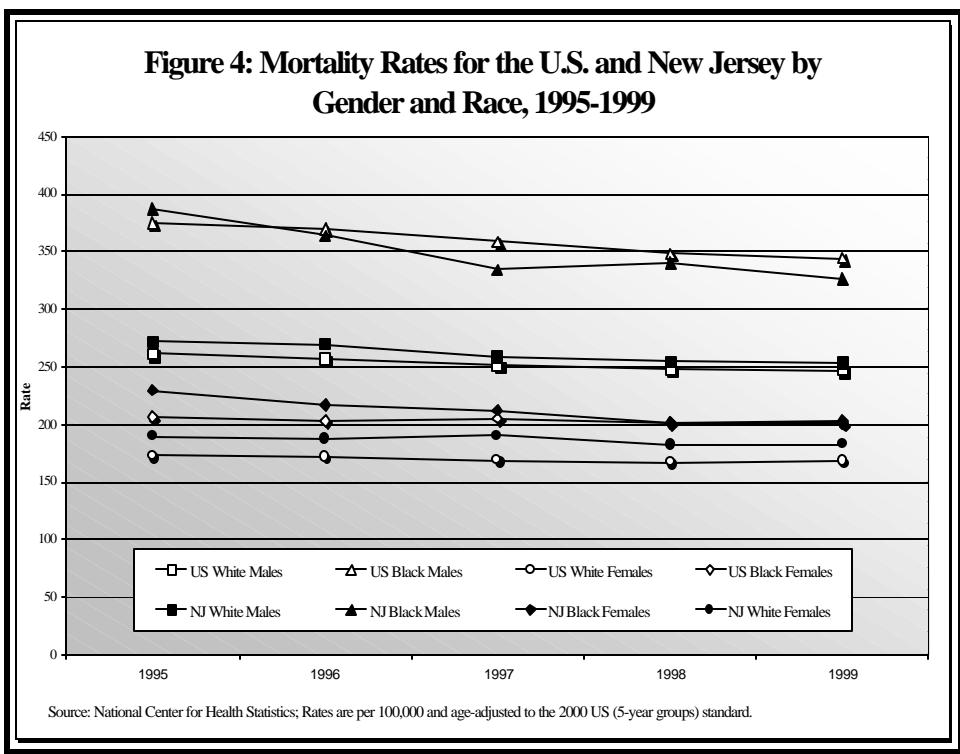
New Jersey cancer mortality rates for males (all races combined) and white males are slightly higher than the rates for the U.S.; however the mortality rates for black males in New Jersey fell lower than the rate for the U.S. in 1996 through 1999. New Jersey cancer mortality rates for females (all races 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 (Figure 4).

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 (5). 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, was long considered immutable. However, given the 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.

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 its 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. It is through the efforts of these dedicated scientists in our state that new approaches and therapies are realized which pave the way to understanding how cells and organisms function normally and what goes wrong in the development of cancer.

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

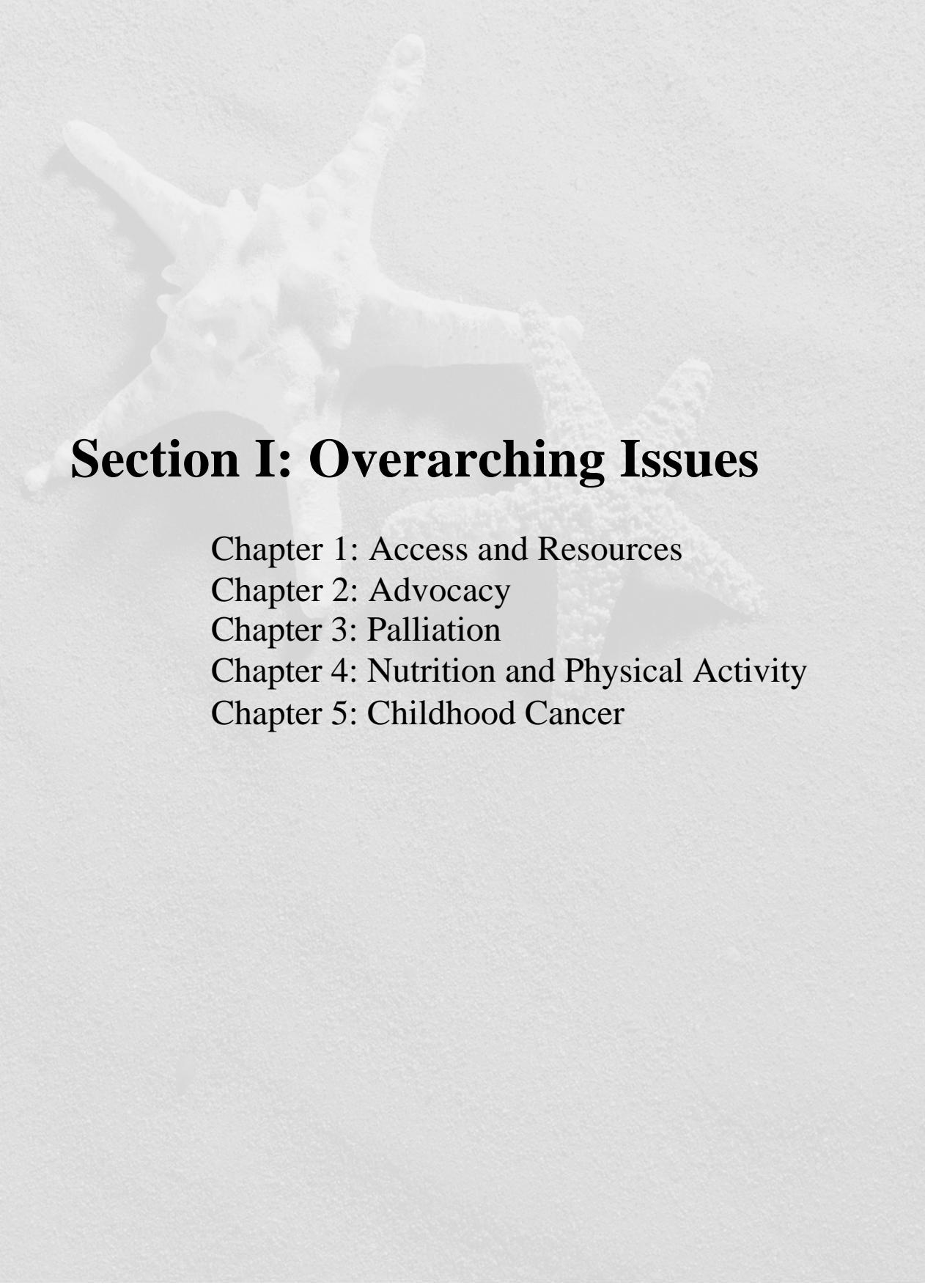


## REDUCING THE CANCER BURDEN

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 incumbent 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 *Comprehensive Cancer Control Plan* and will, once achieved, reduce the burden of cancer in New Jersey.

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## **Section I: Overarching Issues**

- Chapter 1: Access and Resources
- Chapter 2: Advocacy
- Chapter 3: Palliation
- Chapter 4: Nutrition and Physical Activity
- Chapter 5: Childhood Cancer

## **SECTION I: OVERARCHING ISSUES**

*The Overarching Workgroup was formed to focus on cancer control issues that bridge across all cancer types. Healthy New Jersey 2010 provides a systematic approach to monitoring and tracking health promotion and disease prevention objectives by targeting overall health status, access to health care, fundamentals of good health, preventing and reducing disease, and strengthening public health capacity. The Overarching Workgroup used this paradigm in regard to comprehensive cancer control by designated five subcommittees: Access and Resources (Chapter 1), Advocacy (Chapter 2), Palliation (Chapter 3), Nutrition and Physical Activity (Chapter 4), and Childhood Cancer (Chapter 5).*

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## ACCESS AND RESOURCES

### IMPORTANCE OF ACCESS AND RESOURCES FOR CANCER PREVENTION AND CONTROL

Advances in cancer research, education, outreach, screening, surveillance, and treatment are only effective if the public has proper access to healthcare that offers these benefits. As defined by the Institute of Medicine, *appropriate access to healthcare* is “the timely use of personal health services to achieve the best possible outcomes” (1). The Access and Resources Subcommittee of the Overarching Issues Workgroup was formed to develop strategies for increasing resources and physical access to cancer care for New Jersey residents, and the findings of this subcommittee are presented below.

In 1998, 33 million U.S. adults aged 18 to 64 years lacked health insurance (2). Individuals without routine access to primary healthcare do not receive timely care, such as cancer screenings to detect the onset of disease. Without access to proper healthcare, these individuals are more likely to be diagnosed at a later stage of cancer and more likely to experience higher morbidity and mortality. Individuals with insufficient resources and less than optimal access to healthcare tend to belong to ethnic minority groups, are unemployed, and have lower levels of education and income, generally below the poverty line (3). Barriers limiting access to appropriate healthcare can be cultural, systemic, personal, or societal in nature. Determining the unmet needs of underserved populations in the state, as well as the barriers they face in obtaining healthcare, may aid efforts to improve access to cancer care for all New Jerseyans (2).

Low rates of minority participation in cancer screening programs have prompted a number

of initiatives over the past decade, at both national and local levels. While these efforts have begun to narrow the screening gaps between some groups, significant disparities persist (4). Nor is coverage by managed care sufficient to ensure equivalent screening across all income groups. In a recent study analyzing the relationship between household income and mammography utilization in a managed care population, it was found that, even within that population, as income increased, the rate of mammography use increased (5).

Several studies describe proven techniques to increase access to cancer care. By offering mammograms through community-based influenza clinics, researchers found that the bundling of services is a viable means to exploit available interventions to improve health (6). A study conducted in Rhode Island increased accessibility of screening mammographies by reducing cost and implementing a telephone appointment and tracking system (7). Additionally, interventions aimed at increasing participation in health programs should focus on non-economic aspects of access, such as help-seeking behaviors and perceptions of access to care (8).

### ACCESS AND RESOURCES IN NEW JERSEY

Despite public and privately funded programs initiated in the past decade to begin addressing cancer-screening needs for New Jersey’s indigent populations, access issues persist. (See Appendix E for information on efforts by New Jersey’s breast and cervical cancer program to increase access to screening services for underserved populations.) It is paramount that public and professional education efforts to increase access and reduce barriers to cancer

prevention, detection, and treatment be addressed via sound strategic planning.

In 2001, an extensive report detailing access to primary care in New Jersey was published by the Health Research and Educational Trust of New Jersey (3). This report detailed geographic variation in hospitalizations for ambulatory care-sensitive conditions in 1995 and 1997. Of the 14 initiatives outlined in this

report, the Access and Resources Subcommittee chose to focus on four education initiatives that speak to comprehensive cancer control. Additionally, the Access and Resources Subcommittee has adopted three evidence-based tactics proposed by the Oncology Roundtable in 2001: community needs analyses, multimedia outreach campaigns, and education of professionals (4).

The recommendations of the Access and Resources Subcommittee are summarized below for the following four topic areas in priority order:

- Identification of Need
- Public Awareness
- Transportation
- Education for the Public and Professionals

## GOALS, OBJECTIVES AND STRATEGIES

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**Overall Goal: To assure that the people of New Jersey have increased access to high-quality cancer prevention, education, detection, and treatment services, including research studies, and to provide sufficient resources to meet these needs.**

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### IDENTIFICATION OF NEED

While the overall picture of cancer among New Jersey residents is encouraging, there is need for similar improvement among a number of population subgroups. As presented in the introductory section "Cancer Burden in New Jersey," statistics from the New Jersey State Cancer Registry clearly show disparities in cancer incidence and mortality for race, age, geographic location, and gender, among other variables (9;10).

A recently published analysis of the literature by Bach et al, concerning survival of blacks and whites after a cancer diagnosis indicated only modest cancer-specific survival differences for blacks and whites treated comparably for similar stage cancer (11). Researchers concluded that differences in treatment, stage at presentation, and mortality from other diseases should represent the primary targets of research and interventions designed to reduce disparities in cancer outcomes. Although racial differences did remain in the analysis for Bach et al, as well (11), aspects of process of care may also account for at least some of that residual (12). Similarly, a recent study of racial differences in the treatment of early-stage lung cancer suggests that the lower survival rate among black patients with early-stage, non-small-cell lung cancer, as compared with white patients, is largely explained by the lower rate of surgical treatment among blacks (13). Thus, it was concluded by the authors that increasing the rate of surgical treatment for black patients appears to be a promising

means of improving survival in this group. Other research has led to similar recommendations for improving access to diagnosis, treatment, and removal of barriers.

Although some data have been compiled stratifying for each type of cancer the incidence, prevalence, treatment access, mortality, etc., by age, race, gender, and geographic location, these data are largely incomplete (14). Existing data do not permit all factors to be simultaneously assessed, and summary measures frequently hide vast disparities within subgroups, which may be amenable to intervention and improvement. What is needed are studies to develop a more comprehensive database, as well as analytic work targeting those subgroups offering the greatest chances for improvements. Such efforts will help guide the cost-effective deployment of targeted resources toward those areas in need. Also necessary are studies that help define innovative ways to overcome current access barriers. Statistics reported on health indicators should be stratified by a variety of factors. Among women, for example, all age groups do not benefit equally from mammography or cervical cytology screening. Furthermore, population access apparently varies dramatically in different parts of the state. Detailed data are required to identify those in greatest need of services. Resources are necessary to then provide those services. The goal immediately below addresses identification of need, whereas the remaining goals in this chapter involve means to meet that need more effectively by improving access.

**GOAL AC-1:**

**To improve access to cancer-related care and resources in New Jersey, especially for those at high risk and populations in need.**

**Objective AC-1.1:**

To identify relevant ethnic and geographic disparities in access to cancer prevention, education, diagnostic, or treatment services that exist in any age-gender subgroup, including populations with special needs, e.g., physically and/or mentally challenged individuals.

**Strategies:**

- (AC-1.1.1) Review the literature and New Jersey data to identify disparities in cancer burden across populations.
- (AC-1.1.2) Design and perform studies to explore why disparities in cancer burden exist.
- (AC-1.1.3) Develop a communication plan to disseminate the results of the cancer burden study.

**Objective AC-1.2:**

To develop solutions to alleviate disparities and gaps in access to cancer-related care.

**Strategies:**

- (AC-1.2.1) Perform literature review to identify existing strategies to improve access to cancer care and assess evidence of effectiveness.
- (AC-1.2.2) Assess barriers to cancer care that are causing programs to be ineffective, such as unavailability of appointment times or language barriers.
- (AC-1.2.3) Refine *existing programs* designed to alleviate disparities in cancer burden.
- (AC-1.2.4) Develop *new strategies* where needed that address any existing gaps in these strategies to improve access to cancer care among any age-gender subgroup; including populations with special needs.

## PUBLIC AWARENESS THROUGH COMMUNICATION

As recommended by the Oncology Round-table (4), the Access and Resources Subcommittee chose communication through multimedia as the second priority.

Communication techniques encompass three categories: (1) *publicity* or the use of mass media that includes television, magazines, newspapers, radio and/or internet sources; (2) *face-to-face communication* that brings together spokesperson or targeted audience with media personnel who reach those aforementioned audiences via press conference, seminar participation, panel discussion, and/or distance learning; and (3) *controlled communication* or activities that include brochures, booklets, films, and/or internet format.

Some factors that affect the acceptance of public health messages include:

- *Health risk* is an intangible concept.
- People respond to easy solutions, e.g., blood test for cholesterol level as opposed to quitting smoking to reduce cancer risk.
- People want concrete information in order to make decisions.
- Information should not be fear-inducing.
- The public doubts the truth of science.
- Health information may not be a priority issue for an individual.
- People do not feel that a serious illness can strike them.
- The public can hold contradictory beliefs. People may believe, on the one hand, that an illness cannot strike them, while also believing that everything can cause cancer, and thus one cannot avoid it.
- People live for the present and tend not to worry about the future.
- The public does not understand science (15).

The design of a health message may convey facts, alter attitudes, change behavior, and/or encourage participation in decision-making. Generally these purposes overlap and are progressive. "That is, for persuasion to work, the public must first receive information, then understand it, believe it, agree with it and then act upon it." Messages need to be developed with an eye to the desired outcome. Messages should be clear in order to assure understanding and limit the possibility of misunderstanding or inappropriate action. There should be consistency in the health messages disseminated by government, health institutions, industry, non-profit agencies, and public interest groups. The main points should be stressed and repeated. The spokesperson and source of the information should embody credibility. These factors play a pivotal role in acceptance of a health message (15).

New Jersey has experienced some successes in communication. REACH 2010 developed a community action plan through its 33-member organization, Community Coalition. The success of REACH 2010 was due to this action plan and a very involved coalition.

The Access to Primary Care in New Jersey Report (3) recommended development of a comprehensive directory, culturally appropriate patient education classes, and diverse educational materials, as well as provision of cultural competency training for healthcare professionals. Overall, the health message should be based on what the target audience perceives as relevant for them (15). The Access and Resources Subcommittee recommends the goal, objective, and strategies below relating to public awareness through communication.

**GOAL AC-2:**

**To promote public awareness of cancer prevention, detection, and treatment services in New Jersey.**

**Objective AC-2.1:**

To identify and enhance communication methods among all organizations with an interest in cancer prevention, education, detection and treatment services, including research studies.

**Strategies:**

- (AC-2.1.1) Organize a media campaign to highlight the cancer needs in New Jersey (as identified in the Identification of Need section of this chapter), available cancer-related community services, and programs addressing gaps in care.
- (AC-2.1.2) Enhance the cancer resource guide for New Jersey – to be able to locate doctors.
- (AC-2.1.3) Identify/develop logo/symbol for cancer awareness.
- (AC-2.1.4) Assess the extent of the increase of cancer awareness in the public and which strategies are linked to that increase.
- (AC-2.1.5) Encourage public-private partnerships to expand cancer health communication efforts.
- (AC-2.1.6) Promote collaboration with traditional and nontraditional partners to improve communication about access and resources for cancer education, detection, and prevention services, including research studies.
- (AC-2.1.7) Disseminate information about New Jersey Cancer Education and Early Detection Program (NJCEED) services and sites. (See Appendix E)

**TRANSPORTATION**

The complex issue of healthcare access includes many barriers, including a lack of efficient and affordable transportation. According to a report by the New Jersey Department of Health and Senior Services,

“Physicians and clinics may not be located in places which are easily accessible, particularly to people who lack private transportation” (16). In a study of access to primary care in New Jersey, Vali notes, “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" (3).

Vali's report on access to primary care in New Jersey (3) includes a summary of barriers by type and notes that one system-related barrier is "limited public transportation routes and options." 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.

The experience of the Bergen County Cancer Education and Early Detection Program (BCCEED) demonstrates of the importance of including transportation support in designing health programs for the underserved. BCCEED provides opportunities for women and men living in Bergen County to undergo free cancer screenings, if they meet program guidelines concerning age, residency, insurance, and income. The program is designed to provide access to breast, cervical, colorectal, and prostate screenings to clients from underserved populations. Although lack of insurance and prohibitive costs are the primary reasons cited by this population for low screening rates, BCCEED identified another significant barrier as lack of transportation. While the CEED program offers access to screening and diagnostic appointments, and in some cases free access to cancer treatment, the program is unable to provide transportation to program participants.

During the course of a year, nearly 27% of BCCEED clients require transportation assistance to screening and medical appointments funded by the CEED program. Past efforts to utilize existing community transportation resources resulted in frequently missed

appointments due to inefficiencies within the system. Missed appointments, valued at \$200.00 each, were frustrating for both clients and CEED program staff. In January 2001, a grant was received from the Susan G. Komen Breast Cancer Foundation to provide door-to-door taxi service for women requiring this service. As a result, only 3% of clients have missed appointments this year due to transportation-related problems, and no one has missed an appointment due to transportation problems since March 2001.

The American Cancer Society (ACS) offers free transportation services to patients undergoing cancer treatment. This program, staffed by volunteers, provides patients with transportation to radiation or other medical appointments during the treatment phase. A victim of its own success, the program's demand for transportation outstrips the number of ACS volunteers available to provide this important service. To estimate the costs of transportation, the American Cancer Society expenditures for transportation were calculated. In Fiscal Year 1998, ACS provided the following cancer-related transportation services in New Jersey: 473 volunteers transported 1,072 patients to treatment centers representing 11,358 trips. This volunteer service had an estimated dollar value of \$533,772. Approximately 250 patients received direct financial assistance for their transportation in the amount of \$83,688, total.<sup>^</sup>

With a population of nearly 900,000 residents, Bergen County (mentioned above in connection with the BCCEED program) offers a limited number of bus routes across the county. For New Jersey residents living in less urban areas, bus service is even more fragmented. Lack of centralized, efficient public transportation forces vulnerable

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<sup>^</sup> Calculated by American Cancer Society, Eastern Division Internal Documents, 1998.

populations to rely on community resources to meet transportation needs. However, as illustrated, the private sector is often overwhelmed and unable to keep pace with demand.

Although recognizing these as only a beginning, the Access and Resources Subcommittee offers the goal, objective, and strategies below as means to improve transportation services for cancer care in New Jersey.

**GOAL AC-3:**

**To improve transportation in order to increase access to cancer care in New Jersey.**

**Objective AC-3.1:**

To identify obstacles to adequate transportation for cancer-related services encompassing education, screenings, and treatment.

**Strategies:**

- (AC-3.1.1) Identify those counties that currently have successful area-wide transportation (AWT) van services to explore best practices.
- (AC-3.1.2) Identify communications deficiencies within the AWT system.
- (AC-3.1.3) Provide incentives to support low-cost transportation for those in need of cancer services, e.g., by investigating a state tax credit and/or arrangements with private foundations to support provision of low-cost transportation.
- (AC-3.1.4) Explore provision of public transportation vouchers to those in need of cancer services.
- (AC-3.1.5) Support the American Cancer Society's efforts to make transportation services more widely available to cancer patients.
- (AC-3.1.6) Identify principal agency and centralize transportation services for cancer patients.
- (AC-3.1.7) Explore opportunities to provide transportation for cancer patients via faith-based communities, assisted living facilities, and community transportation, e.g., "Assist-a-Ride".

## **EDUCATION FOR THE PUBLIC AND PROFESSIONALS**

The Access and Resources Subcommittee determined that both the public and professionals have a general lack of cancer awareness, especially in regard to cancer screening. A review of the New Jersey public education curriculum revealed that little health prevention and promotion is being taught to children in younger grades. The textbooks currently being used for high school, although more extensive, lack comprehensive information about cancer prevention, risk factors, and early detection. Additionally, the critical shortage of nurses in New Jersey directly impacts all aspects of cancer care and control.

The goal of health education is to impart the necessary knowledge, attitudes, and skills required to effect positive change in an individual's behavior. Public education plays a vital role in disease prevention and health promotion. Health education programs designed to promote changes in health behaviors and to encourage early detection and prompt treatment of illness have demonstrated that mass media and other channels of communication can be effective in reducing the risk of serious illness (15).

In order to be effective, an educational program must be tailored to the targeted audience's needs. Health education activities must take into consideration the physical, behavioral, demographic, psychosocial, and

cultural characteristics of the target audience. In order to ensure that materials are relevant to community needs and interests, educational programs must be developed from the community perspective, and members of the target audience should be included in all phases of the program planning process. Providers are often ill-prepared to communicate the complexities of cancer care to their diverse patient populations; constraints of the medical care system can also impede delivery of care (17).

Oncology-certified nurses specializing in the care of cancer patients play pivotal roles in the delivery of cancer education and treatment. Partnering with Registered Professional Nurses and Advanced Practice Nurses, whose practice arenas involve primary care, these nursing professionals share the burden of integrating ethnic and cultural considerations into best practice models. Nursing shortage issues compound barriers to successful implementation of programs and will require ongoing evaluation and support. Currently, several pending New Jersey Senate and Assembly bills speak to increasing appropriations for nursing programs and nurse-retention programs. (A3345, S2204, A3346, S2205, A3691, S2412, A3193, S2300, A3887, S2443)

To improve these aspects of access to cancer care, the Access and Resources Subcommittee proposes the goal, objectives, and strategies outlined below.

**GOAL AC-4:**

**Enhance current public and professional education efforts to increase access and reduce barriers to cancer prevention, detection, and treatment.**

**Objective AC-4.1:**

To identify strategies to increase cancer service access and resources for all populations through public education.

**Strategies:**

- (AC-4.1.1) Investigate the efficacy of educational and promotional materials designed to improve access to cancer services with regard to literacy level, language, and culture-specific communication media.
- (AC-4.1.2) Conduct a survey of cancer patients to ascertain awareness of appropriate providers, telephone and/or internet information lines, clinical trials, and transportation services.
- (AC-4.1.3) Work with the Department of Education to develop curricula for Cancer Awareness Week.
- (AC-4.1.4) Collaborate with the New Jersey Commission on Cancer Research on a review of the New Jersey Cancer Resource Book and assist with updates.
- (AC-4.1.5) Disseminate the New Jersey Cancer Resource Book to community organizations, including assisted-living facilities.
- (AC-4.1.6) Promote awareness of health insurance benefits for cancer prevention, detection, and treatment.
- (AC-4.1.7) Educate the public regarding the purpose and importance of participating in clinical trials for cancer, with special emphasis on addressing the concerns of minority populations.

**Objective AC-4.2:**

To identify strategies to increase cancer service access and resources for all populations through professional education, including health systems, e.g., hospitals, health plans, clinicians.

**Strategies:**

- (AC-4.2.1) Increase the number of oncology-certified nurses and the number of nurses in the state who hold membership in the Oncology Nursing Society.
- (AC-4.2.2) Launch a statewide educational campaign focusing on cancer prevention, early detection, treatment, and clinical trials.
- (AC-4.2.3) Educate all healthcare professionals on cancer screening guidelines.
- (AC-4.2.4) Address special cancer-related issues of minority and underserved populations at continuing professional education programs.
- (AC-4.2.5) Encourage health plans to promote awareness of appropriate cancer prevention screening intervals and health benefits.
- (AC-4.2.6) Develop and disseminate information to employers/employees regarding the availability of health benefits for cancer services.

**Objective AC-4.3:**

To identify cancer-related deficiencies in the healthcare system and propose solutions for recruiting more healthcare professionals in New Jersey, particularly Registered Professional Nurses.

**Strategies:**

- (AC-4.3.1) Develop a plan for recruiting more healthcare professionals in New Jersey.
- (AC-4.3.2) Develop a plan for educating students, Grades K–12, about healthcare careers.
- (AC-4.3.3) Advocate for state funding for professional healthcare training.
- (AC-4.3.4) Promote incentive programs for advanced-level training of healthcare professionals.

**Principal Change Agents:** The following organizations will contribute to the implementation of the access and resources strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: AC-1.1.1; AC-1.2.1; AC-1.2.2; AC-2.1.1; AC-2.1.2; AC-2.1.3; AC-2.1.4; AC-2.1.5; AC-2.1.6; AC-2.1.7; AC-3.1.1; AC-3.1.2; AC-3.1.3; AC-3.1.4; AC-3.1.5; AC-3.1.6; AC-3.1.7; AC-4.1.1

New Jersey Society for Public Health Education: AC-1.3.1

University of Medicine and Dentistry of New Jersey – New Jersey Medical School: AC-1.1.1; AC-1.2.1; AC-1.2.2; AC-1.3.1

University of Medicine and Dentistry of New Jersey – School of Public Health: AC-1.1.1; AC-1.2.1; AC-1.2.2; AC-1.3.1; AC-2.1.1; AC-2.1.2; AC-2.1.3; AC-2.1.4; AC-2.1.5; AC-2.1.6; AC-2.1.7

## ACCESS/RESOURCES

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1. Improve access to cancer-related care and resources	1.1: Identify ethnic and geographic disparities	AC-1.1.1						
		AC-1.1.2						
		AC-1.1.3						
	1.2: Develop solutions	AC-1.2.1						
		AC-1.2.2						
		AC-1.2.3						
		AC-1.2.4						
		AC-2.1.1						
		AC-2.1.2						
		AC-2.1.3						
2. Promote public awareness	2.1: Identify and enhance communication	AC-2.1.4						
		AC-2.1.5						
		AC-2.1.6						
		AC-2.1.7						
		AC-3.1.1						
		AC-3.1.2						
		AC-3.1.3						
3. Improve transportation	3.1: Identify obstacles	AC-3.1.4						
		AC-3.1.5						
		AC-3.1.6						
		AC-3.1.7						
		AC-4.1.1						
		AC-4.1.2						
		AC-4.1.3						
4. Enhance current education efforts	4.1: Strategies to increase access and resources through public education	AC-4.1.4						
		AC-4.1.5						
		AC-4.1.6						
		AC-4.1.7						
		AC-4.2.1						
		AC-4.2.2						
		AC-4.2.3						
	4.2: Strategies to increase access and resources through professional education	AC-4.2.4						
		AC-4.2.5						
		AC-4.2.6						
		AC-4.3.1						
		AC-4.3.2						
	4.3: Identify deficiencies	AC-4.3.3						
		AC-4.3.4						
<b>Target Completion Date</b>								

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## CHAPTER 2. Advocacy

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## ADVOCACY

### IMPORTANCE OF ADVOCACY FOR CANCER PREVENTION AND CONTROL

Cancer is a political, as well as a medical, social, psychological, and economic issue. Cancer is a personal, tangible, and powerful issue for millions of Americans and thousands of New Jerseyans. Every day legislators make decisions that impact the lives of cancer patients, survivors, their families, and future cancer patients (1). To influence those decisions positively, the *Comprehensive Cancer Control Plan for New Jersey* incorporates 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 and subcommittees (3). Present legislative priorities in the cancer arena will focus on advancing the *Plan* and ensuring that all residents have access to 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.

The recommendations of the Advocacy Subcommittee are summarized below for the following three topics in priority order:

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

## GOALS, OBJECTIVES AND STRATEGIES

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**Overall Goal: Promote public awareness of cancer prevention, early detection and treatment in New Jersey.**

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### 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 8.9 million Americans with a history of cancer were alive in 1997 (4). In fact, for the first time since 1990, cancer death rates are declining. 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 (5).

A highlight of the February stakeholders conference on the Canadian Strategy for Cancer Control was an impassioned presentation by Bob Rae, former Prime Minister of Ontario. Rae first noted the need for a sense of focus and priority. He then observed that the most immediate problem was one of human resources and the setting of national objectives (6). To build and support the advocacy component of the *Plan* as outlined, the Advocacy Subcommittee recommends building an infrastructure to foster its successful implementation.

#### GOAL AD-1:

To advocate for funding of and support for the *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 *Comprehensive Cancer Control 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 *Comprehensive Cancer Control 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 create 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 *Comprehensive Cancer Control 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 more rapidly reduce the burden of the disease. 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 must be removed; and that the unequal burden of cancer carried by the poor, ethnic minorities, and the underserved be relieved (7).

Residents of New Jersey, especially cancer patients and their families, experience a

variety of roadblocks to accessing prevention, early detection, and treatment services. For example, lack of adequate insurance may impede access to cutting-edge treatments provided in a clinical trial or to prevention or early detection tools that have long been accepted by the medical community. Access to needed services can also be adversely affected by reimbursement practices (8). At present, New Jersey has an agreement with the ten largest insurers doing business in the state. This agreement stipulates that residents of New Jersey will have insurance coverage for routine patient costs associated with all phases of cancer clinical trials. This novel agreement, the first of its kind in the nation, has been successful in accessing more patients to clinical trials in New Jersey.

**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 assure 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.

### 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 in 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 The Burden of Cancer in New Jersey for more information.) During 1992-1998, the U.S. incidence rates for all cancer sites was highest among blacks, followed by whites, Asian/Pacific Islanders, Hispanics, and American Indians/Native Alaskans. U.S. mortality rates during the same time period were also highest among blacks, followed by whites, American

Indians/Native Alaskans, Hispanics and then Asian/Pacific Islanders. Despite the high rates of incidence from all cancers combined from 1992-1998, rates among blacks, Hispanics and whites decreased while it remained relatively stable among American Indians/Native Alaskans and Asian/Pacific Islanders. Similarly, mortality rate for all cancer sites decreased annually among blacks, Asian/Pacific Islanders, whites and Hispanics while leveling off among American Indian/Native Alaskans (4). Many disparities among cancer sites also exist and are detailed in the site-specific chapters.

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, new cancer cases will rise dramatically, causing cancer to surpass heart disease as the nation's leading killer (8). A higher percentage of retirement-

age New Jerseyans have cancer and die of it than in the nation as a whole. Among those 65 and older, the cancer rate is 13% higher among men, 12% higher among women, as compared to the national average (9).

**GOAL AD-3:**

**To reduce cancer-related health disparities among minorities, seniors, and the medically underserved.**

**Objective AD-3.1:**

To advocate for a healthcare system that provides cancer services in a humane, patient friendly, and culturally appropriate manner.

**Strategies:**

- (AD-3.1.1) 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-3.1.2) Advocate for organized healthcare systems that reduce fragmentation of available cancer services.
- (AD-3.1.3) Advocate for required quality assurance 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.

**Principal Change Agents:** The following organization will contribute to the implementation of strategies outlined above. This list is not mutually exclusive.

American Cancer Society

## ADVOCACY

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Funding of and support for the Comprehensive Cancer Control Plan	1.1: Involve key stakeholders to garner ongoing support	AD-1.1.1						
		AD-1.1.2						
	1.2: Educate legislative members and staff about importance of funding	AD-1.2.1						
		AD-1.2.2						
2: Advocate for increased access to quality cancer care	2.1: Advocate for adequate health insurance coverage	AD-2.1.1						
		AD-2.1.2						
		AD-2.1.3						
	2.2: Provide access to current therapies and treatments	AD-2.2.1						
		AD-2.2.2						
		AD-2.2.3						
	2.3: Create a centralized resource for cancer information	AD-2.3.1						
		AD-2.3.2						
		AD-2.3.3						
3: Reduce cancer-related health disparities	3.1: Advocate for humane, patient friendly and culturally appropriate health care services	AD-3.1.1						
		AD-3.1.2						
		AD-3.1.3						

Target Completion Date

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## PALLIATION

### DEFINING PALLIATION IN NEW JERSEY

The first challenge facing the Palliation Subcommittee of the Overarching Issues Workgroup was developing a definition of palliative care that was operational, yet inclusive of a variety of perspectives. Subcommittee 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 subcommittee’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 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.” It is this latter, broader definition that the Palliation Subcommittee has chosen as a model for its own definition.

Another issue considered by the subcommittee 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 professionally inclusive enough that the

interdisciplinary approach would not become lost in the more familiar medical model hierarchy, subcommittee 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 subcommittee 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 subcommittee proposes the following definition of palliative care:

*“Palliative care is a coordinated, interdisciplinary approach to healthcare that enhances the quality of life of patients with cancer and other illnesses. It targets the physical and psychological symptoms and spiritual needs of patients from the time of diagnosis to end-of-life care in all settings.”*

(Palliation Subcommittee, 2001)

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

### IMPORTANCE OF PALLIATION IN CANCER CARE

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 (1). Today, the premise of hospice has evolved to *palliation*, a term that encompasses 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 Childhood Cancer Chapter 5 for additional information about Palliation.)

Palliation is frequently described as managing the physical, emotional, and spiritual needs of both patient and family. This comprehensive approach requires a multidisciplinary team for care, including nursing, pharmacy, social work, volunteer services, pastoral care, nutrition, arts, physical therapy, and medicine (1;2).

Palliative care is likely to become the norm of practice in mainstream U.S. healthcare in the coming decade (3) and is a key issue in cancer control. As noted earlier in this plan, the American Cancer Society estimates that 41,100 new cancer cases will be identified and 17,800 cancer deaths will occur in New Jerseyans in 2002 (4). In a recent study of veterans with cancer, it was found that at any time 10% to 20% of the study population urgently needed intensive palliative care (5). The potential for cancer patients needing palliative care services in New Jersey is very high.

Despite advances in palliative care in the past two decades, many cancer patients continue to suffer from unmanageable symptoms, including an unacceptable 70% to 90% experiencing acute pain (6). Cancer patients receiving palliative care reported prevalence of lack of energy, pain, dry mouth, shortness of breath, and difficulty sleeping (5). Pain includes physical and spiritual manifestations (feelings of abandonment, anger, betrayal, despair, fear,

guilt, meaninglessness, regret, self-pity, and sorrow/remorse) (1). Patient barriers to effective pain management include a 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 (1).

Every year the number of New Jerseyans 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 (7). The percentage of Medicare cancer patients enrolled in hospice declined from 75.6% in 1992 to 57.4% in 1998. It is apparent that patients with cancer are increasingly substituting their residence for the hospital as a place of death.

Additionally, the cost of palliative care is increasing. Medicare hospice expenditures climbed from \$205 million in FY1989 to \$2.1 billion in FY1998 (8). Medicaid hospice expenditures rose from \$1.5 million in FY1987 to \$197.2 million in FY1999. New Jersey was the 35<sup>th</sup> state to offer hospice under Medicaid in 1992 (8). 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, and rising healthcare costs.

In the next decade, barriers to effective palliative care must be alleviated. The Palliation Subcommittee 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.

The recommendations of the Palliation Subcommittee are summarized below for the following topics in palliative care presented in priority order:

- Education
- Access

## GOALS, OBJECTIVES AND STRATEGIES

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### Overall Goal: Increasing awareness of and access to palliative care.

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#### 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.

In the palliative care arena, diverse treatment options are available for the seriously or terminally ill. Yet choices for patients and surrogates will always be limited to those offered by the physician or requested by the patient or a surrogate (9). Failure to provide survival estimates may also limit patient choice about palliative care. According to a recent study, physicians reported that even if patients with cancer requested survival estimates, clinicians provided a frank estimate only 37% of the time, rather providing no estimate, a conscious overestimate, or a conscious underestimate most of the time (63%) (10).

The challenges presented to patients and their families at 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 regard this aspect of care as either unimportant or secondary, rather than as a core component. 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 (11).

Despite the many societal and professional barriers to effective pain management, the Palliation Subcommittee has identified physician knowledge gaps in pain management and symptom control and misconceptions regarding pain management as the top priority to improve palliative care in New Jersey. In recent years, several medical and nursing schools have added education regarding palliative care concepts to their curricula. Many require that a hospice rotation be included in the clinical experience, since hospice is pure palliative care. The number of professionals certified in palliative care may be expected to increase, as additional educational opportunities in the field become more numerous.

Initiatives have also been undertaken to build public awareness. In 2000, Bill Moyers' four-part series entitled "On Our Own Terms" reported on the growing movement in America to improve care for people who are dying (Films for Humanity and Sciences). Both the newspaper and movie industries have explored quality-of-life issues related to aggressive, curative treatments as well as supportive care for the terminally ill ([www.lastacts.org](http://www.lastacts.org)).

Many state policy-makers are working to improve care at the end of life, hoping to insulate their states against efforts to secure the right to assisted suicide. "People have to feel confident that the health care system will take good care of them when they are dying," says Assemblywoman Helen Thomson (D-California). "Lack of faith in that system is what moves people to desperate measures" (12). There are legal barriers to quality end-of-life care - one example among several relates to adequate pain management.

Marilyn Webb writes, “Adding to American physician’s apprehension about using narcotics is stringent and increasing pressure from law-enforcement agencies. Indeed, by now the legal scrutiny provoked by narcotics use makes even suffering patients and their families fearful of using opioid drugs and it has left doctors terrified” (13). Legislators can help remove barriers, which would benefit every constituent in their districts. Knowledge of the issues is imperative to understanding the changing needs.

Although small steps have been made toward improving understanding of and access to palliative care, the need for better care that promotes quality of life continues to grow. The transition, however, 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 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 Subcommittee 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 identify incentives for 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.
- (PA-1.1.3) Educate state legislators who can serve as advocates in supporting palliative care policies.

## ACCESS TO PALLIATIVE CARE

**M**embers of the Palliation Subcommittee hold that all patients in New Jersey are entitled to access 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; long-term care facilities, such as nursing homes, mental institutions, centers for the mentally and physically challenged; hospitals; assisted-living facilities; boarding homes; state veterans' hospitals; or prisons. Many of these patients will have family members and/or significant others (hereafter referred to as the family). Family members, as well, 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 the care the patient and family desire and deserve. On the other hand, even when the focus on curative care is no longer the avenue of choice, some healthcare providers may still find it difficult to offer palliative care. Other times, the distinction between curative and palliative care may not be clear-cut, and care approaches may fluctuate between the two.

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. At other times, palliative care may be offered as an option, but another option actually becomes the payer. In the latter case, care needs to be taken that the palliation aspect is not compromised or lost entirely. Another concern is that a patient may be on hospice too long or not long enough. 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 government institutional settings.

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 (3), but also to provide information to and support for patients and their families.

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 management 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 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 services.

**Strategies:**

- (PA-2.3.1) Collect existing data and identify gaps in available palliative care services.
- (PA-2.3.2) Develop strategies to address the gaps in palliative care services.

**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.

**Principal Change Agents:** The following organizations will contribute to the implementation of palliative care strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: PA-2.3.2

New Jersey Hospice and Palliative Care Organization: PA-1.1.1; PA-1.1.2; PA-1.1.3; PA-2.1.1; PA-2.2.1; PA-2.3.1; PA-2.3.2

## PALLIATION

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Integrate palliative care	1: Educate all constituencies regarding rights and benefits of palliative care	PA-1.1.1						
		PA-1.1.2						
		PA-1.1.3						
2: Ensure accessibility to palliative care	2.1: Reimbursement	PA-2.1.1						
	2.2: Palliative care standard development	PA-2.2.1						
	2.3: Reduce system barriers	PA-2.3.1						
		PA-2.3.2						
	2.4: Reduce personal barriers	PA-2.4.1						

**Target Completion Date**

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## CHAPTER 4. Nutrition and Physical Activity

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## NUTRITION AND PHYSICAL ACTIVITY

### IMPORTANCE OF NUTRITION AND PHYSICAL ACTIVITY FOR CANCER PREVENTION AND CONTROL

The role of diet in cancer etiology and prevention is well established. A panel of experts commissioned by the World Cancer Research Fund and the American Institute for Cancer Research concluded that between 30% and 40% of all cancers are preventable by dietary means, physical activity, and maintenance of appropriate body weight (1). Establishing healthy eating patterns can play a major role in cancer prevention, mainly because this is a potentially modifiable behavior. There is also increasing evidence that physical activity may be inversely related to some cancers (2). 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, they all recommend a reduction in fat intake, particularly from animal sources, an increase in fiber intake, the inclusion of a variety of fruits and vegetables in the daily diet, to be physically active and maintain a healthy weight, to consume alcoholic beverages in moderation, if at all, and to minimize the consumption of salt-cured, salt-pickled, or smoked foods.

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 (3). 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. 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 (4).

### 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 for certain cancer types is higher in New Jersey than the national average. The Healthy New Jersey 2010 Report (5) focuses on the following goals for nutrition and health:

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

3. **Objective:** To reduce the percentage of persons aged 18 and over who are *obese* to 12.0% of all adults.
4. **Objective:** Increase the percentage of persons aged 18 and over who participate in frequent, leisure-time *physical activity* during the past month to 42.5%.

**Consumption of Fruits and Vegetables.** As shown in Table 1, according to Behavioral Risk Factor Surveillance System (BRFSS) data, only 27.4% of New Jersey adults reported consuming fruits and vegetables at least five times a day in the year 2000. Although, the proportion of

New Jersey residents eating 5-a-day is higher than the national average for the total population and for each race, gender, and age subgroups (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 efficient nutrition interventions to help New Jersey residents achieve this goal. Males, Hispanics, and young New Jersey residents, aged 18 to 24 years, may derive the most benefit from these interventions (Table 1).

**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 2000\* and specified target % in Healthy New Jersey 2010\*\***

	New Jersey (2000)	Nationwide (2000)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	27.4	23.1	35	50
By race				
White	27.4	23.4	35	50
Black	27.9	21.3	35	50
Hispanic	24.6	23.2	35	50
Other	35.4	24.9	35	50
By gender				
Male	24.0	18.9		
Female	30.6	26.9		
By age				
18-24	23.3	21.6		
25-34	24.8	19.1		
35-44	24.7	19.8		
45-54	26.6	21.8		
55-64	27.2	26.9		
65+	36.0	31.7		
By education				
< High School	25.5	19.9		
H.S. or GED	25.7	19.6		
Some post-HS	24.7	23.9		
College graduate	31.7	27.8		

\*Behavioral Risk Factor Surveillance System data, CDC, 2000

\*\*Healthy New Jersey 2010, New Jersey Department of Health and Senior Services.

**Overweight.** As Table 2 shows, the proportion of overweight subjects in 2000 was slightly higher in New Jersey than the national average (38.3% 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 2000 (Table 2). The data also reveal differences by race, with blacks reporting the highest prevalence of overweight in the year 2000 (Table 2). Also included in Table 2 are the Healthy New Jersey objectives for reducing the percentage of overweight subjects for the year 2010. The

target percentages shown in Table 2 were based on BRFSS 1996-1999 data and reflect discrepancies by race observed during that period. According to BRFSS data for the years 1996-1999 (data not shown), the percentage of overweight New Jersey residents was highest among Hispanics (41.5%), followed by blacks (38.3%), and whites (36.3%). Although male and black populations appear to have the greatest need for the intervention and research programs, all groups are far from the target 27.6% and could benefit from health promotion activities aiming at achieve long-term healthy body weight.

**Table 2. Percentage of New Jersey residents 18 years and older who are overweight (defined as BMI\* between 25 and 29.9) in 2000\*\* and specified target % in Healthy New Jersey 2010\*\*\***

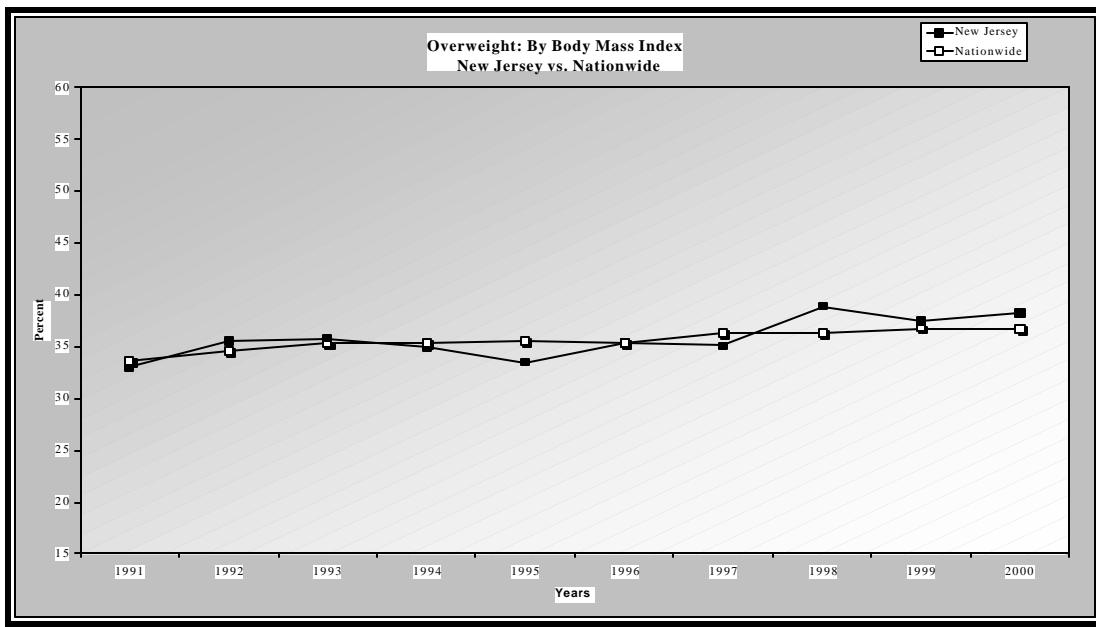
	New Jersey (2000)	Nationwide (2000)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	38.3	36.7	27.6	25
By race				
White	37.4		28.1	25
Black	44.0		28.4	25
Hispanic	38.9		32.4	25
By gender				
Male	48.4	45.1	36.6	25
Female	28.5	28.5	25.1	25
By age				
18-34	32.7	31.1		
35-49	40.9	38.1		
50-64	40.4	40.7		
65+	40.2	40.0		

\* 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, CDC, 2000.

\*\*\*Healthy New Jersey 2010, New Jersey Department of Health and Senior Services.

**Figure 1. Trends in percentages of New Jersey residents who are overweight\* versus nationwide, Behavioral Risk Factor Surveillance System, 1991-2000**



\*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 18.5% to the Healthy New Jersey 2010 target of 12%. The obesity prevalence is particularly high among blacks (25.8%). 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.** The obesity epidemic in the U.S. and in New Jersey is the result of unhealthy diets and lack of exercise. As shown in Table 4, 29% of New Jersey residents reported no leisure-time physical activity, and only 14% engaged in regular and vigorous exercise in the year 2000.

Although the levels of physical activity seem to be similar for males and females, there are striking differences by other demographic characteristics. The level of physical inactivity is particularly high among Hispanics (40%) and is inversely related to education and income. Not surprisingly, stratified analysis by Body Mass Index (BMI) revealed the highest proportion of inactive subjects among those with a BMI of 30+ (obese subjects). Reaching the objective outlined in the Healthy New Jersey 2010 of increasing the percentage of New Jersey adults participating in frequent leisure-time physical activity to 42.5% appears to be a challenge, particularly for certain subgroups, such as the less affluent, less educated, obese, and non-white populations.

**Table 3. Percentage of New Jersey residents 18 years and older who are obese (defined as BMI\* of 30.0 or greater) in 2000\*\* and specified target % in Healthy New Jersey 2010\*\*\***

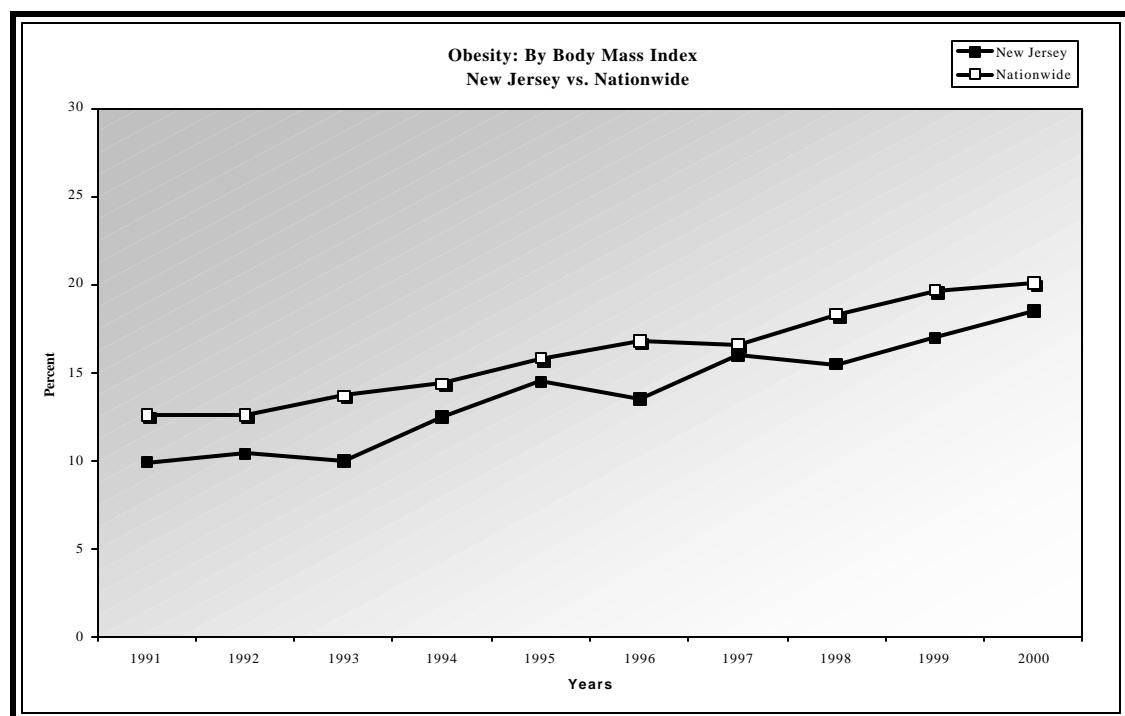
	New Jersey (2000)	Nationwide (2000)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	18.5	20.1	12	12
By race				
White	17.8		12	12
Black	25.8		15	12
Hispanic	19.8		12	12
By gender				
Male	18.4	20.6	14	12
Female	18.5	19.8	12	12
By age				
18-34	11.9	15.8		
35-49	19.9	22.0		
50-64	24.6	26.7		
65+	20.1	18.2		

\* BMI is defined as weight in kilograms divided by height in meters squared ( $w/h^{**2}$ ).

\*\*Behavioral Risk Factor Surveillance System data, CDC, 2000.

\*\*\*Healthy New Jersey 2010, New Jersey Department of Health and Senior Services.

**Figure 2. Obesity trends in New Jersey versus nationwide, Behavioral Risk Factor Surveillance System, 1991-2000**



\*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 subjects participating in four levels of physical activity.**  
**BRFSS 2000, New Jersey adults**

	Inactive*	Irregular**	Regular***	Regular and vigorous****
Total group	29	27	30	14
By gender				
Males	27	27	33	14
Females	31	27	28	15
By race				
White	25	27	31	16
Black	29	32	30	9
Hispanic	40	25	25	10
By age				
18-64	27	27	32	14
65+	35	26	22	18
By education				
< High school	47	26	19	8
High school graduate	35	24	30	11
Some college	24	31	31	14
College graduate	18	34	34	21
By income				
<15,000	46	20	23	11
15,000-24,999	43	23	25	9
25,000-49,999	30	27	30	12
50,000-74,000	23	27	34	16
≥75,000	16	29	34	21
By Body Mass Index				
<25	24	27	32	17
25-29.9	27	28	31	14
≥30	39	24	27	10

\*No leisure time physical activity;

\*\*Some activity but <3 times/week or <20 minutes/session;

\*\*\*3+ times/week, 20+ minutes/session, <50% of capacity;

\*\*\*\*3+ times/week, 20+ minutes/session, 50%+ of capacity

Source: NJ BRFSS, Center for Health Statistics

The recommendations of the Nutrition and Physical Activity Subcommittee are summarized below for the following three topic areas in priority order:

- Cancer Prevention
- Research
- Cancer Survivorship

## GOALS, OBJECTIVES AND STRATEGIES

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**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.

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### CANCER PREVENTION AND NUTRITION/PHYSICAL ACTIVITY

According to the Centers for Disease Control and Prevention, dietary factors play a major role in the development of many cancers, especially those of the digestive and reproductive organs (5). It has been estimated that approximately one-third of all cancers occurring in the U.S. might be attributed to dietary factors (1). The precise biological impact for any single dietary factor is difficult to determine given the endless number of substances present in diet and the interactions among them. However, we do know that the foods we eat contain substances with carcinogenic and anticarcinogenic 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 (6). The type of dietary fat consumed, rather than total fat, seems to be a more important factor in determining cancer risk (2). Nevertheless, the epidemiologic literature provides strong support for a role of fruits and vegetables, whole grains, dietary fiber, and physical activity against some cancers, whereas obesity, alcohol, some fatty acids, and food preparation methods may increase cancer risk (2).

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 (7). A report by a group of experts commissioned by the American Institute for Cancer Research and

the World Cancer Research Fund concluded that increasing consumption of fruits and vegetables from ~250 to 400 g per day may be associated with a 23% decreased risk of cancer worldwide. The numerous constituents in fruits and vegetables, including dietary fiber and phytochemicals (e.g., carotenoids, flavonoids, phytoestrogens, glucosinolates, isothiocyanates, and indoles), or interactions among them, may be responsible for the observed beneficial effect of these foods.

A growing body of evidence suggests that obesity increases the risk of colon and prostate cancer for males and of post-menopausal breast cancer, endometrial, ovarian, gall bladder, and cervical cancer for females. 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 (2). These hormonal factors have been implicated in the etiology of breast, endometrial, and colon cancer (2).

Evidence for a role of physical activity in reducing cancer risk is accumulating. 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 (8). 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 (8).

A decrease in physical activity can be linked to the increase 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. The growing popularity and availability of fast foods and snack foods is increasing caloric intake while physical activity continues to slow.

A recent 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 (9).

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 (10).

Several reports have been published that provide suggestions to improve healthy eating habits and increase physical activity to decrease the risks of cancer (10;11). 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 (e.g., 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 (10). 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 excess alcohol intake, 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. Governments are advised to support physical and health education for all grades and to monitor food supplement programs for a nutritional balance (11).

Throughout New Jersey, current efforts to address the role of nutrition and cancer are limited, despite attempts to implement suggestions in the cited reports. Programs and services have been instituted to improve the nutrition and physical activity of all New Jersey residents. However, there is no allocation of state funds to any department in state government dedicated to planning comprehensive and statewide programs that coordinate, implement, and evaluate nutrition and physical activity programs.

In New Jersey, the Department of Health and Senior Services and the U.S. Department of Agriculture (USDA) cosponsor the 5 A Day for Better Health Program in partnership with the National Cancer Institute and the Produce Better Health Foundation. Commonly known as "5 A Day," the program is a national effort to achieve the Healthy People 2010 objective to increase the per capita consumption to five or more servings of fruits and vegetables daily. In 1995, representatives from other public sector organizations in the areas of health, nutrition and education, private non-profit organizations, and the food industry were invited to create the New Jersey 5 A Day Coalition. Approximately 30 organizations

participate in the coalition, which in 2001 developed the following 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."

Through the effort and commitment of the 5A Day Coalition, many awareness and educational activities and events take place throughout New Jersey to spread the word about the health benefits of fruits and vegetables. New Jersey residents hear about the importance of 5 A Day at WIC clinics, hospitals, HMO and health clinics, schools, worksites, government offices, churches, produce distri-butors, farmers markets, supermarkets and health fairs, and other community events.

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%."

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. Age, literacy level, and culturally appropriate tools are needed, as well. While, the plethora of state and national nutrition and physical activity programs provide many opportunities to decrease the cancer risk for New Jersey citizens, a statewide coordinating body does not yet exist. This leads to lack of communication among initiatives and duplicated efforts.

The 5 A Day Program is the only nutrition program that addresses the role of nutrition and cancer prevention at the New Jersey Department of Health and Senior Services. The 5 A Day State Coordinator position is not funded by federal or state funds, specifically for this function. Currently the 5 A Day state coordinator position is supported by the WIC program, which receives funding from the USDA. Therefore, the coordinator cannot devote full-time responsibilities to the 5 A Day program. This lack of funding affects program materials and other resources. At this time, nutrition services in the state of New Jersey are fragmented and gaps in services exist. There is no comprehensive plan for nutrition and the continued need for advocacy for reimbursement of preventive and medical nutrition therapy exists.

The Nutrition and Physical Activity Subcommittee recommends a fully funded comprehensive nutrition unit at the state level to coordinate and improve existing and identified needed programs. The plan also needs to include recognition that many existing health programs include a nutrition component, but lack the resources and direction for successful implementation.

To enhance existing nutrition and physical activity programs/services, the Nutrition and Physical Activity Subcommittee advises that New Jersey residents be educated about healthy eating patterns and exercise. Various nationwide research has shown successful community education (12;13) and worksite education programs (14-16) focusing on the importance of healthy eating patterns and moderate physical activity for cancer prevention. Additionally, school-based curricula (17) have a positive impact on the eating patterns of students. Therefore, the Nutrition and Physical Activity Subcommittee 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 (11) and services provided can enhance existing public health programs. Additionally, high-risk groups, such as certain ethnic groups (15), those with lower incomes, and those at lower educational levels, should be targeted for education about cancer-risk reduction (18). The Nutrition and Physical Activity Subcommittee

also recommends a fully funded comprehensive nutrition program at the state level to coordinate and improve new and existing programs, focusing on high-risk populations. The Nutrition and Physical Activity Subcommittee further proposes the installation of a high-level individual in the state to coordinate and improve existing activities.

**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 amount and proportion of healthy foods, especially fruits and vegetables, that New Jersey residents consume each day.

**Strategies:**

- (NP-1.1.1) Review the New Jersey school curriculum 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.
- (NP-1.1.2) Conduct an evaluation of food services in educational institutions, day care 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, 5 A Day, 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:**

To enhance, or develop where necessary, statewide nutrition programs to help New Jersey residents reduce the risk of developing cancer.

**Strategies:**

- (NP-1.2.1.) Establish an infrastructure within state government to coordinate and collaborate activities among existing nutrition programs.
- (NP-1.2.2) Incorporate an evaluation component in nutrition education programs to evaluate effectiveness toward modifying behaviors that affect cancer risk.
- (NP-1.2.3) Coordinate and support comprehensive nutritional education programs in allied fields by sponsoring collaboration.

**Objective NP-1.3:**

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

**Strategy:**

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

**Objective NP-1.4:**

To reduce alcohol consumption in the State of New Jersey particularly at high levels.

**Strategy:**

- (NP-1.4.1) Educate the public about the dangers of heavy alcohol consumption.

## **RESEARCH ON NUTRITION/PHYSICAL ACTIVITY AND CANCER**

Although the importance of diet and nutrition in cancer prevention is well recognized, more scientific information is needed in order to effectively reduce cancer risk through dietary approaches. Three major research areas can be identified. One concerns the effects of different dietary aspects (e.g., individual food items, food groups, food patterns, dietary diversity, nutrients) and physical activity on cancer risk. For example, even the previously accepted concepts that a high-fat diet increases breast cancer risk and a high-fiber diet decreases colon cancer risk have been challenged (7). Although nutritional guidelines for cancer survivors have been issued, there is insufficient information on how certain dietary practices can increase survival. Many dietary constituents and herbs have been developed commercially as diet supplements for the prevention or even cure of cancer based on over- or misinterpretation of data or unscientific extrapolation. The possible efficacy and harmful effects of these products need to be studied.

### **GOAL NP-2:**

**To increase research on effective dietary and physical activity approaches for the prevention of cancer and increasing survivorship of cancer patients.**

#### **Objective NP-2.1:**

To evaluate the needs of New Jersey residents with respect to nutrition, physical activity, and cancer and to implement the necessary changes for cancer reduction.

#### **Strategies:**

- (NP-2.1.1) Conduct a needs assessment survey of New Jersey residents, including multiple multi-ethnic groups, to assess their current dietary quality, alcohol consumption, use of special diets and dietary supplements in general, their barriers to healthy food choices, their knowledge of the relationship between nutrition, BMI and cancer, physical activity, their attitudes about changing their dietary habits, and what would be useful for them to change

The second area of research that the Nutrition and Physical Activity Subcommittee recommends concerns the development and evaluation of effective approaches of behavior modification with regard to dietary pattern and physical activity; that is, how to motivate an individual to adopt and maintain healthy eating habits and to exercise regularly and/or what kind of environmental changes are needed to support these changes in the State of New Jersey.

The Nutrition and Physical Activity Subcommittee further recommends research into the etiology of cancer cachexia. Preventing the loss of appetite that is so often associated with malignancy is a major cause of the nutritional complications found in cancer patients. In some, but not all, an activity program increases intake. If cachectic patients increase activity without parallel increases in intake, tissue wasting rather than tissue gain will occur.

their dietary behavior. This survey could provide baseline data and could be repeated for surveillance purposes.

- (NP-2.1.2) Develop recommendations for future research, improvement of nutrition education strategies, and policy changes based on the results of the survey and the nutrition interventions.

### **Objective NP-2.2:**

To increase the knowledge of the relationship among physical activity, nutrition, and cancer risk.

### **Strategies:**

- (NP-2.2.1) Promote preclinical and clinical research on dietary substances that can potentially reduce cancer risk, including nutraceuticals/functional foods and nutrient-gene interactions.
- (NP-2.2.2) Promote behavioral research on effective, culturally sensitive approaches for dietary modification and exercise promotion.
- (NP-2.2.3) Promote research on dietary and physical activity practices, including use of dietary supplements, that will increase survival and quality of life of cancer patients.
- (NP-2.2.4) Conduct research in the nutritional, metabolic, and gene-expression abnormalities that result in cancer cachexia.
- (NP-2.2.5) Identify seed money or pilot grant to support new research in this area. The successful pilot projects will facilitate obtaining other grants from governmental and private funding agencies.

## **CANCER SURVIVORSHIP AND NUTRITION/PHYSICAL ACTIVITY**

Proper nutrition and appropriate levels of physical activity are likely important to the optimal efficacy of cancer treatment regimens and may reduce the chances of disease recurrence. Dr. Harmon J. Eye recently stated in the *American Cancer Society Journal CA: A Cancer Journal for Clinicians* that: “Unfortunately, although we currently know a great deal about nutrition and physical activity as they influence cancer

incidence, much less is known about how they affect cancer recurrence and prognosis” (19).

Cancer patients and 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 (20;21).

Currently every year over 1.2 million people are diagnosed with cancer in the U.S. and there are about 9 million survivors (3). Modern oncologic medical care strives to cure cancer or at the very least to transform it into a chronic disease, e.g., to extend the meaningful survival of those afflicted with cancer. Success on either front will increase the numbers of survivors.

Therefore, it is necessary for patients undergoing cancer treatment and cancer survivors to

have access to solid evidenced-based information on dietary habits and physical activity that will permit optimal health and well-being. Cancer patients and survivors should be able to obtain this information and to avail themselves of appropriate professional advice and services. Access should be equivalent regardless of socioeconomic or education level. Finally, to generate this information more research into the impact of dietary habits, nutrition, and physical activity on cancer survivorship is necessary.

### **GOAL NP-3:**

**To assure proper nutritional care for cancer patients.**

#### **Objective NP-3.1:**

To encourage health care professionals to use nutrition guidelines for cancer patients/survivors during and after cancer treatment.

#### **Strategy:**

- (NP-3.1.1) Establish and then promote practice guidelines targeted to healthcare professionals relating to nutritional care for cancer patients.

#### **Objective NP-3.2:**

To provide cancer patients/survivors information about proper nutrition and physical activity during and after treatment.

#### **Strategies:**

- (NP-3.2.1) Assure that each cancer patient meets with a Registered dietitian *before* and during cancer treatment to provide education concerning nutrition and physical activity and cancer treatment.
- (NP-3.2.2) Lobby for reimbursement coverage for Medical Nutrition Therapy.
- (NP-3.2.3) Provide specific assistance to those New Jersey residents who are receiving/or have received cancer treatment and are currently battling a nutritional problem.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society:

Cancer Institute of New Jersey: NP-1.2.2; NP-1.4.1; NP-2.1.1; NP-2.1.2; NP-2.2.1; NP-2.2.2; NP-2.2.3; NP-2.2.4

New Jersey Department of Health and Senior Services: NP-1.1.1; NP-1.1.2; NP-1.1.3; NP-1.1.6; NP-1.2.1; NP-1.2.2; NP-1.2.3; NP-1.3.1; NP-1.4.1; NP-2.1.1; NP-2.1.2; NP-3.1.1; NP-3.2.1; NP-3.2.3

Rutgers, the State University of New Jersey: NP-1.1.2; NP-1.1.4; NP-1.1.5; NP-1.2.2; NP-1.3.1; NP-1.4.1; NP-2.1.1; NP-2.1.2

University of Medicine and Dentistry of New Jersey, Center for the Study of Alternative and Complementary Medicine: NP-2.1.1; NP-2.2.1; NP-2.2.2

University of Medicine and Dentistry of New Jersey, School of Health Related Professions (SHRP) – Dietetics: NP-1.1.1; NP-1.1.4; NP-1.1.5; NP-1.2.2; NP-2.1.1; NP-2.1.2; NP-2.2.1; NP-2.2.2; NP-2.2.3; NP-2.2.4;

## NUTRITION/PHYSICAL ACTIVITY

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Promote health nutrition and physical activity	1.1: Diet education	NP-1.1.1						
		NP-1.1.1						
		NP-1.1.1						
		NP-1.1.4						
		NP-1.1.5						
		NP-1.1.6						
	1.2: Statewide nutrition programs	NP-1.2.1						
		NP-1.2.2						
		NP-1.2.3						
	1.3: Increase physical activity	NP-1.3.1						
	1.4: Reduce alcohol consumption	NP-1.4.1						
2: Increase research	2.1: Evaluate nutrition and physical activity	NP-2.1.1						
		NP-2.1.2						
	2.2: Conduct epidemiologic research	NP-2.2.1						
		NP-2.2.2						
		NP-2.2.3						
		NP-2.2.4						
		NP-2.2.5						
3: Assure nutritional care for cancer patients	3.1: Encourage healthcare professional utilization of nutrition guidelines	NP-3.1.1						
	3.2: Educate patient on nutrition guidelines	NP-3.2.1						
		NP-3.2.2						

**Target Completion Date**

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## CHAPTER 5. Childhood Cancer

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## CHILDHOOD CANCER

### IMPORTANCE OF CHILDHOOD CANCER FOR CANCER PREVENTION AND CONTROL IN NEW JERSEY

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, Wilm’s tumor, and non-Hodgkin’s lymphomas constitute the top five diagnoses under 14 years of age. This is in contrast to Hodgkin’s disease (HD), germ cell tumors, non-Hodgkin’s lymphomas (NHL), melanoma, and soft tissue sarcomas, which are more frequent in youngsters 15 to 19 years of age (Table 1). Many adult cancers have identified risk factors; some adult cancers may be preventable. However, there is very little evidence to indicate the causes of childhood cancer other than cancer genetics.

Although the incidence of cancer in children is much lower than in adults, about 80% of children with cancer will be long-term survivors. 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.

Most adults have already completed their education and are employed (or even retired) before they are diagnosed with cancer; many have already had children. Some children have not even started school before they are diagnosed with cancer; they still have years 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 sometimes radiation) that improves the probability of survival can also have profound effects on a child who is still growing. For these reasons the Childhood Cancer Subcommittee in contributing to this *Plan* has been challenged to develop solutions for the children with cancer in New Jersey.

**Childhood Cancer in New Jersey.** Cancer in children and young adults is relatively rare. An estimated 9,100 new cases are expected to occur among children aged 0-14 in 2002, compared to 1,284,900 adults (1). For the period 1979-1995 in New Jersey, the childhood cancer incidence is slightly higher in New Jersey children compared to U.S. children. In New Jersey, the total childhood cancer rate among boys was slightly higher than among girls, mirroring U.S. rates. The incidence of cancer among white children in New Jersey was higher than the corresponding rate for the U.S., but among black children in New Jersey was slightly lower than the U.S. rate (2).

Mortality rates for childhood cancer in the U.S. and New Jersey have declined since the 1970’s (2), representing a nearly 46% decline in mortality in New Jersey alone. The largest declines in mortality have occurred for Hodgkin’s lymphoma, soft tissue sarcoma, and leukemia (acute lymphocytic leukemia, in particular). These trends reflect dramatic successes in the treatment of childhood cancer (2). An estimated 1,400 deaths are expected to occur among children aged 0-14 in 2002, 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 of most common cancers  
in 0 to 14 year olds and 15 to 19 year olds, 1990-1997**

<b>TOTAL</b>	<b>&lt;15</b>	<b>15 - 19</b>
Total	141.3	206.8
Acute Lymphocytic Leukemia (A.L.L.)	29.3	11.5
A.M.L.	6.6	8.8
Hodgkin's Disease	5.7	34.7
Non-Hodgkin's Lymphoma	8.5	17.1
Central Nervous System	31.8	20.3
Malignant Bone Tumors Osteogenic & Ewing's	7.0	15.8
Rhabdomyosarcoma	5.1	3.6
<b>TOTAL</b>	<b>94</b>	<b>111.8</b>

Rates are per 100,000

\*Abstracted from (3)

**Age patterns.** Incidence patterns for different types of cancer in children vary dramatically by age. For example, lymphoid leukemia incidence increases to a peak before age five and declines thereafter, while acute myeloid (nonlymphocytic) leukemia incidence is constant throughout childhood. The incidence of Hodgkin's lymphoma increases throughout childhood and is highest in adolescence. Neuroblastoma, retinoblastoma, and Wilm's tumor

incidence rates are highest between birth and age one and decline with increasing age (2).

**Risk Factors.** Overall, the causes of most childhood cancers remain unknown. Many types of pediatric cancers are related to genetic conditions. There also has been considerable research into the effects of environmental contaminants associated with childhood cancer; however direct causation has not been proven (4;5).

The recommendations of the Childhood Cancer Subcommittee are summarized below for the following six topic areas in priority order:

- Adolescent and Young Adult Treatment
- Secondary Malignancies
- Pain and Palliative Care
- Family Support
- Education
- Advocacy

## GOALS, OBJECTIVES AND STRATEGIES

**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

**Treatment.** Cancer survival in children under 14 is a great success story of the 20th century. In the 1960s, the five-year survival rate for a child diagnosed with cancer

was 28%. By the 1990s this had risen to over 75%. The greatest success was witnessed in acute lymphoblastic leukemia, a virtually incurable disease in the 1960s with a median survival of six months. Today, more than 75% of the children are cured.

**Table 2. Five years survival rates in 15 to 19 year olds of selected diagnoses**

Time Period	1975-84 (%)	1985-94 (%)
A.L.L.	35	51
A.M.L.	22	42
Hodgkin's	88	90
N.H.L.	56	69
Rhabdo	40	45
Osteo	49	59
Ewing's	36	56

\*Abstracted from (7)

As may be seen from Table 2, there have been substantial gains in survival in the 15- to 19-year age group from an earlier period (1975-1984) to the late 1990s. However, this gain lagged behind the significant improvements seen in the younger age group. In 1975 the older group had a survival rate of 64% versus 55% for children under 15. In the 1990s this increased to 76% and 75% for the respective groups. This shows relatively greater improvement in the younger age group. In fact the younger group is approaching an overall survival rate of 85%. This may be attributable to the following:

- Over 95% of the children under 15 are being treated at pediatric cancer centers, and over 60% are treated on national clinical trials. There has been a direct correlation between participation in national protocols and being treated at pediatric cancer centers and the incremental rise in cure rates.
- Only 10% of 15 to 19-year-olds are entered into clinical trials.
- The biology of the disease in the older group may be different.

However, it can be argued that results for the older group may improve through their participation in national clinical trials. The evidence for this is seen in the case of T-cell acute lymphocytic leukemia, which is common in young adults. The Children's Oncology Group with their protocol has demonstrated survival advantage with intensive therapy, and T-cell leukemia is no longer considered a poor prognostic criteria.

- The mortality burden is a function of survival and incidence.
- One example of this are acute leukemias, which constitute only 11% of all cancers in 15- to 19-year-olds as compared to 35% in children under 15 years. The survival rate, on the other hand, is 46% versus 75%.
- Over 80% of mortality in the older group is attributed to four malignancies: sarcomas, leukemias, central nervous system, and germ cell tumors.
- There has been a substantial gain among the younger group in the above diagnoses treated with intensive multimodal therapy. Children's Oncology Group in fact extends the age to 30 years for certain diagnoses, e.g., rhabdomyosarcoma, Ewing's tumor, etc.

To investigate the differences between childhood cancer in ages 0-14 and childhood cancer in ages 15-19, the Childhood Cancer Subcommittee suggests that more clinical research should investigate cancer up to age 21.

**Psychosocial support.** “The greatest difference in the management of adolescents and young adults is in supportive care, particularly psychosocial care” (3). Every adult can identify with adolescence. It is the most difficult period of any one’s life without the added “curse” of cancer. Medical management (chemotherapy) is only a small portion of the overall supportive care the youngster deserves not only to achieve a cure, but also to become a productive citizen. This requires a multi-disciplinary team approach, perhaps best accomplished at a pediatric oncology center for this group of young adults.

Cancer in adolescents and young adults is more common than in younger children. However, the survival rate has not kept pace in certain types of cancers seen in both groups. This may be due to relative lack of participation by the older group in national clinical trials (6-14).

#### **GOAL CC-1:**

**To improve care for adolescents and young adults.**

#### **Objective CC-1.1:**

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

**Strategy:**

- (CC-1.1.1) Conduct a pilot study to validate the existing research and assess any difference in cancer survival based on treatment regime between adult treatment centers and pediatric treatment centers.

**Objective CC-1.2:**

To identify how the current psychosocial needs are met for this group of patients.

**Strategies:**

- (CC-1.2.1) Develop and distribute a questionnaire on cancer services for adolescents and young adults to the participating centers (oncologists, social workers, community agencies involved and a group of randomly selected patients at the centers).
- (CC-1.2.2) Utilize results of the survey on cancer services for adolescents and young adults to identify gaps in service and provide feedback to participants in order to address unmet needs.

## **SECONDARY MALIGNANCIES**

**S**urvivors of childhood cancer represent a growing population. This pool is expanding because of the increase in survival and cure rates. Over the past three decades, the incidence of childhood malignancies has increased slightly from 12 to 14 per 100,000 population of under-15-year-olds. The mortality rate has decreased from 6 to 3 per 100,000 (15) and the five-year survival is approaching 80% (16). This creates a pool of survivors, which currently is estimated at 1 in 900 individuals between 15 and 45 years old. It is projected that this number may reach 1 in 250 young to mid-aged adults by 2010 (17;18).

This population will challenge their healthcare providers to address the medical, emotional, and societal sequelae of cure. One

question already being asked on behalf of the survivor is: What is the mortality rate of the survivor population compared to that of the general public?

Several studies have addressed this issue and some degree of consensus has been reached. Of those that die having been off therapy greater than five years but in most cases less than 15 years, the primary cause of death has been recurrence of the primary disease. This has accounted for about 65% of deaths, whereas about 25% occur from issues related to the primary disease and its treatment. Second malignant neoplasms (SMN) are the most common cause in this latter category (16;19-21).

Overall approximately 10% of survivors may die in the first several decades after therapy. SMN accounted in one study for 6.8% of the

deaths representing 20 of 2,319 survivors originally followed or 0.86% of the survivor population of that study (19).

The cumulative risk of SMN remains unknown, but various studies have put that risk between 1.2% and 12% at 20 years off therapy. A long prospective longitudinal study of our pediatric survivors is needed to ascertain whether known adult type malignancies will occur at a younger age and with increased frequency in the survivor population.

There is an ample body of literature suggesting SMN as a risk to the childhood cancer survivor. Age at diagnosis, gender, primary cancer, type/dose therapy received, and genetic predisposition have an impact upon the risk of SMN.

One of the most comprehensive reports of SMN comes from the Childhood Cancer Survivor Study (CCSS) looking at a cohort of 13,581 children diagnosed with the common childhood cancers prior to age 21 years between January 1, 1970 and December 31, 1986, and followed at 25 selected institutions. The cohort was five years or greater survivors. The median age was 23 years (range 8 to 47 years). There were a total of 140,792 person-years of follow-up with median time of 15.4 years (range 6.4 – 28.7 years). Excluded were those who died of SMN before five years off therapy and those with a diagnosis of retinoblastoma.

For the most part results supported previous studies. Three hundred fourteen SMNs were found in 298 individuals. Twenty years after the childhood cancer diagnosis, the cumulative estimated SMN incidence was 3.2%. Those with a primary diagnosis of Hodgkin's Disease had the highest cumulative incidence at 20 years: 7.6%. The most frequent SMNs were breast (n=60), thyroid

(n=43), and central nervous system (n=36) (22).

Second malignant neoplasms are rare events, but they exact a considerable emotional toll on young adult survivors and their families. All primary care physicians who treat survivors of childhood cancer should have an increased index of suspicion for a second malignant neoplasm 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.

Subsets of patients in numerous publications have been identified as being at higher risk of SMN. These include:

- Those exposed to radiation: bone/soft tissue sarcoma, central nervous system, breast, and thyroid.
- Those exposed to specific chemo-therapeutic agents: alkylators, epipodophyllotoxins, anthracyclines (CCSS).
- Genetic predisposition: those with bilateral retinoblastoma (or unilateral hereditary retinoblastoma), Li-Fraumeni syndrome, neurofibromatosis, familial adenomatous polyposis, hereditary nonpolyposis colorectal cancer, multiple endocrine neoplasias, basal nevoid syndrome, ataxia telangiectasia, Bloom's syndrome, and Fanconi's syndrome.
- SMN is highest among those with Hodgkin's Disease as primary diagnosis.
- Female gender ( $p < .001$  CCSS).
- Childhood cancer diagnosis at younger age ( $p < .001$  CCSS).
- Female children with radiation therapy to the chest and possibly radiation therapy to the abdomen if less than 7 years old should be surveyed for breast cancer.

The CCSS stated: "At the time of analysis 91.9% of the cohort members who had not developed an SMN were alive compared with 59.4% of cohort members who had developed an SMN." The analysis was done on data collected as of January 1, 2000. This finding emphasizes the need for surveillance to possibly detect and intervene early in the occurrence of second malignant neoplasms (22).

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.

The issue statement would refer to surveillance and possibly early detection and diagnosis of SMN. Subsets relative to one type of SMN can be developed with screening options.

**GOAL CC-2:**

**To reduce incidence of and mortality from secondary malignancies.**

**Objective NP-2.1:**

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

**Strategies:**

- (CC-2.1.1) Conduct a literature survey 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 environmental factors contributing to second malignant neoplasms.

## Strategy:

- (CC-2.2.1) Develop media campaign and brochures to educate childhood cancer survivors on environmental risk factors for second malignant neoplasms.

## PAIN AND PALLIATIVE CARE

Approximately 12,400 children under 21 are diagnosed each year with cancer. The majority of these children are expected to survive, with five-year survival rates now approaching 80%. However, over 2,000 children each year still die as a result of cancer, which is the second leading cause of childhood mortality, following accidental deaths and homicides. Therefore, not only are these children and the families of these children faced with the prospect of having a serious disease with treatment that can result in life-threatening or life-altering complications, but they must also come to terms with the possibility that the child might die. As a consequence, it has been advocated that all children with life-threatening medical conditions regardless of the prognosis, including cancer, should be involved in a palliative care program early in the diagnosis, with the special needs of children being addressed.

There is some disagreement 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 Palliation Chapter 3). As recently as 1987, when palliative care was 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.” Clearly by adopting this broader concept, palliative care would be introduced 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. 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. In one recent study by the Dana Farber Cancer Center, published in the *New England Journal of Medicine* in 2000, 80% of children dying of cancer experienced significant pain. Unfortunately, according to the parents' perceptions, only 20% of these

children had their pain adequately managed. So, while we have the tools necessary to alleviate a great deal of the suffering associated with cancer pain, all too often these tools are inadequately utilized. As in adults, there appear to be significant barriers to the successful treatment of children with cancer-related pain during all phases of the disease process. These barriers are related to inadequate knowledge by health professionals regarding the proper use and the side effects of analgesics, especially narcotics, as well as misunderstanding by patients and their families (23-29).

#### **GOAL CC-3:**

**To increase the awareness of healthcare professionals, patients, and families on the use of palliative care strategies in the child with cancer. 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) Develop a statewide educational forum for providers, childhood cancer patients, and family members 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 (30). 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 (31) found that clinical interventions during treatment reduced not only the family's immediate stress levels, but 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" (31). 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 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 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 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

Each year approximately 7,500 U.S. children younger than the age 15 are diagnosed with cancer; of 80% are expected to be cured of their disease. Currently it is estimated that 1 in 900 persons ages 15 to 45, are childhood cancer survivors in the U.S. In the year 2010, the statistics are expected to increase to as many as 1 in every 250 persons. According to estimates in the U.S. college-age population this would mean that approximately 67,000 individuals between the age of 18 to 21 would be childhood cancer survivors. By these estimates childhood cancer survivors would comprise a large portion of the population. 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.

The available literature has well documented late effects of treatment for survivors of childhood cancer, whether surgical, chemotherapy or radiation induced. Adverse effects have been shown to many organ systems, such as CNS, 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); ACTH deficiency (muscular weakness, anorexia, nausea, weight loss, dehydration, hypotension, abdominal pain, increased pigmentation); 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, osteocartilaginous 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 (3;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 (3;32; 33).

#### GOAL CC-5:

To increase awareness of healthcare providers of late effects in childhood cancer.

#### Objective CC-4.1:

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

**Strategies:**

- (CC-5.1.1) Research and develop guidelines for screening childhood cancer patients previously treated with chemotherapy or radiation therapy.
- (CC-5.1.2) Collate and condense guidelines for referral and/or management recommendations of childhood cancer survivors for primary care physicians.
- (CC-5.1.3) Disseminate guidelines for management of childhood cancer survivors through the development of a public brochure and/or website and/or letter updates for all practitioners. Update as new information becomes available.

**GOAL CC-6:**

**To increase the awareness of neurocognitive 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) Develop 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 negotiating with an individual school system, but 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 knowledge is further complicated by the changes frequently made in these plans requiring prior authorization or lab tests to be performed at designated facilities. Different insurance companies and HMOs vary greatly in their procedures and requirements related to the patient's care.

**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)" (36). 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 inarguably have more difficulty obtaining insurance than their peers, and this situation is not likely to improve. Within the past two to three years, the results of several studies of five-year (and more) survivors of childhood cancer have reported the incidence of second 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 (16). 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 second malignancies (22). 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 (37). 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 years (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.

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 (38;39). 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 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” (40). Strickland et al. reported that among those surviving patients transfused between 1961 and March 1992, 66% were found to be infected with Hepatitis C (41).

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.

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 (42). The booklet for survivors over the age of 14 years 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.

#### **Strategy:**

- (CC-7.1.1) Investigate the establishment of a grassroots childhood survivorship organization.
- (CC-7.1.2) Develop and fund 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.
- (CC-7.2.2) Host a statewide conference for parents and childhood cancer survivors utilizing the model with demonstrated effectiveness for teaching advocacy.
- (CC-7.2.3) Collaborate with multi-disciplinary organizations, e.g., American Cancer Society, 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.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: CC-2.1.3; CC-5.1.3

New Jersey Pediatric Hematology Oncology Network: CC-1.1.1; CC-1.2.1; CC-1.2.2; CC-2.1.1; CC-2.1.2; CC-2.1.3; CC-2.2.1; CC-3.1.1; CC-4.1.1; CC-4.2.1; CC-4.2.2; CC-5.1.1; CC-5.1.2; CC-5.1.3; CC-7.1.1; CC-7.2.1; CC-7.2.2; CC-7.2.3; CC-7.3.1

Tomorrows Children's Institute: CC-6.1.1

## CHILDHOOD CANCER

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Adolescent and young adult treatment	1.1: Improve care	CC-1.1.1						
	1.2: Address psychosocial needs	CC-1.2.1						
		CC-1.2.2						
2: Reduce incidence and mortality from secondary malignancies	2.1: Identify guidelines for screening	CC-2.1.1						
		CC-2.1.2						
		CC-2.1.3						
3: Palliative care awareness	2.2: Disseminate healthy lifestyle information to survivors	CC-2.2.1						
	3.1: Provide palliative care education	CC-3.1.1						
		CC-4.1.1						
4: Foster psychosocial health	4.1: Maximize quality of life	CC-4.1.2						
	4.2: Assess psychosocial care	CC-4.2.1						
		CC-4.2.2						
5: Educate healthcare providers of late effects	4.3: Ensure continuous psychosocial support	CC-4.3.1						
		CC-4.3.2						
		CC-4.3.3						
6: Neurocognitive deficits	5.1: Identify guidelines for screening and management	CC-5.1.1						
		CC-5.1.2						
		CC-5.1.3						
7: Advocacy	6.1: Provide post treatment education	CC-6.1.1						
	7.1: Educate legislators/key decision-makers	CC-7.1.1						
		CC-7.1.2						
	7.2: Educate survivors and families	CC-7.2.1						
		CC-7.2.2						
		CC-7.2.3						
	7.3: Educate insurance companies	CC-7.3.1						

**Target Completion Date**

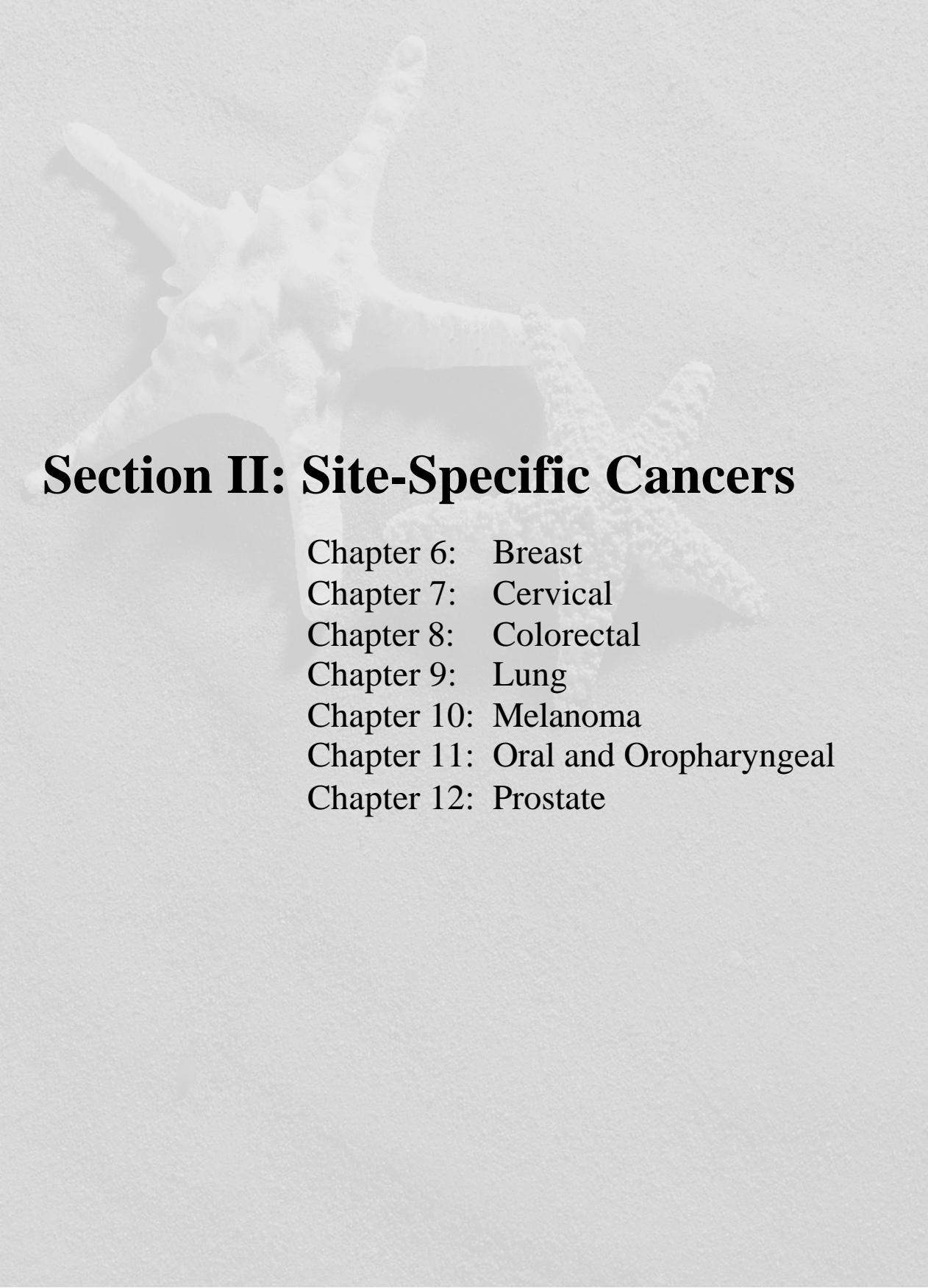
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## **Section II: Site-Specific Cancers**

- Chapter 6: Breast
- Chapter 7: Cervical
- Chapter 8: Colorectal
- Chapter 9: Lung
- Chapter 10: Melanoma
- Chapter 11: Oral and Oropharyngeal
- Chapter 12: Prostate



## CHAPTER 6. Breast Cancer

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## BREAST CANCER

### IMPORTANCE OF BREAST CANCER FOR CANCER PREVENTION AND CONTROL

The greatest impact on reducing the number of years lost to cancer will come from progress against common cancers such as breast cancer. Nationally, female breast cancer is the most common cancer among women, comprising an estimated 31% of new cancer cases and causing 15% of cancer deaths in U.S. females for 2002 (1). (Information about breast cancer in males can be found by contacting [www.nci.nih.gov](http://www.nci.nih.gov).) In the National Cancer Institute's (NCI) *Annual Report to the Nation*, breast cancer was cited as the most common cancer diagnosed among women in all five racial and ethnic populations studied (2). In 1998, breast cancer caused 790,000 person-years of life lost, ranking second after lung cancer (2,272,000) (3). Between 1980 and 1998 the rate of new cases of late-stage breast cancer remained relatively stable, indicating that the impact of breast cancer screening must be examined further. According to the *Cancer Progress Report* of the National Cancer Institute, breast cancer in women has been identified as a major cancer on the rise and one that therefore warrants greater efforts at control (3).

The Breast Cancer Workgroup of the Task Force on Cancer Prevention, Early Detection and Treatment has compiled evidence to indicate that breast cancer is also a key area to address in New Jersey. As will be shown later in this chapter, invasive breast cancer incidence among New Jersey females continues to increase. The decline of breast cancer mortality is not consistent across all populations in New Jersey. Effective breast cancer early detection techniques are not being used consistently across all populations in New Jersey. Below is a brief discussion of

the known risk factors for breast cancer and some of the means available to detect and control the disease.

The causes of breast cancer are not all known; however, some risk factors are well recognized. The risk of breast cancer increases greatly with age. The risk factors also include family history, familial cancer syndrome, as well as reproductive and hormonal factors such as early menarche (early onset of menstruation), late menopause, late parity (bearing children late), and nulliparity (not bearing children). High educational and socioeconomic levels are linked with greater risk, probably due to their association with the 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. Certain types of benign breast disease (fibrocystic, fibroadenoma), obesity after menopause, and moderate to heavy alcohol consumption (3 or more drinks per day) also are associated with breast cancer. Very high doses of radiation, such as that used in radiation therapy, have been shown to cause breast cancer. Long-term use of estrogen replacement therapy after menopause may increase the risk of breast cancer. Some recent studies suggest a possible increase in breast cancer before the age 45 among women who used oral contraceptives for a long time or who started oral contraceptive use at an early age. Other factors that may be associated with breast cancer are a lack of physical activity and a diet high in fat. Other risk factors, such as pesticide and other chemical exposures that mimic or modify the action of estrogens and gene-environmental interactions are being investigated (4-6).

Breast-Self-Examination (BSE), Clinical Breast Examination (CBE), and mammography are methods for screening and early detection of breast cancer. Although many organizations recognize these three screening techniques, guidelines for frequency of testing differ by organization (7-10). For more information about screening guidelines for breast cancer see Appendix F.

Regular use of mammograms can reduce the chances of dying from breast cancer. Randomized clinical trials have demonstrated a 30% reduction in breast cancer mortality in women aged 50 to 69 years who are screened annually or biennially with mammograms (5). For women in their 40s, the risk can be reduced by about 17%. For women aged 70 and older, mammography may be helpful, although firm evidence is lacking (10). Since implementation of the Mammography Quality Standards Act in 1994, all U.S. mammography centers must be certified by the Food and Drug Administration (FDA) (5). A complete list of all certified mammography centers in New Jersey can be found at <http://www.fda.gov/cdrh/mammography/certified.html>. The six currently FDA-approved digital mammography centers in New Jersey can be found at [www.hersource.com](http://www.hersource.com).

In terms of primary prevention, tamoxifen, a selective estrogen-receptor modulator, has been shown to reduce breast cancer incidence among women at elevated breast cancer risk. Five-year adjuvant treatment of tamoxifen has also been shown to significantly reduce recurrence of secondary malignancies in early stage breast cancer patients (11;12). The American Society of Clinical Oncology conducted a technology assessment of tamoxifen and concluded that, for women with a defined five-year projected risk of breast cancer equal to or greater than 1.66%,

tamoxifen (20 mg/day for up to five years) may be offered to reduce risk (13;14). However, tamoxifen may also increase the risk of contracting other serious disease, including endometrial cancer, stroke, and blood clots in veins and in the lungs (14). Women concerned that they may be at increased risk of developing breast cancer should talk with their doctor about whether to take tamoxifen to prevent breast cancer.

Genetic testing for breast cancer is relatively new. The “breast cancer gene,” BRCA1, was identified in 1994 (15) and BRCA2 in 1995 (16). A positive on a mutation test result 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). Women with BRCA1 or BRCA2 mutations have approximately a 33% to 50% risk of developing breast cancer by age 50 (17;18). By age 70, a mutation carrier’s risk of developing breast cancer is 56% to 87% (18-20).

Other prevention strategies recognized by the National Cancer Institute include suppression of hormonal factors, reducing radiation exposure, dietary factors, and prophylactic mastectomy (21;22).

## BREAST CANCER IN NEW JERSEY

**Incidence.** The American Cancer Society estimates that, among women in the U.S., 203,500 cases of breast cancer will be newly diagnosed in 2002. In New Jersey alone, approximately 6,900 breast cancer cases will be diagnosed in 2002 (1).

The breast cancer incidence rates in New Jersey increased from 1979 to the early 1990s and have remained fairly stable since

that time\* (Figure 1). New Jersey females had similar incidence rates to U.S. females in 1999; 141.0 versus 139.1 per 100,000\*\*. However, incidence rates in white females were higher in New Jersey than in the U.S. in 1999; 146.6 versus 143.0 per 100,000\*\*. Incidence rates in black females in New Jersey were lower than in the U.S.; 111.7 versus 123.9 per 100,000\*\*. In a recent report published by the New Jersey State Cancer Registry, a lower proportion of Hispanic and black women were diagnosed in the earlier stages of breast cancer than were non-Hispanic women (23-25).

In New Jersey, the percent of breast cancers diagnosed in the early stage (in situ and localized) 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 (68% versus 60%) in 2000\* (Figure 2).

**Mortality.** The American Cancer Society estimates that about 39,600 breast cancer deaths will occur among women in the U.S. in 2002 (1). Approximately 1,400 New Jersey women will die from breast cancer in 2002 (26). Consistent with 1999 U.S. mortality rates, black women in New Jersey have a higher mortality rate compared to white women, despite the incidence rates of black women being lower (Figure 1 & 3). In 1999, white females in New Jersey had a higher rate of breast cancer mortality than the U.S. (29.5 per 100,000\*\* versus 26.3 per 100,000\*\*). However, New Jersey has lower rates of breast cancer mortality in black females than in the U.S. (32.8 per 100,000\*\* versus 35.8 per 100,000\*\* (Figure 3). Breast cancer mortality in Hispanic females in New Jersey was only half of the mortality rate of non-Hispanic white and blacks (25;27).

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 (28), *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 half a decade later in 2002, 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 report.

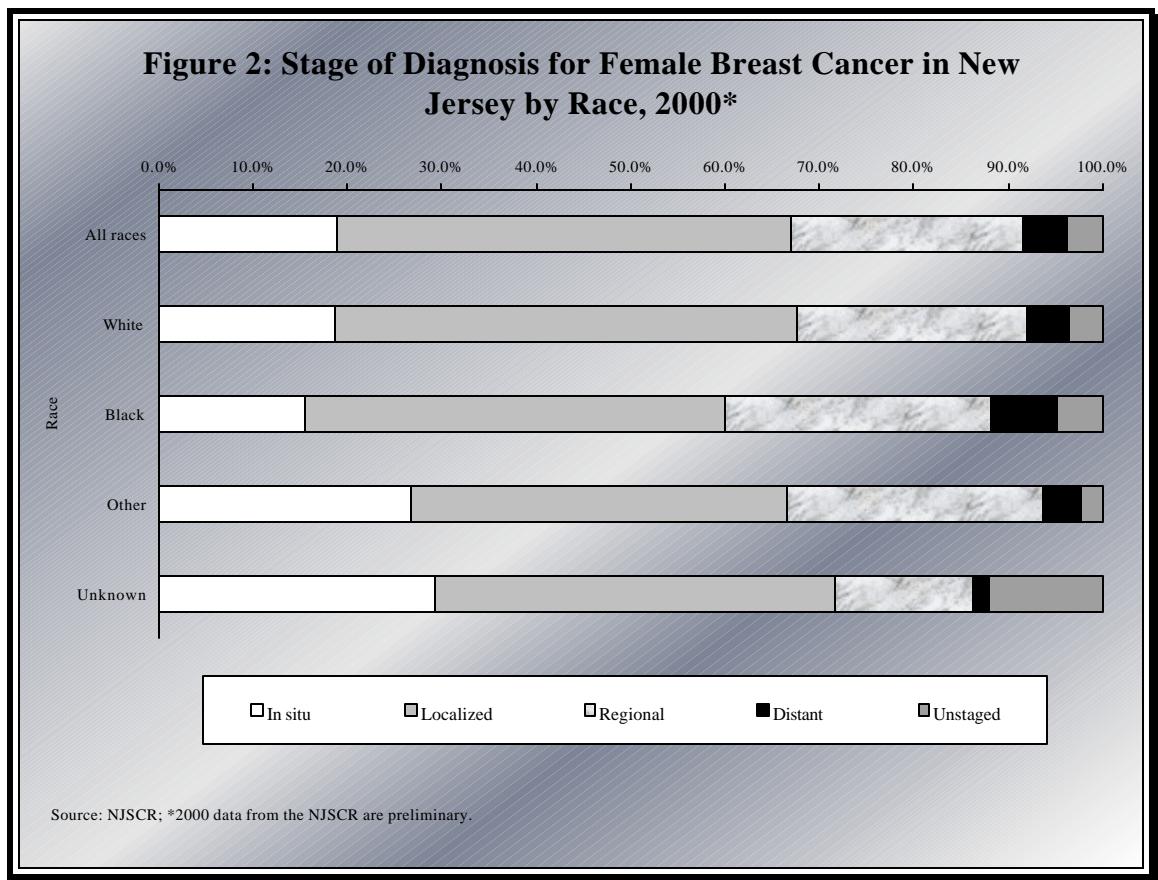
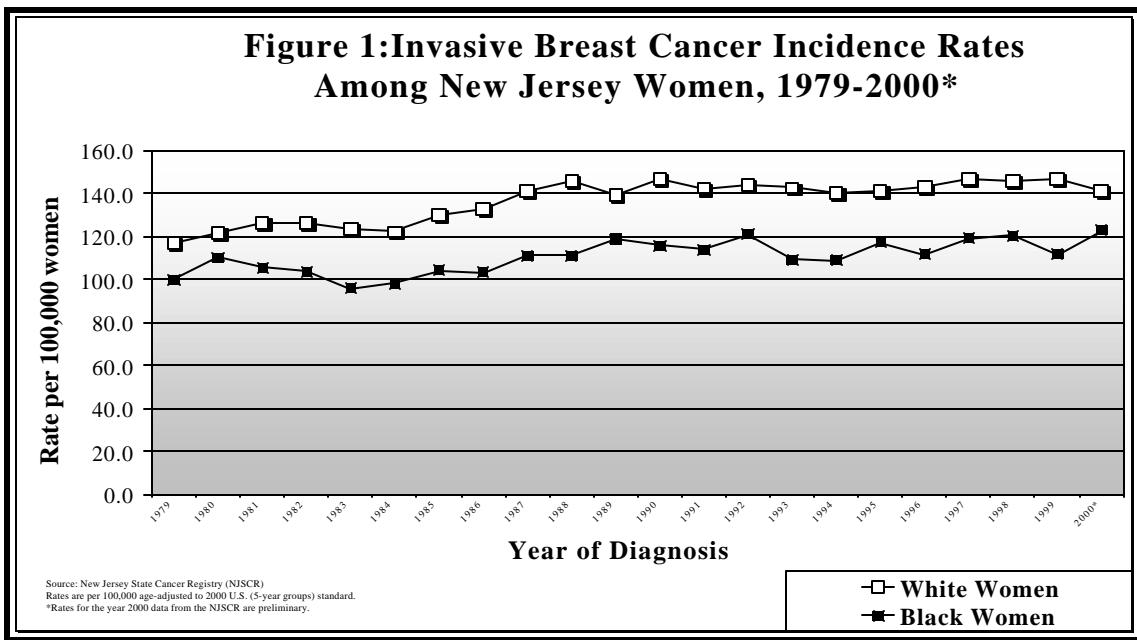
**Prevention and Early Detection.** Data from the Behavioral Risk Factor Surveillance System (BRFSS) indicate that the percent of New Jersey women receiving mammography increased greatly between 1991 and 2000. The number of women reporting that they never had a mammogram and a breast exam decreased in all age groups (Figure 4). This increase in screening rates occurred across all age groups. Despite positive trends in New Jersey mammography use, New Jersey rates remain below U.S. rates for breast cancer screening in women over age 50.

**Conclusion.** New Jersey data reveal that white women have the highest incidence of breast cancer in every age group. However, black women have a higher mortality from breast cancer, with major differences occurring at ages 45 to 64. These differences may result from the disparity observable by race in healthcare prevention and treatment services, which is reflective of access-to-care problems in New Jersey.

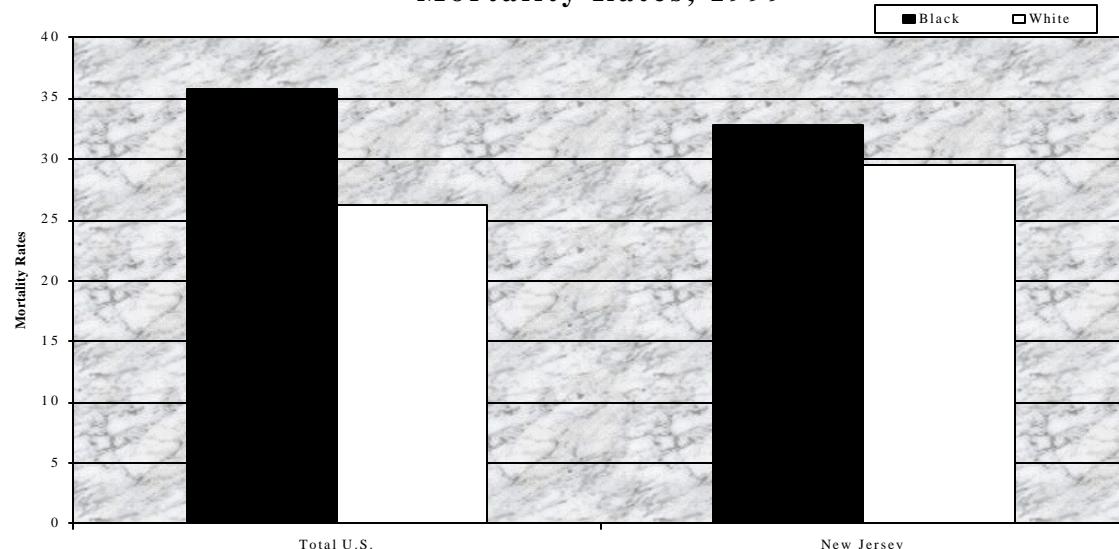
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\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

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

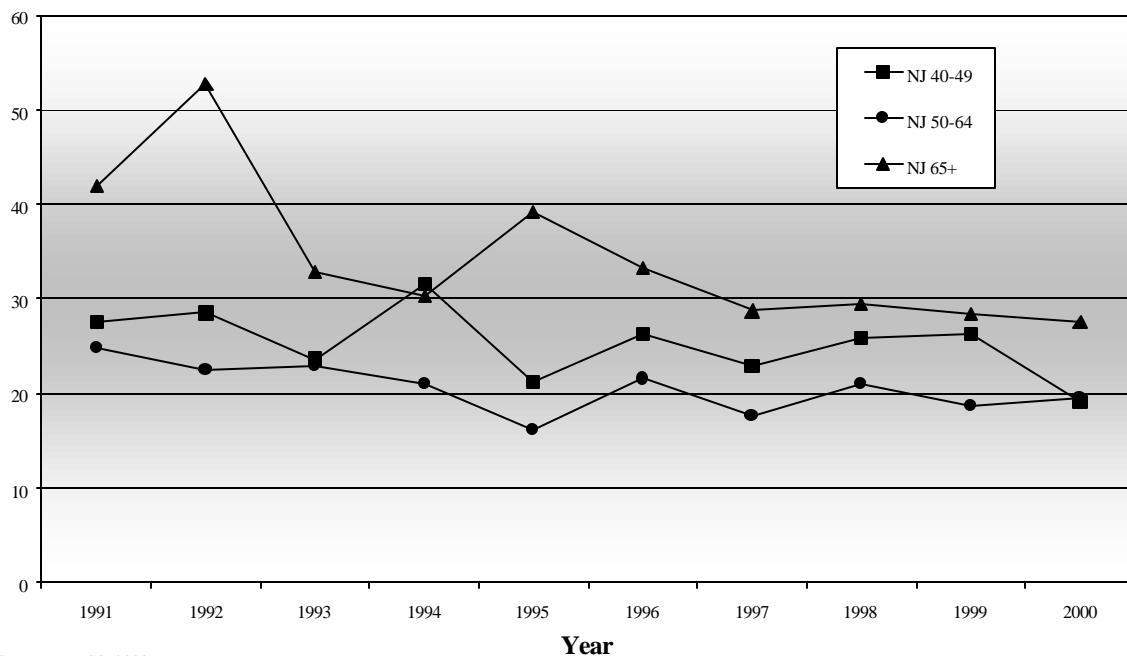


**Figure 3: U.S. and New Jersey Female Breast Cancer Mortality Rates, 1999**



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, age 40 and older, who report that they have never had a mammogram and a breast exam**



Source: BRFSS, 2002

Below are the Healthy New Jersey 2010 goals relating to breast cancer.

**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. Baseline data and projected target rates to reduce the death rate from female breast cancer.**

Populations	1997-1999 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total females 40+	65.0	75.0	+15.4	85.0	+30.8
White non-Hispanic females	66.2	75.0	+13.3	85.0	+28.4
Black non-Hispanic females	62.8 <sup>^</sup>	75.0	+19.4	85.0	+35.4
Asian/Pacific Islander	#	#	#	#	#
Hispanic females	56.7 <sup>^</sup>	75.0	+32.3	85.0	+49.9
Females 50-64	70.9	85.0	+19.9	90.0	+26.9
Females 65+	60.4	75.0	+24.2	85.0	+40.7
MCO records older enrolled females (1998-1999)	68.3	85.0	+24.5	90.0	+31.8

<sup>^</sup>Estimate has a relatively large standard of error or more than two percent.

#Data are statistically unreliable.

Source: Healthy New Jersey 2010

**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. Baseline data and projected target rates to increase the percentage of females who received a clinical breast examination and a mammogram within the past 2 years.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total	65.9	75.0	+13.8	85.0	+29.0
White	66.7	75.0	+12.4	85.0	+27.4
Black	58.5	75.0	+28.2	85.0	+45.3
Asian/Pacific Islander	#	#	#	#	#
Hispanic <sup>‡</sup>	69.0	75.0	+8.7	85.0	+23.2
Females 65+	64.6	75.0	+16.1	85.0	+31.6

<sup>‡</sup>1998 Hispanic data unavailable, using 1996 data.

#Data are statistically unreliable.

Source: Healthy New Jersey 2010

**Healthy New Jersey Goal 3: Reduce the age-adjusted death rate from female breast cancer, by 2010.**

**Table 3. Baseline data and projected target rates to increase the percentage of female breast cancers being diagnosed in early stages.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	24.7	17.0	-31.2	17.0	-31.2
White age-adjusted	24.7	17.0	-31.2	17.0	-31.2
Black age-adjusted	28.1	23.3	-17.1	17.0	-39.5
Asian/Pacific Islander age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#
Females 50-64	56.2	47.3	-15.8	20.0	-64.4
Females 65+	143.7	120.0	-16.5	103.0	-28.3

*#Data are statistically unreliable.*

Source: Healthy New Jersey 2010

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 three topic areas in priority order:

- Awareness and Education
- Research and Surveillance
- Treatment

## GOALS, OBJECTIVES AND STRATEGIES

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### AWARENESS AND EDUCATION FOR BREAST CANCER

To increase screening for breast cancer, increase early diagnosis, and decrease death rates, the Breast Cancer Workgroup identified education as a priority for New Jersey. The education process 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, 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. Please see the Research component of this chapter for more 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, for example. Most organizations recommend annual mammograms for women ages 40 and older based on strong evidence that mortality is reduced (7;8;10;29). However, recommendations for breast self-examination and clinical breast examination vary drastically. The U.S. Preventive Services Task Force concludes that the evidence is insufficient to recommend for or against teaching or performing routine breast

self-examination and that the evidence is insufficient to recommend for or against routine clinical breast examination alone to screen for breast cancer (10). Conversely, the American College of Radiology recommends that BSEs be performed monthly and that CBEs be performed annually (7). 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 suffering disproportionately from breast cancer. Although white New Jerseyans have higher incidence of breast cancer, more black women are dying from it. 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. However, according to data from BRFSS, women in New Jersey are not utilizing breast cancer screening effectively. In 2000, more New Jersey women than the U.S. median (47.0 versus 32.9) reported never having had a mammogram or clinical breast exam (Figure 4). According to the Peer Review Organization of New Jersey, approximately 50% of women with Medicare eligible to receive a mammogram do not take advantage of this Medicare-covered service.

Many studies have been conducted to identify both barriers to screening and interventions needed to overcome barriers, such as

cost (30), lack of knowledge regarding screening (31), physician recommendation (32), language (33), cultural sensitivity issues (33), inaccessible screening sites and transportation (33). In a recent New Jersey study, participants revealed that they are not motivated to obtain screening services because “prevention is not a priority” (33). (See the Access and Resources Chapter for additional information on this study.)

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 (34-39). Some have used social networks (40;41), community or healthcare systems approaches (42;43) rather than focusing exclusively on individual behavior change.

Teaching breast self-care as breast changes occur in the adolescent girl can influence positive behaviors such as performing breast self-examinations and seeking regular professional breast examinations. 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 (44). Another study found that educational lessons could improve knowledge and attitudes of adolescent girls with respect to breast self-examination (45).

Interventions should focus not only on improving one-time screening but also on improving repeat adherence. 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 (46). 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 (9). 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 patient population. For a number of reasons, follow-up for evaluation and treatment is often not completed. In a study of 10,434 mammograms conducted between 1995 and 1997, 44% of women with abnormal mammograms had no further follow-up (47). Lack of understanding by the patient about the next steps often contributes to incomplete follow-up, as does inconsistent sharing of information (20). Women also report that lack of communication that follow-up was necessary, cost of lost wages and medical care, system factors, and fear represent barriers to appropriate follow-up (48).

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 (49). Also, pre-consultation education appears to be an effective clinical strategy for helping patients gain an accurate understanding of treatment options before meeting with their physicians (50). This information must be presented in an understandable and culturally appropriate format.

### **Awareness and Education for Healthcare Practitioners.**

More than 20% of New Jersey women reported no mammogram within the past two years, for ages 40 to 64. Data from BRFSS 2000 indicate that, for women over 65, nearly 26% reported no mammogram within the past two years, which is slightly higher than the U.S. average percentage of 23%. These numbers must be improved to effectively decrease mortality and increase early detection of breast cancer.

As noted earlier, primary care physicians are in a strategic position to influence 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 (49). Tailored interventions, using a package that addresses specific professional barriers 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 (49).

The Breast Cancer Workgroup recommends that healthcare professionals encourage their female patients 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 multidimensional approach to addressing breast cancer education in New Jersey.

#### **GOAL BR-1:**

**To improve public understanding of breast health, breast cancer, and screening to promote the value of early detection.**

#### **Objective BR-1.1:**

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-1.1.1) Convene a diverse group of breast cancer experts, advocates, and consumers at state and community levels.
- (BR-1.1.2) Review and summarize the most current scientific literature about breast cancer screening, early detection, and treatment.
- (BR-1.1.3) 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-1.1.4) Establish priorities to most effectively reach the targeted population with breast cancer information.

**Objective BR-1.2:**

To develop and implement a statewide breast cancer public awareness 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-1.2.1.) Develop media campaigns specifically promoting the availability of no-cost breast cancer screenings for those eligible through the New Jersey Cancer Education and Early Detection (NJCEED) 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-1.2.2) Collaborate with organizations and entities to communicate messages and effectuate the breast cancer campaign, including (but not limited to): the New Jersey Primary Care Association, American Cancer Society, Breast Cancer Resource Center/YWCA Princeton, Susan G. Komen Breast Cancer Foundation, Medical Society of New Jersey, New Jersey Association of Osteopathic Physicians and Surgeons, New Jersey Hospital Association, New Jersey State Commission on Cancer Research, Cancer Institute of New Jersey, Health Research and Educational Trust of New Jersey, and Peer Review Organization of New Jersey, Inc.
- (BR-1.2.3) Provide public service announcements and media information on breast cancer in English, Spanish, and other languages as needed.

- (BR-1.2.4) Provide training for multi-level, multi-lingual, multi-cultural Speaker's Bureau to implement community breast cancer education and screening activities.
- (BR-1.2.5) Distribute promotional incentives to encourage women to undergo mammography and become educated about breast cancer by offering free or discounted items from local retailers.
- (BR-1.2.6) Establish and publicize a central toll-free telephone number in the New Jersey Department of Health and Senior Services that will act as a clearinghouse for *all New Jersey cancer information* (e.g., programs, services, support groups, etc.). Breast cancer screening services, especially sites with free and reduced-charge screening for low-income and uninsured women, will be emphasized.

### **Objective BR-1.3:**

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-1.3.1) Identify existing, and develop as needed, breast cancer *educational materials* to use in reaching all women, especially those at highest risk. Disseminate materials appropriately.
- (BR-1.3.2) Identify existing, and develop as needed, *educational programs*, and projects to promote breast cancer early detection and assist all women, especially those at highest risk.
- (BR-1.3.3) Identify existing, and develop as needed, breast cancer educational materials that are translated into multiple languages as appropriate, including Spanish, Arabic, Polish, Russian, Chinese, and other Asian languages.
- (BR-1.3.4) Provide comprehensive breast cancer educational materials to appropriate local and statewide community organizations for distribution to their constituencies.
- (BR-1.3.5) 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-1.3.6) Disseminate breast cancer educational materials to high-risk groups through appropriate community members who care for them (e.g., healthcare providers, laypersons, and survivors).

- (BR-1.3.7) 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-1.3.8) Expand culturally sensitive education and outreach programs for low-income, underserved communities who do not meet the NJCEED criteria.
- (BR-1.3.9) Provide cultural competency training to the individuals interfacing with the community (especially minority communities) for breast cancer awareness and education.
- (BR-1.3.10) 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 community, especially high-risk women.

**Objective BR-1.4:**

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

**Strategies:**

- (BR-1.4.1) Develop a formal breast health high school curriculum in New Jersey in response to New Jersey state promotion of teaching BSE (breast self-examination).
- (BR-1.4.2) Work with the New Jersey Department of Education and advocate for full implementation of this breast health curriculum in all New Jersey high schools.
- (BR-1.4.3) Develop thoughtful, age-appropriate educational materials for teen-age students to teach breast health at an early age, including multi-media presentations, supporting posters, and brochures.
- (BR-1.4.4) Widely distribute high school focused breast educational materials for either assembly or classroom venues.
- (BR-1.4.5) Identify a method(s) to track the impact of teaching young women about breast health and breast cancer on later adherence to screening recommendations.

**GOAL BR-2:**

**To improve patient/client awareness and education about the importance of breast cancer rescreening and follow-up visits to maximize optimal outcomes.**

**Objective BR-2.1:**

To educate women who come in for breast cancer screening about early detection and the need to return for appropriate rescreening or diagnostic testing.

**Strategies:**

- (BR-2.1.1) Identify existing, and develop as needed, culturally 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. Distribute this information widely.
- (BR-2.1.2) Identify existing, and develop as needed, information for dissemination to community groups and advocacy groups about 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.

**Objective BR-2.2:**

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

**Strategies:**

- (BR-2.2.1) 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, treatment options available if they have been diagnosed with breast cancer, especially clinical trials.
- (BR-2.2.2) 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-2.2.3) 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.

**GOAL BR-3:**

**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 encouraging more referrals.**

**Objective BR-3.1:**

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

**Strategies:**

- (BR-3.1.1) Create 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. This curriculum should be interactive and developed in different formats and media, e.g., internet, audiotape, CDs, etc. by partnering with professional organizations.
- (BR-3.1.2) Widely distribute and promote this breast cancer curriculum through the Medical Society of New Jersey, the Academy of Medicine, and other professional and specialty groups.

**Objective BR-3.2:**

To measure and then increase the number of primary care providers who recommend mammography to appropriate patients.

**Strategies:**

- (BR-3.2.1) Educate primary care providers regarding which patients are appropriate for mammograms, focusing on those serving ethnically diverse and minority communities.
- (BR-3.2.2) Provide primary care providers with a current list of mammogram providers.
- (BR-3.2.3) Encourage primary care providers to increase referrals and improve patient awareness about breast cancer early detection and screening measures.

## **RESEARCH AND SURVEILLANCE FOR BREAST CANCER**

Earlier in this chapter the risk factors for breast cancer and disparities surrounding breast cancer care were identified. While the overall picture of breast cancer among New Jersey women is encouraging, there is need for improvement among specific subgroups of women. Statistics from the New Jersey State Cancer Registry demonstrate that between 1986 and 1995 the percentage of breast cancer cases diagnosed in the early stages (*in situ* and localized) varied by county of residence (4). Additionally, age-adjusted mortality rates for the years 1986-1995 varied among the 21 counties in New Jersey (4). The disparities in mortality rates by state likely depend on stage of disease at diagnosis, socioeconomic status, access to care, and adequacy of medical care (51). Although this information is well documented in the literature, New Jersey lacks a comprehensive needs and capacity assessment for breast cancer to identify populations in greatest need and their healthcare barriers.

It is a well-recognized fact that the incidence of breast cancer is generally higher for white than black women, with population-based data showing an approximately 20% higher rate for white women (52). However, there is a reverse trend among women less than 40 years old (52). Among older women (40 to

54 years), most of the difference between whites and blacks can be attributed to varying prevalences and effects of well-recognized reproductive and menstrual factors. However, among younger women (20 to 39 years), the ethnic differences are less well understood (52).

In 1999, the Susan G. Komen Breast Cancer Foundation, North Jersey Affiliate, completed an updated community needs assessment (53) for the nine northern counties in New Jersey. The Breast Cancer Resource Center/Princeton YWCA completed a community needs assessment in Central New Jersey (54). 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 the 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 (55). 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. Similar analyses conducted on a periodic basis are needed to continue to identify areas in need of breast cancer education and screening services and to evaluate the effect of provision of these services, including income level and insurance status.

Although some data have been compiled stratifying for each type of cancer the incidence, prevalence, treatment access, mortality, etc. by age, race, gender, and geographic location, these data are largely incomplete (55). Existing data do not permit all factors to be simultaneously assessed, and summary measures frequently hide vast

disparities within subgroups, which may be amenable to intervention and improvement. Needed are studies to develop a more comprehensive database, as well as analytic work targeting those subgroups offering the greatest chances for improvements. Such efforts will help guide the cost-effective deployment of targeted resources toward those areas in need. Also needed are studies that help define innovative ways to overcome current barriers. Statistics reported on health indicators should be stratified by a variety of factors. Among women, for example, all age groups do not benefit equally from mammography screening. Furthermore, population access apparently differs dramatically in different parts of the state. Detailed data are required to identify those in greatest need of services. Resources are necessary to then provide those services.

#### **GOAL BR-4:**

**To adequately identify and address areas and populations at higher than expected risk of breast cancer incidence and mortality in New Jersey in order to learn where education and awareness efforts are most needed.**

#### **Objective BR-4.1:**

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

#### **Strategies:**

- (BR-4.1.1) Update existing maps and develop new maps, tables, etc. that identify and describe geographic areas and population groups at high risk of breast cancer mortality, using demographic, service utilization, and epidemiologic data.

- (BR-4.1.2) Assess consumer-related 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).

**Objective BR-4.2:**

To monitor and evaluate new and existing strategies that are developed and implemented for breast cancer early detection and treatment in high-risk populations with regard to the barriers identified in BR-4.1.2.

**Strategies:**

- (BR-4.2.1) Conduct a cost analysis to determine the cost-effectiveness of educational programs and interventions to increase breast cancer screening in higher risk populations in New Jersey.
- (BR-4.2.2) After implementation of a strategy to promote breast cancer screening in a higher risk group, evaluate the success of the strategy.
- (BR-4.2.3) Partner with groups developing breast cancer education and awareness programs in order to build in continuous quality improvement mechanisms during the planning stages of educational programs and interventions, especially evaluation plans.

## TREATMENT FOR BREAST CANCER

Many treatment options are available for women diagnosed with breast cancer. However, many women find it difficult to make decisions about treatment. 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 (3).

Several New Jersey organizations provide current information about breast cancer treatment. Currently, the Commission on Cancer Research produces a publication that describes cancer resources available in New Jersey. Websites, such as emerging-med.com, provide resources to match individuals to clinical trials worldwide. State programs, such as NJCEED, provide treatment for eligible women who are diagnosed through the NJCEED program (Appendix E). However, all of these resources are not coordinated to provide comprehensive information about breast cancer resources available in New Jersey.

A new NCI initiative, the Cancer Care Outcomes Research and Surveillance Consortium, will provide more detailed information on how to link measures of quality care to outcomes important to patients as we develop systems for evaluating quality of care. Similar studies are being supported by major professional organizations as well as by NCI (3). A report from the Institute of Medicine suggests that future research is needed to eliminate breast cancer mortality, as screening mammography does not detect all cancers (56).

The Breast Cancer Workgroup realizes that much additional work can be done to improve treatment techniques for breast cancer in New Jersey. However, the group determined that the first priority is to increase awareness and access to state-of-the-art treatment. As

research and development progresses at a rapid pace, so must a parallel system to assure that individuals are aware of the treatment options that exist and can access state-of-the-art treatment readily. After all, without awareness and access, even the most beneficial interventions will not be effective.

The Breast Cancer Workgroup recommends that improving breast cancer treatment should begin by increasing awareness of state-of-the-art treatment. Continuing medical education should be offered to physicians, and a centralized clearinghouse of breast cancer information should be available for the public. Additionally, the Breast Cancer Workgroup recognizes the importance of clinical trial enrollment for state-of-the-art breast cancer treatment.

#### **GOAL BR-5:**

**To ensure that all New Jersey residents diagnosed with breast cancer receive state-of-the-art cancer treatment and services, taking into consideration all variables (including age, stage of tumor, residence, and socioeconomic status), including clinical trials that comply with nationally recognized guidelines**

#### **Objective BR-5.1:**

To enroll all interested and eligible patients in evidence-based, currently approved clinical research trials for breast cancer and provide similar treatment options for those not interested or eligible.

#### **Strategies:**

- (BR-5.1.1) Provide healthcare professionals with information about how to screen all patients diagnosed with breast cancer in New Jersey for their eligibility for currently approved clinical research trials.

- (BR-5.1.2) Educate healthcare professionals about the need to use evidence-based, currently recognized community standards of care for those breast cancer patients not eligible for clinical research trials, or those patients not choosing to be a part of a clinical research trial, or those patients who do not have clinical research trial availability. This can be done through continuing medical education programs partnering with professional organizations.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

Breast Cancer Resource Center / YWCA Princeton: BR-1.1.3, BR-1.2.2, BR-1.2.3, BR-1.2.4, BR-1.2.5, BR-1.2.6, BR-1.3.2, BR-1.3.4, BR-1.3.6, BR-1.3.7, BR-1.4.4, BR-2.1.1, BR-2.1.2, BR-2.2.1, BR-2.2.2, BR-3.2.3

New Jersey Department of Health and Senior Services: BR-1.2.2; BR-1.2.3; BR-1.2.6; BR-2.1.9; R-2.1.10; BR-3.1.1; BR-3.2.2; BR-4.1.1; BR-4.2.1; BR-4.2.1; BR-4.2.2; BR-4.2.3

New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection (NJCEED): BR-1.1.1; BR-1.1.2; BR-1.1.3; BR-1.1.4; BR-1.2.1; BR-1.2.2; BR-1.2.6; BR-1.3.1; BR-1.3.2; BR-1.3.3; BR-1.3.4; BR-1.3.5; BR-1.3.6; BR-1.3.7; BR-1.3.9; BR-1.3.10; BR-2.1.1; BR-2.1.2; BR-3.1.1; BR-3.1.2; BR-3.2.1; BR-3.2.2; BR-3.2.3; BR-4.1.2; BR-4.2.1; BR-4.2.2; BR-4.2.3

New Jersey Hospital Association: BR-1.3.7; BR-2.2.3; BR-3.2.2; BR-3.2.3

Komen NJ Race for the Cure: BR-1.2.3, BR-1.2.4, BR-1.2.5, BR-1.3.1, BR-1.3.3, BR-1.3.4, BR-1.3.5, BR-1.3.6, BR-1.3.8, BR-1.3.9, BR-1.3.10, BR-1.4.2, BR-1.4.4, BR-2.1.1, BR-2.1.2, BR-2.2.1, BR-2.2.2, BR-2.2.3, BR-4.1.1, BR-4.1.2, BR-4.2.3

Susan G. Komen Breast Cancer Foundation, North Jersey Affiliate: BR-1.1.1; BR-1.1.2; BR-1.1.3; BR-1.1.4; BR-1.2.1; BR-1.2.2; BR-1.2.3; BR-1.2.4; BR-1.2.5; BR-1.2.6; BR-1.3.1; BR-1.3.2; BR-1.3.3; BR-1.3.4; BR-1.3.5; BR-1.3.6; BR-1.3.7; BR-1.3.8; BR-1.3.9; BR-1.3.10; BR-1.4.1; BR-1.4.2; BR-1.4.3; BR-1.4.4; BR-1.4.5; BR-2.1.1; BR-2.1.2

## BREAST

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
	1.1: Build consensus on public message	BR-1.1.1 BR-1.1.1 BR-1.1.1 BR-1.1.4						
	1.2: Develop/implement statewide public awareness campaign	BR-1.2.1 BR-1.2.2 BR-1.2.3 BR-1.2.4 BR-1.2.5 BR-1.2.6						
	1.3: Develop/disseminate educational materials and resources	BR-1.3.1 BR-1.3.2. BR-1.3.3 BR-1.3.4 BR-1.3.5 BR-1.3.6 BR-1.3.7 BR-1.3.8 BR-1.3.9 BR-1.3.10						
	1.4: Increase education of high school students	BR-1.4.1 BR-1.4.2 BR-1.4.3 BR-1.4.4 BR-1.4.5						
1: Improve public understanding	2.1: Educate women regarding appropriate re-screening or diagnostic testing	BR-2.1.1 BR-2.1.2						
	2.2: Increase treatment and follow-up for those with abnormal mammograms or clinical breast exams	BR-2.2.1 BR-2.2.2 BR-2.2.3						
2: Patient awareness and education regarding rescreening and follow-up	3.1: Increase professional education	BR-3.1.1 BR-3.1.2						
	3.2: Measure/increase healthcare provider referral	BR-3.1.1 BR-3.1.2 BR-3.1.3						
3: Improve healthcare practitioners' knowledge								

Target Completion Date

## BREAST

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
4: Identify/address high-risk incidence and mortality	4.1: Identify high-risk areas	BR-4.1.1						
		BR-4.1.2						
		BR-4.2.1						
	4.2: Monitor/evaluate strategies for high-risk populations	BR-4.2.2						
		BR-4.2.3						
		BR-5.1.1						
5: Ensure state-of-the-art treatment for all New Jersey residents	5.1: Enroll interested and eligible patients in clinical research trials	BR-5.1.2						

Target Completion Date

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## CERVICAL CANCER

### IMPORTANCE OF CERVICAL CANCER FOR CANCER PREVENTION AND CONTROL

**C**ervical 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 smear, developed by George Papanicolaou and implemented for widespread screening in the 1940s (3), is the most common test used to screen for cervical cancer, and is widely available, and is 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. Despite the tremendous progress made with cervical cancer, it is estimated that 13,000 U.S. women will be diagnosed with cervical cancer and 4,100 will die from this disease in 2002 .

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, most treatable stages (3). However, due to lack of regular screening or inadequate follow-up and treatment of precancerous changes found during routine screening, not all populations have experienced a reduction in mortality (5). In the absence of screening, a 20-year-old average-risk woman has approximately a 250 in 10,000 chance of developing invasive cervical cancer during the rest of her life and approximately a 118 in 10,000 chance of dying from it (3). In addition, rates for carcinoma in situ peak between the ages of 20 and 30 (6). The lead-time from the development of precancerous lesions to invasive cancer is estimated at 8 to 9 years (6). During this process, abnormal tissue can easily be detected by a Pap smear and then removed by a clinician (7). Most of

the cervical cancer deaths occur in women who have never had a Pap test, and some occur in women who recently received negative test results (8). Nearly one-half of all U.S. women with invasive cervical cancer are diagnosed at a late stage (9). Case control studies clearly demonstrate that women with invasive cervical cancer were less likely to have been screened compared to controls (3;10), and decreased mortality and incidence of invasive cervical cancer have been described in populations following implementation of Pap screening (6). 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.

Women at risk for developing cervical cancer are those who are or who ever have been sexually active (6;10); are not being screened on a routine basis (6;11) had an early onset of sexual intercourse (6;12) have a history of multiple partners (6;12); have a history of sexually transmitted disease (6), especially HPV (2;13;14) and HIV (15); suffer from obesity (16); and/or smoke (6;17;18). 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 (7). It is generally agreed that the most important risk factor for cervical cancer is infection by Human Papilloma Virus (HPV). In fact, HPV DNA is present in 93% of cases involving cervical cancer and its precursor lesions. Although there is currently no cure for HPV infection, providers can treat the warts and abnormal cell growth caused by these viruses and prevent 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 (19-21).

Screening with HPV plus Pap tests every two years appears to save additional years of life at reasonable costs compared with Pap testing alone (incremental cost: \$76,183 / Quality Adjusted Life Year [QALY] (21). Another study found that AutoPap, a new cervical cancer screening technology, increased survival at the lowest cost, estimating that cost per year of life saved rose from \$7,777 with quadrennial screening to \$166,000 with annual screening (22).

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 through the New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection Programs (NJCEED), with federal or state funds, and who are diagnosed with breast or cervical cancer, are eligible for treatment under Medicaid. (See Appendix E 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 yet eradicated this cancer completely in any population (5). 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;7). Clearly needed are a better understanding of and increased attention to the reasons why

women are not utilizing this screening procedure more effectively.

## CERVICAL CANCER IN NEW JERSEY

**Incidence.** The American Cancer Society estimates that, in 2002, there will be 400 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 10.0 per 100,000\*\* women in 2000\*, population subgroups have experienced substantially different rates (23) (Figure 1). Despite the decline in incidence rates, black women in New Jersey still had approximately twice the rate of white women (17.0 versus 8.9 per 100,000\*\*) in 2000\* (23) (Figure 1).

Of the 10.0 per 100,000\*\* new cases of invasive cervical cancer diagnosed in 2000\*, more than one-quarter (27.5%) were diagnosed at the regional stage, a stage at which these women statistically have only a 49% chance of surviving five years (19). In addition, 7.1% of new cervical cancer diagnoses are at the distant metastasis stage, a stage at which women statistically have only a 9% chance of surviving for five years (19) (Figure 2).

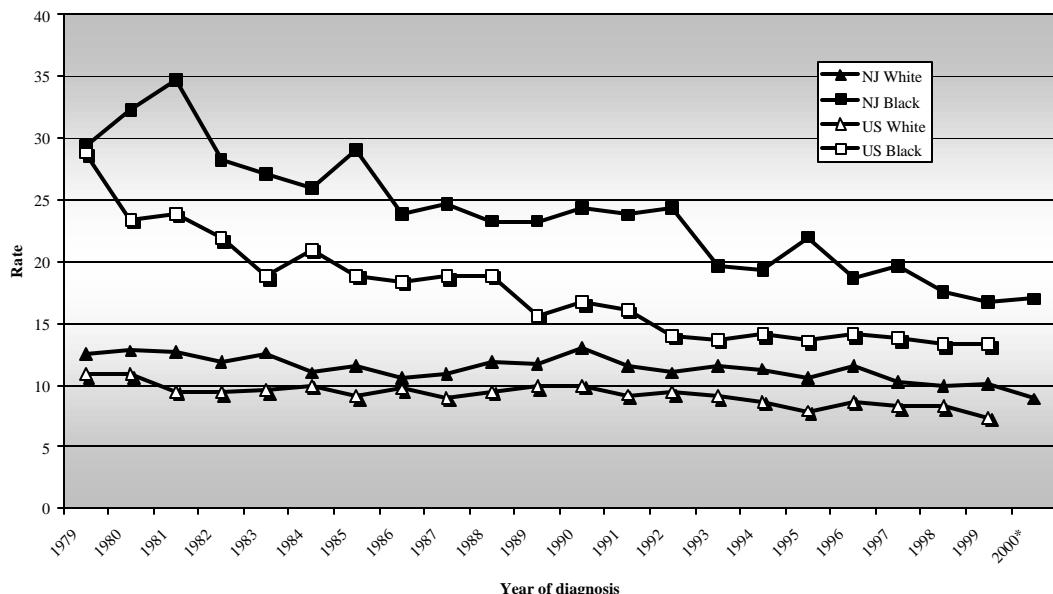
Trend data are not currently available for Hispanic women. However, a recent report from the New Jersey State Cancer Registry found that for the period 1990-1996, Hispanic women had a cervical cancer rate of 16.7 per 100,000 compared to 8.8 among white women and 15.6 among black women. Data from other states and the U.S. as a whole show similar cervical cancer rates among Hispanic and black women (24).

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\*Incidence rates for the year 2000 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.

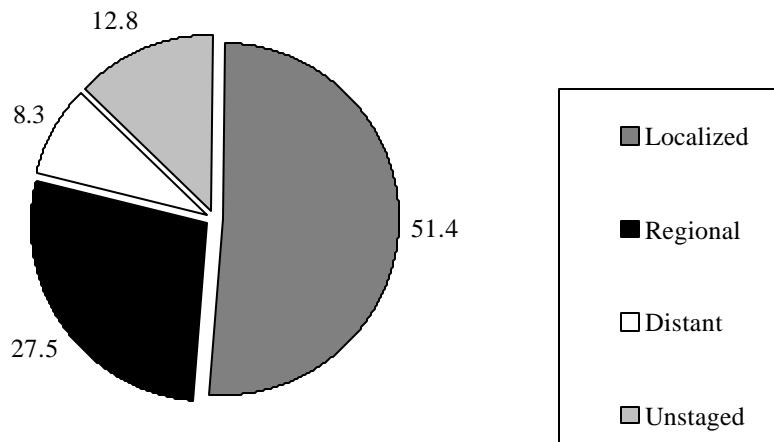
**Figure 1: Cervical Cancer Incidence in the U.S. and New Jersey by Race, 1979-2000\***



Source: New Jersey State Cancer Registry (NJSCR); Rates are per 100,000 and age-adjusted to the 2000 US standard.

\*Incidence rates from the NJSCR for the year 2000 are preliminary.

**Figure 2: Stage at which Invasive Cervical Cancer was Diagnosed in New Jersey, by Percentage, in the year 2000\***



Source: New Jersey State Cancer Registry (NJSCR); Age-adjusted for the 2000 U.S. standard population.

\*Data from the NJSCR for the year 2000 are preliminary.

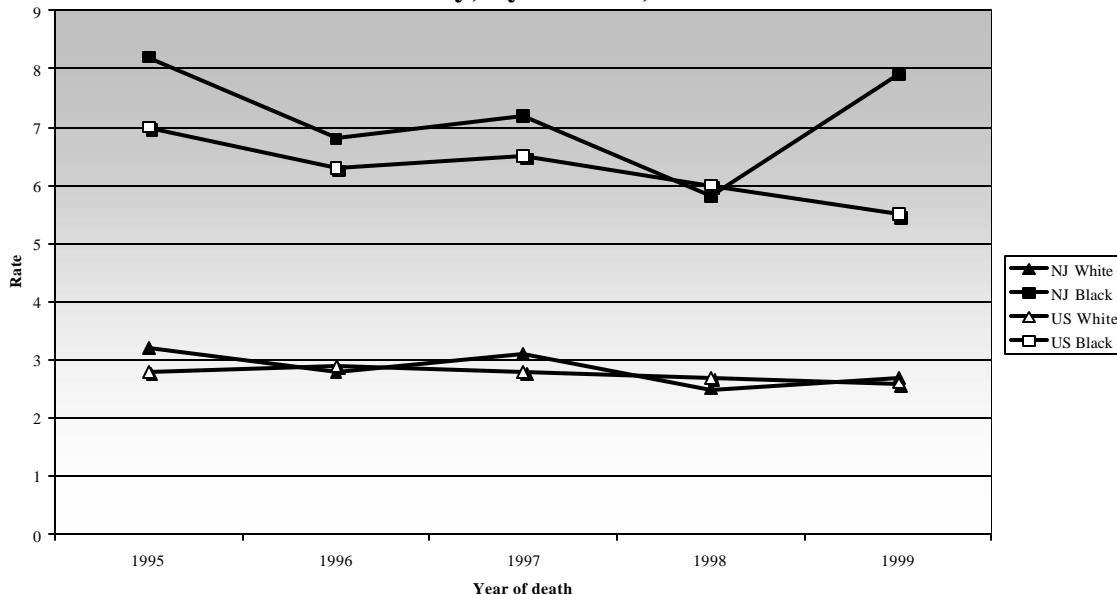
Note: Data for cervical cancer in situ are not available.

**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 1999, the New Jersey mortality rates were 2.7 per 100,000\*\* in white women and 7.9 per 100,000\*\* in black women (Figure 3).

The New Jersey State Cancer Registry's report on cancer among Hispanics in

New Jersey included data on mortality. The patterns vary from those reported on incidence. The age-adjusted cervical cancer mortality rate among Hispanics during 1990-1996 was 4.1 per 100,000 Hispanic women, compared to 2.3 among white and 6.3 among black women. The cervical cancer mortality rate among Hispanics is lower than among blacks, while the reverse is true for cancer incidence. This pattern is consistent with that observed for the rest of the U.S.

**Figure 3: Mortality Rates for Cervical Cancer in the U.S. and New Jersey, by Gender, 1995-1999**



**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 (25). National data from the 2000 Behavioral Risk Factor Surveillance Survey (BRFSS) indicate that 70.5% of all women aged 18 years and over reported having had a

Pap test within the previous year, and 87.4% reported having had one within the previous three years. New Jersey reported rates for having had a Pap test within the past three years are lower for white women (88.1%) than for black women (89.6%) or Hispanic women (94.8%). The proportion of women who report having had a Pap test within the past three years begins to decline after age 50;

\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

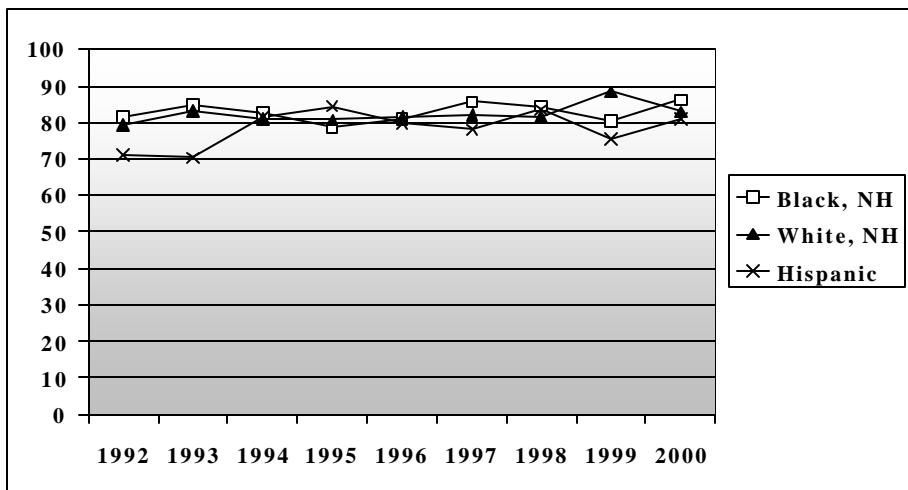
\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

rates are 95% for women 18 to 49, but 89.2% for women 50 to 59, 87.0% for women 60 to 64, and only 71.52% for women aged 65 or older (26).

The high rates of screening in all populations (Figures 4 and 5) are not adequate due to the effectiveness of the Pap test in reducing incidence and mortality from cervical cancer. Although New Jersey black women report

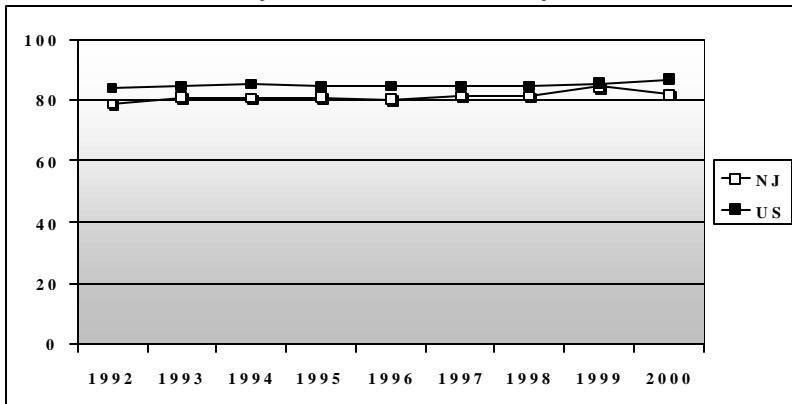
receiving Pap tests at approximately the same rate as white women, the incidence and mortality rates of invasive cervical cancer are much higher in black women. Equal targets have been set by Healthy New Jersey 2010 for all tracked populations to decrease the disparity in the incidence rate of cervical cancer discovered at the more serious late stage.

**Figure 4: Percent New Jersey Women, with uterine cervix, 18 & older, Pap Smear within 3 years**



Source: BRFSS

Figure 5: Percent of women with uterine cervix, 18 and older, who had a Pap smear in the last 3 years, New Jersey and U.S.



Source: BRFSS

### WHAT CAN BE DONE ABOUT CERVICAL CANCER IN NEW JERSEY

To lower cervical cancer incidence and mortality rates, it will be necessary to address barriers to screening and follow-up care to better understand who is contracting cervical cancer in New Jersey and why.

To these ends, the Cervical Cancer Workgroup of the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey has devised strategies that includes 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 screening barriers.

The Cervical 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.

Below are the Healthy New Jersey 2010 goals relating to cervical cancer.

**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. Baseline data and projected target rates to increase the percentage of women who had a Pap test in the past two years.**

Populations	1997-1999 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total	78.6	85.0	+8.1	90.0	+14.5
White non-Hispanic	79.9	85.0	+6.4	90.0	+12.6
Black non-Hispanic	80.3^	85.0	+5.9	90.0	+12.1
Asian/Pacific Islander	#	#	#	#	#
Hispanic	74.0^	85.0	+14.9	90.0	+21.6
Females 65+	62.7^	75.0	+19.6	85.0	+35.6

*Source: Healthy New Jersey 2010*

*^Estimate has a relatively large standard error of more than two percent*

*#Data are statistically unreliable*

**Healthy New Jersey Goal 2: Reduce the age-adjusted incidence rate of invasive cervical cancer in females per 100,000 standard population to 5.4, by 2010.**

**Table 2. Baseline data and projected target rates to reduce the age-adjusted incidence rate of invasive cervical cancer.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	8.6	5.4	-37.2	2.0	-76.7
White age-adjusted	8.0	5.4	-32.5	2.0	-75.0
Black age-adjusted	13.9	5.4	-61.2	2.0	-85.6
Asian/Pacific Islander Age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#

*Source: Healthy New Jersey 2010*

*#Data are statistically unreliable*

**Healthy New Jersey Goal 3: Reduce the age-adjusted death rate from cervical cancer per 100,000 standard population to 1.0 for all females (age-adjusted), 1.0 for white females (age-adjusted), 2.9 for black females (age-adjusted), and 5.0 for females age 65+, by 2010.**

**Table 3. Baseline data and projected target rates to reduce the age-adjusted death rate from cervical cancer.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	2.0	1.0	-50.0	0.5	-75.0
White age-adjusted	1.8	1.0	-44.4	0.5	-72.2
Black age-adjusted	3.7	2.9	-21.6	0.5	-86.5
Asian/Pacific Islander Age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#
Women 65+	7.8	5.0	-35.9	0.5	-93.6

*Source: Healthy New Jersey 2010*

*#Data are statistically unreliable*

In support of the Healthy New Jersey 2010 goals for cervical cancer, the recommendations of the Cervical Cancer Workgroup are summarized below for the following five topic areas in priority order:

- Access to Care
- Public Awareness and Education
- Patient Awareness and Education
- Professional Awareness and Education
- Research

## GOALS, OBJECTIVES AND STRATEGIES

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### ACCESS TO CARE

Cervical cancer incidence and mortality can be reduced effectively through early detection using the Pap test. The decline in death rates from cervical cancer in the United States has been widely attributed to the use of Pap smears for early detection (27). The Pap test is routinely performed (28) 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 (28).

New Jersey Public Law, Chapter 415, Laws of 1995 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 E). However, as discussed above, many New Jersey women are not being screened consistently (Figure 3).

A recent study conducted in New Jersey identified reasons women were not being screened for cervical cancer. Barriers include lack of awareness of risk factors, cost, and feelings of embarrassment and discomfort related to the Pap test. Many women failed to recognize age as a risk factor and also reported that women in the higher age groups think they are too old to contract cervical cancer (31). This revelation is reflected in the decrease in screening rates after age 50. In a

report published by the New Jersey Hospital Association, hassles with the healthcare system, prevention not being a priority, inconvenience of professional services, language, transportation, childcare, and cultural sensitivity were identified as barriers for New Jersey women (32). (Chapter 4.1 Access and Resources offers additional detail about access issues in New Jersey.) 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 (27;33). Another study concludes that access to care is a confounding variable when analyzing the impact of race on disease (34).

In addition to identifying access barriers to cervical care, we need to better understand who and where populations are that are not receiving adequate care. Although some data have been compiled stratifying for each type of cancer the incidence, prevalence, treatment access, mortality, etc. by age, race, gender, and geographic location, these data are largely incomplete (35). Existing data do not permit all factors to be simultaneously assessed, and summary measures frequently hide vast disparities within subgroups, which may be amenable to intervention and improvement. Population access dramatically differs within New Jersey and linking data sources into a comprehensive database, as well as analytic work targeting those subgroups, will provide detailed data to target those most in need of services. The Cervical 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 (2;36).

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 beginning to reduce cervical cancer incidence and mortality by increasing screening rates, the Cervical Cancer Workgroup proposes the following goal, objectives, and strategies to improve access.

**GOAL CE-1:**

**To improve access to cervical cancer screening in New Jersey.**

**Objective CE-1.1:**

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

**Strategies:**

- (CE-1.1.1) Use Geographic Information Systems (GIS) technology and other appropriate data to locate population subgroups with a high risk for developing cervical cancer.
- (CE-1.1.2) Identify barriers to cervical cancer screening in New Jersey by reviewing the literature for barriers that have been identified in the state and developing and implementing pilot studies (where needed) to investigate additional barriers that exist, especially for the populations at increased risk identified in Strategy CE-1.1.1.

**Objective CE-1.2:**

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

**Strategies:**

- (CE-1.2.1) Develop and evaluate the effectiveness of specific solutions to help individuals overcome the cervical cancer screening and treatment barriers identified above.
- (CE-1.2.2) Identify and refer New Jersey populations to existing programs for screening, education, and treatment for cervical cancer.

- (CE-1.2.3) Develop solutions for those not qualified for existing New Jersey programs, so they can 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. In the previously mentioned New Jersey study, women failed to recognize age as a risk factor and reported that many women in higher age groups think they are too old to contract cervical cancer. Almost all study participants reported that some older women believe a woman is not at risk for cervical cancer and does not need to have a Pap test if she has gone through menopause. Although participants correctly linked cervical cancer with sexually transmitted disease, some mistakenly believed that personal hygiene was a factor in cervical cancer causation. Additionally, they noted that women might also think Pap tests are necessary only if they are having sexual relations (31). Although the study may not be representative of all New Jersey women because many were qualified for NJCEED, the study results provide a good example of misconceptions and barriers to screening among New Jersey women.

A national study asking questions about cancer to measure knowledge revealed that only 86% of the public had “heard of” cervical cancer, compared to 96% who had heard of skin cancer and 97% who had heard of lung cancer (37). Data from BRFSS indicate that nearly 18.1% of New Jersey females (over 18 with an intact cervix) have not had a Pap test in the past three years. Additionally, the screening rate has remained the same over the past several years (Figures 6,7). Clearly, the effectiveness of the Pap test in reducing cervical cancer incidence and

mortality is not evident from the surveyed populations.

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. In 2001, funding emphasis was on 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 (38). Additional research has shown that the rate of cervical cancer screening can be increased through worksite education programs and peer interventions (39).

Although educational resources exist, services are provided only to specific populations. There is no comprehensive, consistent message for cervical cancer screening and treatment. One example is a New Jersey study which revealed that many women do not obtain Pap tests because inconsistency in the guidelines caused confusion (31).

To address these issues, the Cervical Cancer Workgroup proposes that a public education program be developed and disseminated to all New Jersey women. In conjunction with the National Institutes of Health, 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 also 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 Cervical Cancer Workgroup notes that these steps represent only a beginning in a comprehensive approach to cancer prevention and control in New Jersey and that through evaluation of programs, and continuous quality improvement methods will help the public education component of this plan evolve.

#### **GOAL CE-2:**

**To increase public awareness and education about cervical cancer among all women, especially increased risk populations.**

#### **Objective CE-2.1:**

To educate the public about cervical cancer by using appropriate educational materials and programs to reach all women, especially those at increased risk (identified in the Access section above).

#### **Strategies:**

- (CE-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).
- (CE-2.1.2) Outreach to increased-risk populations with 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.
- (CE-2.1.3) Design a progressive, age-appropriate cancer prevention core curriculum in schools, including the importance of cervical cancer screening and early detection, especially targeting populations at increased risk as identified above.
- (CE-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 important to increase awareness of cervical cancer and the need for screening, patient education is equally important 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% (40). Barriers, such as cost of follow-up treatment, beliefs about cancer, lack of trust in the medical system, lack of access to transportation, and staff attitudes at healthcare facilities, all contribute to patients' reactions to abnormal test results and may influence whether follow-up recommendations are followed (41;42).

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 of hearing the results and her willingness to seek additional care (7). The Cervical 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 (25). 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 (40). 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% (43).

To begin to increase patient awareness about the importance of cervical cancer rescreening, follow-up care, and treatment options, the Cervical Cancer Workgroup proposes that patients be educated using multimedia 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 Cervical Cancer Workgroup recommends the following goal, objective, and strategies as important next steps.

**GOAL CE-3:**

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

**Objective CE-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:**

- (CE-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.
- (CE-3.1.2) Review cervical cancer educational brochures and posters annually in order to continuously update materials developed in Strategy CE-3.1.1 with new information as needed.
- (CE-3.1.3) Develop and distribute a resource listing of cervical cancer information sources (including clinical trial information) to all medical facilities on an annual basis.
- (CE-3.1.4) Review the methods that different medical facilities and laboratories use to notify patients of their Pap smear results. Determine the method easiest for patients to understand, and share the study results with all medical facilities and laboratories for possible implementation.
- (CE-3.1.5) Survey appropriate medical facilities for the use of an electronic follow-up/diagnostic Pap test reminder. Based on survey findings, identify and encourage the appropriate medical facilities to use an electronic Pap smear reminder system.

**PROFESSIONAL AWARENESS AND EDUCATION**

The Cervical Cancer Workgroup identified Professional Education as the third arm of the education recommendations. Issues identified were the importance of physician referrals and the high error rate of Pap tests.

To improve cervical cancer incidence and mortality in New Jersey, the Cervical Cancer Workgroup proposes solutions to each of these issues.

It has been estimated that 40% or more of women with abnormal Pap smears fail to comply with follow-up recommendations (40). Appropriate follow-up and treatment

may not occur because of issues of patient education and understanding, provider promotion, access, or cost (7).

A physician recommendation is a very strong motivator for obtaining a Pap test (44;45). A recent study of national trends in the use of preventive healthcare showed that most women who did not receive a Pap test did have recent contact with a physician (46). These findings suggest that, although women are visiting physicians and are open to receiving medical advice, recommendations are not provided consistently. A literature review identified reasons why primary care providers do not adhere to cervical cancer screening guidelines. Reasons 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 the cost of the test (46). For these reasons the Cervical Cancer Workgroup proposes that professionals be given additional education and materials to increase their awareness of cervical cancer.

Furthermore, it appears there are important differences in screening rates among provider specialties (47). Women receiving care from nurses or from obstetricians/gynecologists are most likely to report having had a recent Pap test. Those receiving care from an internist are least likely to report being screened. If a woman is being seen regularly for more acute, life-threatening care such as blood pressure or diabetes, her provider may also be less likely to recommend a Pap test because of the added inconvenience to the patient and lack of time during the clinic visit to do a Pap test (28). Many interventions have been found to be successful in increasing screening rates among women receiving medical care. These include opportunistic screening (recom-

mending Pap test screening when a woman is in an emergency room, provider's office, or hospital) or prompts, such as stickers on patient charts (48). Studies have been done of invitation and recall systems and identified specific factors that appear to increase rates of utilization. These include, for example, clearly explaining the benefits of screening and using personal contact with healthcare staff to allay anxiety (7;25). The Cervical Cancer Workgroup 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.

Any screening program that focuses solely on "percent population reached" is concentrating efforts on only half of the problem. The other arm of that program must emphasize accuracy in diagnosis. A single Pap test has a false-negative rate estimated to be between 15% and 30% (2;49). One-half of the false negatives are due to inadequate specimen sampling, and the other half are attributed to a failure to identify the abnormal cells or to interpret them correctly (2;36;50). 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 (51). Examples include incomplete sampling of the transformation zone, a poorly prepared slide with drying artifact or clumping of cells, and failure of the cytotechnologist to detect the presence of abnormal cells on the slide. Thus, 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 smear tests (50). There must be an accurate

and timely reading of the smear, including a clear report of results to the provider. After collection, the Pap test sample is sent with a clinical requisition form to the laboratory for interpretation. The quality of the reading of the smear 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 (7;50). The Clinical Laboratory Improvement Amendments 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 less than eight hours (51). In accordance with recommendations by the Agency for Healthcare Research and Quality, the Cervical Cancer Workgroup proposes that screening rates be monitored to ensure compliance with the workload limits established for each individual (50).

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. Terminology currently used is varied, resulting in confusion about the clinical implications of the report. The Bethesda System for reporting the results of cervical cytopathology was developed as a uniform system of terminology that would provide clear guidance for clinical

management (52;53). More than 90% of U.S. laboratories use some form of the 1991 Bethesda System in reporting cervical cytology (54). In 2001, the Bethesda System was updated to reflect increased utilization of new technologies and findings from research (55). In accordance with the National Institutes of Health, the Cervical Cancer Workgroup encourages the use of the Bethesda System 2001 as a method to increase uniformity of Pap smear reporting and decrease error (2).

Clinical Laboratory Improvement Amendments of 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 (51). Recent developments (56) 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 Cervical Cancer Workgroup recommends that continuous quality improvement methods be increased to further decrease error rates.

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

#### **GOAL CE-4:**

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

**Objective CE-4.1:**

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

**Strategies:**

- (CE-4.1.1) Develop and disseminate cervical cancer educational brochures appropriate for healthcare providers.
- (CE-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.
- (CE-4.1.3) Survey general practitioners, obstetricians/gynecologists, family practice physicians, internists, and advanced practice nurses to elicit the 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.
- (CE-4.1.4) Disseminate clinical guidelines for cervical cancer screening and follow-up to appropriate healthcare providers.

**Objective CE-4.2:**

To decrease the error rate of Pap smears.

**Strategies:**

- (CE-4.2.1) Educate clinicians on optimal conditions for obtaining a Pap smear and appropriate methods for collecting and handling Pap smears.
- (CE-4.2.2) Recommend legislation that the maximum number of slides read by each cytotechnologist be decreased from 100 slides per 24-hour period.
- (CE-4.2.3) Identify areas where there is a lack of cytotechnologists and recommend training and continuing education programs to the appropriate agencies.

- (CE-4.2.4) Recommend that laboratories standardize the system for reporting cervical cytopathology results using Bethesda 2001.
- (CE-4.2.5) Support continuous quality improvement methods to reduce the Pap smear error rate, including methods such as computerized rescreening.

## RESEARCH

Cervical cancer literature has noted that research is warranted in many areas, including the areas of behavior change, improving accuracy and interpretation of cytologic sampling techniques, and screening methods (2). At the research forefront of prevention and treatment of cervical cancer is the development and testing of prophylactic and therapeutic vaccines against HPV (2).

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 (57).

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 Cervical Cancer Workgroup suggests the following goal, objectives, and strategies as next steps.

### GOAL CE-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 CE-5.1:

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

#### Strategies:

- (CE-5.1.1) Contact pharmaceutical companies and medical organizations to identify current clinical trials for cervical cancer in New Jersey.
- (CE-5.1.2) Identify a department within the state that practitioners can use as a resource for identifying cervical cancer clinical trials in New Jersey for which their patients are eligible.

**Objective CE-5.2:**

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:**

- (CE-5.2.1) Link the state website to agencies such as emergingmed.com to make cervical cancer clinical trials more accessible to New Jersey residents.
- (CE-5.2.2) Determine reasons for lack of participation in cervical cancer clinical trials.
- (CE-5.2.3) Collaborate with key associations/organizations to publicize cervical cancer clinical trials in New Jersey.
- (CE-5.2.4) Outreach to healthcare providers and community leaders to improve client participation in cervical cancer clinical trials.
- (CE-5.2.5) Collaborate with the New Jersey Commission on Cancer Research and others to support cervical cancer clinical trials in New Jersey.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: CE-1.1.1; CE-1.1.2; CE-1.2.1; CE-1.2.2; CE-1.2.3; CE-2.1.1; CE-2.1.2; CE-2.1.3; CE-2.1.4; CE-3.1.1; CE-3.1.2; CE-4.1.4; CE-5.1.1; CE-5.1.2; CE-5.2.1; CE-5.2.2; CE-5.2.3; CE-5.2.4; CE-5.2.5

New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection (NJCEED): CE-1.1.1; CE-1.1.2; CE-1.2.1; CE-1.2.2; CE-1.2.3; CE-2.1.1; CE-2.1.2; CE-3.1.1; CE-3.1.2; CE-4.1.1; CE-4.1.2; CE-4.1.3; CE-4.1.4; CE-4.2.1; CE-4.2.4

## CERVICAL

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going	
1: Improve access to cervical cancer screening	1.1: Locate populations not being screened	CE-1.1.1							
		CE-1.1.2							
	1.2: Increase access to populations identified as high risk	CE-1.2.1							
		CE-1.2.2					■		
		CE-1.2.3					■		
2: Increase public awareness and education, especially with high-risk populations	2.1: Educate the public, especially those at increased risk	CE-2.1.1				■	■		
		CE-2.1.2				■	■		
		CE-2.1.3				■	■		
		CE-2.1.4				■	■		
	3.1 Educate patients regarding screening guidelines, care and treatment	CE-3.1.1				■	■		
3: Improve patient education		CE-3.1.2				■	■		
		CE-3.1.3				■	■		
		CE-3.1.4				■	■		
		CE-3.1.5				■	■		
4: Increase awareness of healthcare professionals	4.1: Educate healthcare professionals	CE-4.1.1							
		CE-4.1.2							
		CE-4.1.3							
		CE-4.1.4							
	4.2: Decrease Pap smear error rate	CE-4.2.1				■	■		
		CE-4.2.2				■	■		
		CE-4.2.3				■	■		
		CE-4.2.4				■	■		
		CE-4.2.5				■	■		
		CE-4.2.6				■	■		
5: Increase awareness and participation in clinical trials	5.1: Identify existing research	CE-5.1.1							
		CE-5.1.2							
	5.2: Attract/encourage clinical trial participation	CE-5.2.1							
		CE-5.2.2							
		CE-5.2.3							
		CE-5.2.4							
		CE-5.2.5							

**Target Completion Date**

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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 2002 in the United States there will be 148,300 new cases of colorectal cancer diagnosed and 56,600 deaths, accounting for almost 11% of all cancers among men and 12% among women. Colorectal cancers account for an almost equal proportion of cancer deaths (10% among men and 11% among women). Nationwide, the lifetime risk for developing colorectal cancer is approximately 1 in 18 persons. Between 1985 and 1997 colorectal cancer incidence rates declined 1.6% per year. Mortality rates from colorectal cancer have also declined, at about 1.8% per year, as a result of decreasing incidence and improvements in survival rates (1)(2;3).

### COLORECTAL CANCER IN NEW JERSEY

**Incidence.** Consistent with US colorectal cancer incidence rates, rates in New Jersey have declined since 1979 among white males, white females, and black females but has increased among black males (Figure 1). Although the number of colorectal cancer cases is approximately equal for men and women (principally because women live longer than men) (1), men have consistently had higher incidence rates than women,

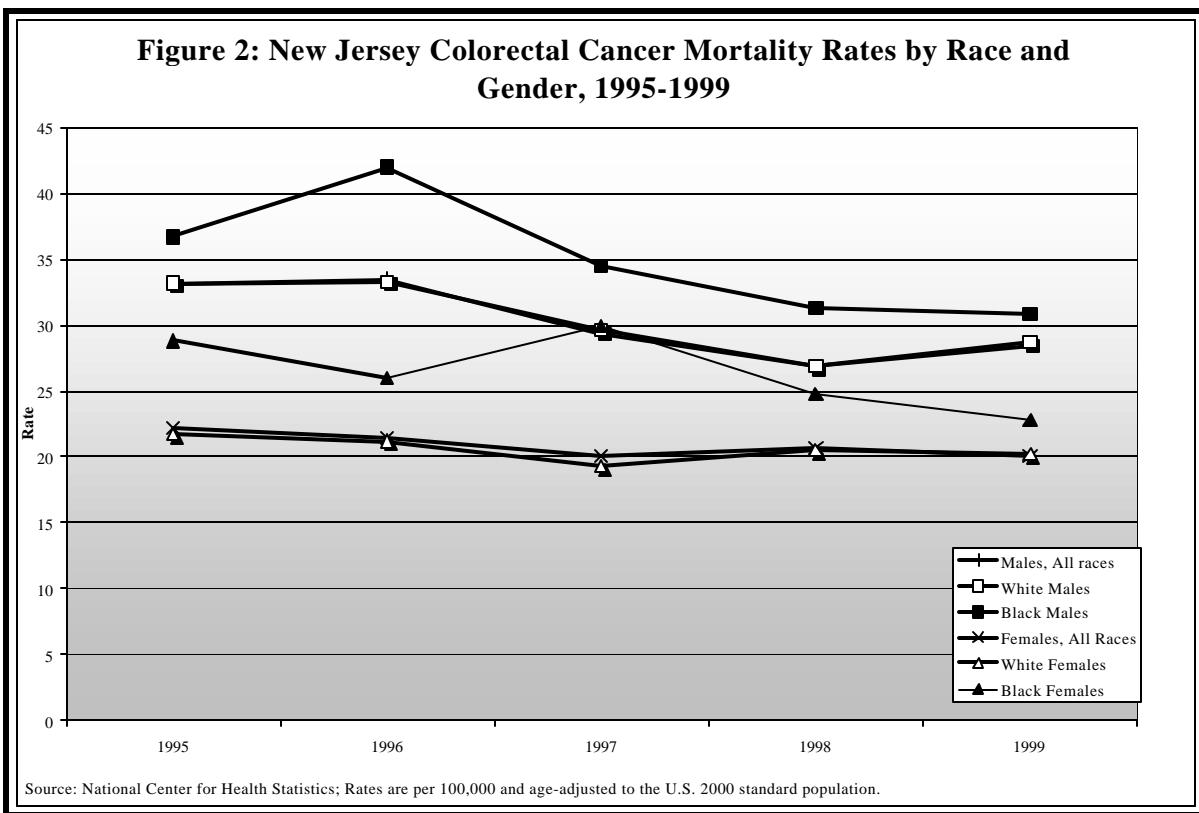
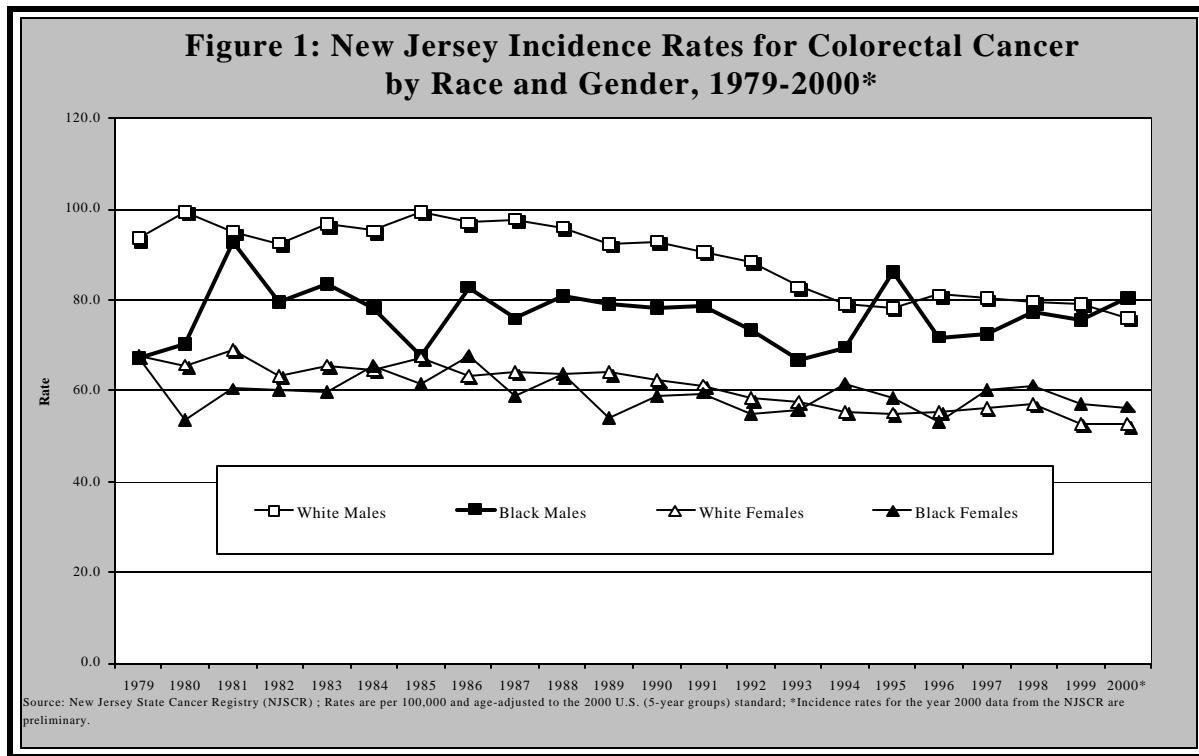
regardless of race. According to preliminary 2000\* data from the New Jersey State Cancer Registry, the incidence rate of colorectal cancer among New Jersey men (all races combined) was 76.0 per 100,000\*\*; the incidence rate for white males was 76.0 compared to 80.3 per 100,000 for black males. Incidence rates among New Jersey females (all races combined) was 53.6 per 100,000\*\*; the incidence rate for white females was 52.6 compared to 56.4 per 100,000\*\* for black females in 2000\* (4). The American Cancer Society estimates that, in 2002, 4,900 new colorectal cancer cases will be diagnosed in New Jersey (1).

**Mortality.** Mortality from colorectal cancer comprises approximately 12% of all cancer deaths in New Jersey (5). According to the colorectal cancer mortality rates from the National Center for Health Statistics, rates for New Jersey males (all races combined) decreased from 33.2 per 100,000\*\* in 1995 to 28.4 per 100,000\*\* in 1999 (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 22.2 per 100,000\*\* in 1995 to 20.1 per 100,000\*\* in 1999 (Figure 2). This decrease was evident in both white females and black females in New Jersey. The American Cancer Society estimates that, in 2002, there will be 1,900 deaths in New Jersey due to colorectal cancer (1).

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\*Incidence rates for the year 2000 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.



**Screening.** While the incidence of colorectal cancer overall is decreasing in New Jersey, cancers of the proximal colon (including the cecum, ascending colon, hepatic flexure, transverse colon, and splenic flexure) are on the rise. Only about 30% of these cases are diagnosed in the early stages when treatment is most effective (6). For this reason, screening and early detection are important factors in decreasing incidence and mortality from colorectal cancer.

Several methods are currently in use to screen for colorectal cancer: digital rectal exam (DRE), fecal occult blood test (FOBT), flexible sigmoidoscopy (flex sig) 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 59% (6). 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 colon (7;8). The colonoscopy, however, has higher sensitivity than the DCBE; it has been shown to detect new cancers by up to 66% (9). New screening tests on the horizon include virtual colonoscopy, immunochemical testing, and genetic-based fecal screening (1). See table below for a summary of current colorectal cancer screening options.

**Centers for Disease Control and Prevention**  
**Current Colorectal Cancer Screening Guidelines**  
**For Average Risk Individuals Over Age 50\* (1;7;9)**

Test Type	General Frequency**	Benefits	Limitations***
Fecal Occult Blood Test	Every Year	<ul style="list-style-type: none"> <li>• 33% mortality reduction</li> <li>• Low cost</li> <li>• No bowel preparation</li> </ul>	<ul style="list-style-type: none"> <li>• Performed at home and subject to patient error</li> <li>• Not specific for colorectal cancers</li> <li>• Pre-test dietary restrictions</li> <li>• Will miss some polyps</li> <li>• Additional procedures needed if positive</li> </ul>
Flexible Sigmoidoscopy	5 years	<ul style="list-style-type: none"> <li>• 60% mortality reduction from distal colon/rectal cancers</li> <li>• Minimal preparation/discomfort</li> </ul>	<ul style="list-style-type: none"> <li>• No reduction in deaths from proximal colon cancers</li> <li>• Views approx. 1/3 of colon</li> <li>• Small risk of infection or bowel tear</li> <li>• Additional procedures needed if positive</li> </ul>
Colonoscopy	10 years	<ul style="list-style-type: none"> <li>• Provides view of entire colon</li> <li>• 66% reduction of new cancers.</li> <li>• Most accurate test for detecting polyps</li> <li>• Can biopsy and remove polyps</li> <li>• Can diagnose other disease</li> </ul>	<ul style="list-style-type: none"> <li>• Can miss small polyps</li> <li>• Sedation needed</li> <li>• Not recommended for patients with advanced age</li> <li>• Subject to provider capability</li> <li>• Potential risk of infection or bowel tears</li> </ul>
Double Contrast Barium Enema	5-10 years	<ul style="list-style-type: none"> <li>• Provides view of the entire colon</li> <li>• Few complications</li> <li>• No sedation needed</li> </ul>	<ul style="list-style-type: none"> <li>• Can miss small polyps</li> <li>• Lower sensitivity to detecting polyps than colonoscopy</li> <li>• Full bowel preparation needed</li> <li>• Additional procedures needed if positive</li> </ul>

\*For average risk individuals. Individuals with increased or high risk should begin screening before age 50. See the Appendix F for more information.

\*\*Suggested frequencies vary and may change as new information becomes available. See the Appendix F for a list of screening guideline resources. Patients should consult a physician to determine the best screening program to meet their needs.

\*\*\*Information on the limitations of screening tests are from both the Centers for Disease Control and Prevention (9) 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 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 (7).

**Percent of New Jersey Residents Age 50 and Over  
Who have had Colorectal Cancer Screening  
New Jersey versus U.S. by Gender, 1997 and 1999\***

TYPE OF SCREENING	PERCENT OF MALES				PERCENT OF FEMALES			
	1997		1999		1997		1999	
	N.J.	U.S.	N.J.	U.S.	N.J.	U.S.	N.J.	U.S.
Ever had a blood stool test from a home kit?	24.8	27.1	29.3	26.6	32.1	34.1	37.3	35.2
Had a blood stool test from a home kit in the past year?	65.3	47.3	60.5	47.4	56.1	45.9	57.0	47.0
Ever had a sigmoidoscopy/colonoscopy?	34.7	34.6	37.2	-	28.8	30.4	32.0	-
Had sigmoidoscopy/colonoscopy in the past 5 years?	39.3	35.1	21.8	-	27.0	26.8	22.9	-

\*Data are from a sample of people surveyed through the Behavioral Risk Factor Surveillance System, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. U.S. sigmoidoscopy/colonoscopy screening data are not available for 1999.

Below is the Healthy New Jersey 2010 goal relating to colorectal cancer.

**Healthy New Jersey Goal: Reduce the age-adjusted death rate from colorectal cancer per 100, 000 standard population\* to: 10.0 for the total population (age-adjusted), 10.0 for whites (age-adjusted), 14.0 for blacks (age-adjusted) and 122.7 for persons 65+, by 2010.**

**Table 3. Baseline data and projected target rates  
to reduce the death rate from colorectal cancer**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	12.4	10.0	-19.4	7.0	-43.5
White age-adjusted	12.2	10.0	-18.0	7.0	-42.6
Black age-adjusted	16.3	14.0	-14.1	7.0	-57.1
Asian/Pacific Islander age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#
Persons 65+	143	122.7	-14.2	80.0	-44.1

\*Data are statistically unreliable.

Source: Healthy New Jersey 2010

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 topic areas in priority order:

- Awareness and Education
- Treatment

## GOALS, OBJECTIVES AND STRATEGIES

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### 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 second highest rate for females. The mortality rates show a similar trend (1). Yet despite these statistics, colorectal cancer has not received the attention breast and prostate cancers have.

Colorectal cancers account for approximately 11% of all cancer deaths resulting in 785,000 person years of life lost and costing \$6 billion annually in treatment (10). Without preventive intervention, about 5% to 6% of the population (or 1 in 17 persons) will develop colorectal cancer at some point during their lives (10). The vast majority of colorectal cancers are diagnosed in those over age 50, and men and women are equally affected. Blacks are more likely than other racial and ethnic groups to contract colorectal cancer. While some groups are at increased risk for the disease (such as those with inflammatory bowel disease or certain familial syndromes), most cases develop in individuals with no predisposing risk factors.

It is well established that early detection of cancer through screening tests offers significantly improved chances for survival. 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., minorities, the uninsured, and the medically underserved) contributes to higher colorectal cancer mortality in these populations (10-12).

Strong evidence indicates that screening is an effective tool in reducing the incidence and mortality rates of colorectal cancers. In fact, incidence and mortality rates declined 1.6% and 1.8%, respectively, between the years 1985 and 1997 (2). Research suggests that the decline may be due to increased screening and polyp removal preventing progression of polyps to invasive cancers (2;10;12). However, while colorectal cancer screening increased over the past decade, it still lags behind the use of mammography and Pap smear as screening tools (3;11). In the Centers for Disease Control and Prevention's 1999 Behavioral Risk Factor Surveillance System (BRFSS) survey, only 26.1% of New Jersey respondents reported having had a recent FOBT (within the last year) and 35.3% reported having had a recent sigmoidoscopy or colonoscopy (within the preceding five years). These percentages are in stark contrast to the 66.8% of women who reported a mammogram in the last year.

Colorectal cancer has received relatively little publicity, even though it has a well-defined, identifiable, and treatable precursor lesion (13). Cancer screening rates continue to be low among minorities and 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 (2;3;10;12). Blacks and other minority groups are more likely to be diagnosed with more advanced colorectal cancer than their white counterparts (12). 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 (2;3;14). 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.

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. Approximately 70% to 80% of all colorectal cancers occur among people at “average risk” (defined as anyone without an identifiable risk factor), and 15% to 20% occur among those with “increased risk” or “high risk” (2;3;10). 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 (2). 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 educational initiatives must be part of a complete and comprehensive prevention program that integrates age-related screening with the promotion of healthy lifestyles.

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. Most also report that their doctors do not talk to them about colorectal cancer or their screening options. 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.

Evidence suggests that when a screening recommendation comes directly from the clinician, compliance with colorectal cancer screening can be quite high (2;3;10;11;13). 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 only 37% of incident cases are diagnosed while still localized (2;13;14) and disparities among racial and ethnic minorities continue to be of concern. To alleviate this public health burden, a commitment to preventive screening among healthcare professionals 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 (2;3;10-12). At this time, economic and healthcare system disincentives to screening are impinging on the choices available to physicians and patients. 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 (2). To achieve this requires commitment and collaboration among healthcare providers, insurance companies, and regulatory agencies.

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 PSA 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 (11;15). 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.

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 targeting and reaching multiple

audiences – including those at increased risk, minorities, and other underserved audiences – with messages that encourage specific behavior change. 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 for the public, for the payers, as well as for healthcare professionals, must be employed to open and facilitate dialogue between patients and their healthcare providers in order to increase the usage of colorectal cancer screening tests and to 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 age 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 of 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.
- (CO-1.2.4) Partner with NJCEED to educate and change behaviors of target populations regarding measures available for prevention, detection, and treatment of colorectal cancer.

**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) Assess the knowledge, attitudes, and practices of healthcare providers regarding colorectal cancer screening through a statewide survey.
- (CO-1.3.2) Recommend healthcare professional societies educate their members based on identified gaps regarding screening for colorectal cancer.
- (CO-1.3.3) Collaborate with insurers to provide appropriate patient educational materials regarding colorectal cancer screening.

## TREATMENT

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 (16). 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 in two ways: (1) by accrediting cancer programs using the American College of Surgeons (ACoS) Commission on Cancer guidelines and (2) by increasing the number of patients enrolled in clinical trials.

Meeting the ACoS Commission on Cancer criteria for an approved cancer program will allow centers to demonstrate their expertise in treating colorectal cancer, help identify disparities in treatment, and facilitate improvement in the care of persons with colorectal cancer. The ACoS Commission on Cancer is dedicated to establishing standards for cancer programs and evaluating and accrediting programs according to those standards. Each approved program provides all patients with a full range of diagnostic, treatment, and supportive services either on site at the facility or by referral. Cancer

programs must improve the quality of patient care by implementing multidisciplinary cancer programs that cover prevention, early diagnosis, pretreatment evaluation, staging, optimal treatment, rehabilitation, surveillance, psychosocial support, and end-of-life care (17). The ACoS collaborates with many different organizations to assure that high-quality prognostic standards are used for cancer management (18).

No published studies have evaluated the effectiveness of ACoS “Approved Cancer Programs” as compared to programs in hospitals whose cancer programs are not approved. However, no other entity exists that provides an extensive set of guidelines against which centers of excellence can be gauged. Nevertheless, 1,400 U.S. cancer programs are accredited by ACoS, and nearly 82% of newly diagnosed patients with cancer are treated in programs accredited by the Commission on Cancer. According to the American College of Surgeons, in 2002, New Jersey has 53 institutions already providing patients with ACoS-approved programs.

One method employed by ACoS to improve patient care is through maintaining the National Cancer Data Base (NCDB), the empirical data collection arm of the ACoS Commission on Cancer supported by the American Cancer Society. The NCDB

collects information about cancer patients through hospital-based cancer registries throughout the U.S. Data are aggregated and reported back to participating hospitals to allow individual facilities to evaluate local patient care practices and outcomes (19). The NCDB has also promoted recognition of important trends, such as the utility of adjuvant therapy for Stage III colon cancer (20).

In addition to increasing the number of ACoS-approved programs, high-quality treatment for colorectal cancer in New Jersey can be promoted through support of 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 (21). 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 (22).

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.

#### **GOAL CO-2:**

**To ensure that all those with colorectal cancer receive care from healthcare providers and hospitals with demonstrated proficiency in treatment of colorectal cancer.**

#### **Objective CO-2.1:**

To ensure that hospitals that treat cancer patients in New Jersey will have an American College of Surgeons approved cancer program by 2005.

**Strategy:**

- (CO-2.1.1) Recommend that the New Jersey Department of Health and Senior Services develop licensing regulations that mandate American College of Surgeons Commission on Cancer-approved cancer programs in all New Jersey acute care facilities.

**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.

**Strategy:**

- (CO-3.1.1) Develop an educational program to promote participation in and enhance public visibility and understanding of important clinical trials for colorectal cancer.

**Objective CO-3.2:**

To ensure access to participation in clinical trials for residents with colorectal cancer.

**Strategy:**

- (CO-3.2.1) Expand the number of insurers who offer clinical trial participation.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: CO-1.2.4; CO-2.1.1

New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection (NJCEED): CO-1.1.1; CO-1.1.2; CO-1.2.2; CO-1.2.3; CO-1.2.4; CO-1.3.2

## COLORECTAL

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Raise awareness	1.1: Target specific educational efforts for subpopulations	CO-1.1.1						
		CO-1.1.2						
	1.2: Increase knowledge and change behaviors of the public	CO-1.2.1						
		CO-1.2.2						
		CO-1.2.3						
		CO-1.2.4						
	1.3: Increase knowledge and change behaviors of healthcare providers	CO-1.3.1						
		CO-1.3.2						
		CO-1.3.3						
2: Ensure treatment by healthcare providers with demonstrated proficiency	2.1: Ensure ACoS-approved cancer programs in hospitals	CO-2.1.1						
3: Increase participation in clinical trials	3.1: Increase awareness of clinical trials	CO-3.1.1						
	3.2: Ensure access to participation in clinical trials	CO-3.2.1						

Target Completion Date

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## CHAPTER 9. 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 death among women since 1987, when it surpassed breast cancer (1;2). Smoking is by far the leading risk factor for lung cancer, and the most effective way to reduce lung cancer morbidity and mortality is to reduce tobacco use. Tobacco smoking is responsible for 87% (almost 9 out of 10) cases of lung cancer (1).

Smoking is the single most preventable cause of death and disease. 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 \$157 billion and 440,000 premature deaths each year (3). Entering tobacco dependence treatment is among the most cost-effective health measures second only to immunization. Overall, smoking is responsible for more than 13,000 deaths annually in New Jersey alone. Annual tobacco-related healthcare costs in New Jersey are \$2.6 billion (4).

Early detection is necessary if we are to decrease mortality from lung cancer. Currently, however, there is no recommended screening or early detection method for lung cancer. New treatment approaches and early treatment for lung cancer are needed to reduce mortality, increase survival, and improve quality of life. When appropriate, physicians in New Jersey should promote participation in

clinical trials for their patients at high risk for lung cancer and for those who have been diagnosed with lung cancer.

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) (5). New Jersey must also address existing lung cancer morbidity and mortality disparities by race and gender, especially for black men, through funded research.

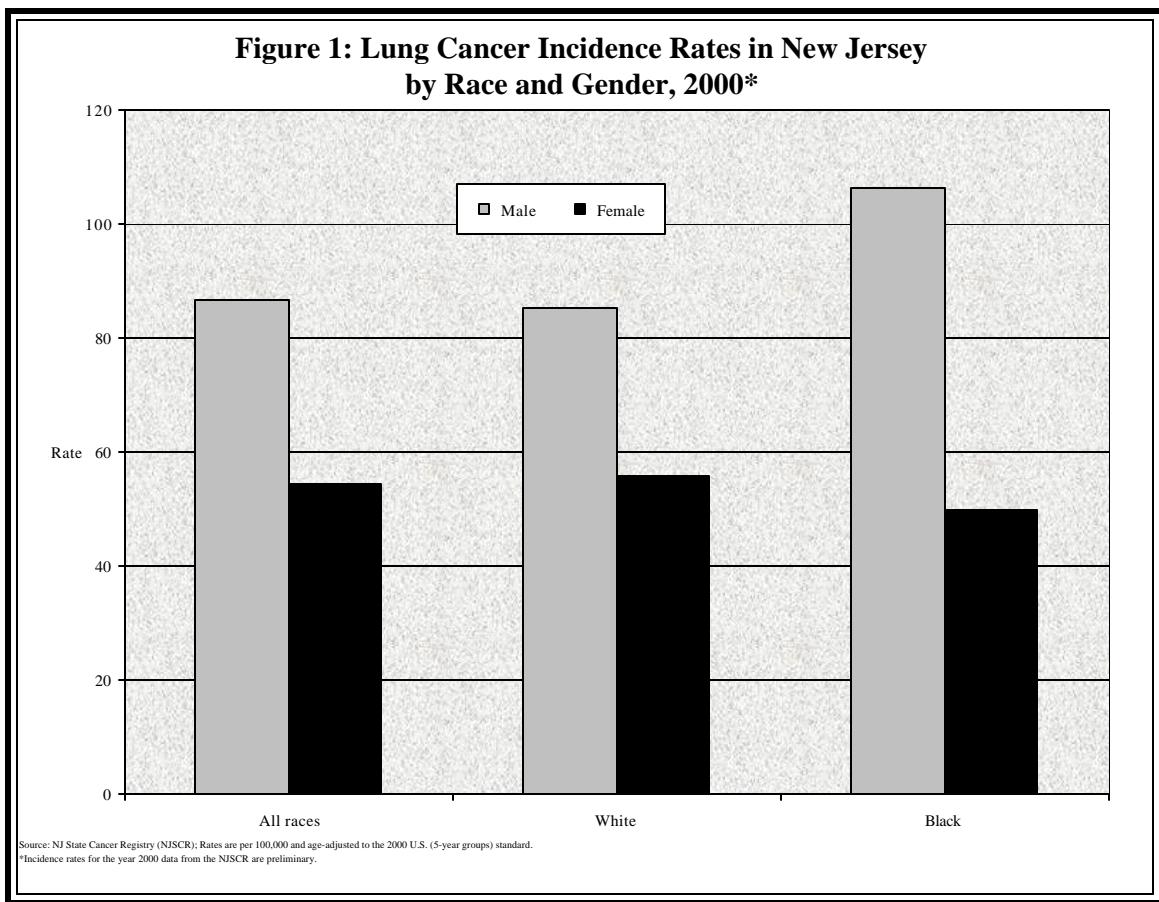
### LUNG CANCER IN NEW JERSEY

**Incidence.** Lung cancer is the second most common cancer in the U.S. and in New Jersey, accounting for about 13% of all cancer diagnoses. Reflecting the national trend of decreasing lung cancer incidence among men, New Jersey has seen a decreasing trend in incidence since late 1980s. Female lung cancer incidence rates have been rising in New Jersey and the U.S. While lung cancer incidence rates for white females in New Jersey are slightly higher than those among black females (55.7 versus 49.8 per 100,000\*\* in 2000\*), the incidence rates for black males in New Jersey are substantially higher than for white males (106.3 versus 85.3 per 100,000\*\* in 2000\*) (Figure 1). In 2002 the American Cancer Society estimates that only 4,900 new lung cancer cases will be diagnosed in New Jersey compared to about 6,200 diagnosed in New Jersey in 1998, again reflecting the national trend in decreasing lung cancer incidence (1).

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\*Incidence rates for the year 2000 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.

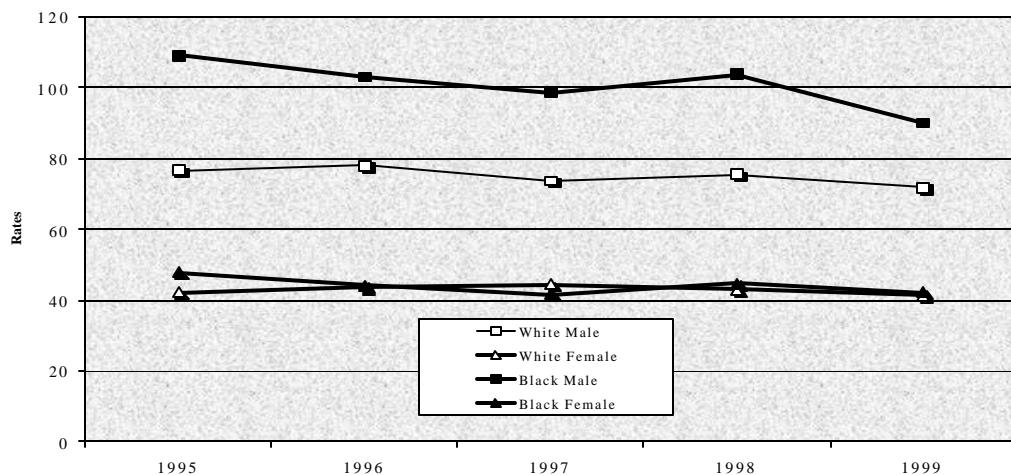


**Mortality.** Lung cancer is the most common cause of Lung cancer is the most common cause of cancer death in the U.S. and in New Jersey, accounting for about 28% of all cancer deaths. U.S. mortality rates from the National Center for Health Statistics revealed that lung cancer among men (all races combined) has decreased from 84.5 per 100,000\*\* in 1995 to 77.2 per 100,000\*\* in 1999. For New Jersey females, mortality rates during the same time period remained

relatively stable. For the years 1995 through 1999, black males in New Jersey have the highest mortality rate, followed by white males. Both white and black females in New Jersey during the same years were similar (Figure 2). The American Cancer Society estimates that, in 2002, 4,500 new lung cancer deaths will occur in New Jersey compared to about 4,800 deaths that occurred in 1998, representing a very small change (1).

\*\*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, 1995-1999**



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

Below is the Healthy New Jersey 2010 goal relating to lung cancer.

**Healthy New Jersey Goal: Reduce the age-adjusted death rate from lung cancer per 100,000 standard population to target below, by 2010.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	35.2	28.5	-19.0	25.0	-29.0
White age-adjusted	35.0	28.5	-18.6	25.0	-28.6
Black age-adjusted	43.8	31.6	-27.9	25.0	-42.9
Asian/Pacific Islander age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#
Male age-adjusted	46.4	29.0	-37.5	25.0	-46.1
Female age-adjusted	26.6	25.5	-4.1	25.0	-6.0
Persons 65+	322.1	296.9	-7.8	274.7	-14.7

#Data are statistically unreliable.

Source: Healthy New Jersey 2010

In support of the Healthy New Jersey 2010 goal for lung cancer, the recommendations of the Lung Cancer Workgroup are summarized below for the following four topic areas in priority order:

- Tobacco Control
- Provider Education
- Early Detection and Treatment
- Research

## GOALS, OBJECTIVES AND STRATEGIES

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### TOBACCO CONTROL

The major intervention in the prevention of lung cancer is tobacco control. The most effective approach 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 (6;7). Tobacco control programs in New Jersey should build on an existing activity, the New Jersey Comprehensive Tobacco Control Program (8-11).

Other issues surrounding Tobacco Control include:

- Targeting racial, gender, and cultural disparities
- Reducing exposure to Environmental Tobacco Smoke (ETS)
- Educating healthcare providers and insurers

- Access to and funding for smoking cessation
- Promoting public information/support
- Active advocacy for smoke-free environments
- Countermarketing to tobacco industry marketing and promotional activities (8)

For each of these issues, the Comprehensive Tobacco Control Program has identified specific problems and specific strategies for overcoming them. For example, relating to provider education, the literature clearly shows that, although we now have clear guidelines for the treatment of tobacco dependence, the implementation and execution of these by providers has been less than optimal. The next step is to look at implementation barriers and facilitate provider actions to achieve the desired practices.

#### 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 (10)

#### 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 (CDC).

### 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) Support an increase in the state tobacco excise tax.
- (LU-1.1.3) Support giving local governments authority to regulate public smoking by repealing existing state statutes that pre-empt such authority.
- (LU-1.1.4) Increase the awareness of state-sponsored tobacco treatment resources in communities.

## PROVIDER EDUCATION

One of the most important advancements in tobacco dependence treatment has been the recent update of the Public Health Service Guidelines for Treating Tobacco Use and Dependence (henceforth referred to as the PHS Guidelines) (12). Now that these guidelines exist, the next challenge is to persuade healthcare providers to implement the recommendations in their respective practices. The 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.

The importance of enlisting healthcare providers in tobacco-related treatment has been demonstrated in several ways. It is reported that 70% of smokers visit a healthcare provider each year (13), and smokers visit their doctor on average six times per year (14), 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 of the dangers they are risking (15). 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 (16). Reviews show that clinician advice to quit alone can cause a 2.5% increase in cessation rates (17). Although this percentage may seem small, 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 it is 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.

There is good evidence that healthcare providers are not fully aware of recommendations published by experts in the tobacco arena. The National Cancer Institute's "4 A's: Ask, Advise, Assist, Arrange" Strategy for physician counseling was published in 1994, and in 1996, the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and

Quality) released evidence-based clinical practice guidelines for physician practices. Despite these clear recommendations, studies have shown that several years later these basic recommendations are not universally executed. In one study examining patient report, 51% of smokers were “asked” about their smoking, 45% were “advised” to quit, 15% were offered help (“assisted”), and only 3% had follow-up “arranged” (18). In another study looking at physician practices in the 1990s, smoking status (ask) was identified in 67% of visits, counseling of smokers occurred in only 21% of visits, and prescription of nicotine replacement therapy occurred in only 1.3% of visits (19). In New Jersey, two out of three adults and one-half of youth reported being asked their smoking status by their clinician, and more than one-half of adult smokers were advised to quit (8). Nearly one-half of current smokers were not given specific advice to stop. Providers are not meeting the recommended levels of tobacco treatment. Now that we have another updated, evidence-based guideline, we need to improve providers’ utilization of the guidelines in order to prevent lost opportunities.

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 intense the intervention and

the more resources utilized the higher the rates of success (12). 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. Unfortunately, these specialized resources suffer the same drawbacks as the Guidelines; if providers are unaware of them, they cannot refer smokers to them. Therefore, for all of the reasons outlined above, a concerted effort must be made to inform providers of the resources available for specialty referral. We must first establish how providers can best be reached and informed, and then interventions must be implemented to disseminate the information. Only in this way can the state’s efforts at reducing tobacco use be fully realized.

In terms of reducing barriers for tobacco dependence treatment, Healthy People 2010 includes an objective to “increase insurance coverage of evidence-based treatment for nicotine dependency” (20). 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 dependence 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 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 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 for 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.

**Strategy:**

- (LU-2.3.1) Advocate for third-party payer reimbursement of tobacco dependency treatment.

## **EARLY DETECTION AND TREATMENT**

According to 2002 estimates, lung cancer remains the number one 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 1997 (21). Despite poor survival in general, five-year survival for resected Stage I lung cancers can be as high as 40% to 70%, although only 15% of lung cancers are localized at the time of diagnosis. Advanced 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 (22).

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 (23). Any significant change in the stage distribution at presentation offers the possibility of a profound impact on cancer death rates, given the prevalence of lung cancer. During the 1970s, the National Cancer Institute (NCI) 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 (24;25).

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 (CT) scan (26). Low dose CT 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 (27).

Recent trials in Japan and in the United States, the Early Lung Cancer Action Project (ELCAP), compared low dose spiral CT with chest x-ray (CXR) and found that the CT was able to detect early stage tumors six times more often (27). These promising results have become the basis for broader randomized trials using low dose CT scanning with lung cancer mortality as an end point. Before spiral CT is accepted into medical practice, it is critical to determine whether this modality will reduce lung cancer mortality. Toward this goal, the National Cancer Institute is implementing the Lung Screening Study (24).

The second issue identified by the Lung Cancer Workgroup was detection and treatment that would ensure adequate access to state-of-the-art and investigational therapy for all New Jerseyans. This issue also included a compassionate outreach effort through psychosocial support, education, and other modalities to promote improved quality of life for those diagnosed with lung cancer and their caregivers. There is a dire need to make a clinical impact on lung cancer through new strategies for treatment of established disease, earlier treatment intervention and prevention, as well as to ensure that best practices for the management of lung cancer are adopted and appropriately applied across the state. Because of the need to make therapeutic progress against this disease, it is important that models of care optimize the delivery of best-known clinical practice. It is also important to determine the effects of these models on the processes and outcomes of care and on accrual of patients to clinical trials (28).

**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 NCI'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) Promote efforts to have the screening tests covered by health insurers and third-party payers.
- (LU-3.1.4) Promote the State of New Jersey's participation in a national trial for determining the effectiveness of spiral CT.

**GOAL LU-4:**

**To increase survival, decrease mortality, and improve quality of life through early detection and treatment of lung cancer.**

**Objective LU-4.1:**

To develop Centers of Excellence throughout the state for early detection and treatment of lung cancer.

**Strategy:**

- (LU-4.1.1) Advocate for Centers of Excellence throughout the state for early detection and treatment of lung cancer.

## RESEARCH

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, further research is needed to develop more effective measures for tobacco control and early detection.

In 2000 the NCI estimates that it will spend only \$950 for research per lung cancer death compared to \$8,860 per breast cancer death, \$3,667 per prostate cancer death, and \$3,192 per colon cancer death (29). The need for increased funding for lung cancer research is apparent.

As discussed previously, many early detection methods are still in the research stage. We should encourage New Jersey residents 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.

### **GOAL LU-5:**

**To increase accrual and broaden access to lung cancer clinical early detection and treatment trials 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.

The percentage of adults and children with cancer who participated in NCI Cooperative Group trials from 1991-1994 was 2.5% (30). A requirement for every American College of Surgeons-certified oncology program is that 2% of the patient population be enrolled in clinical trials (31). These numbers should be increased, especially concerning lung cancer early detection trials.

Of those with lung cancer, a majority is diagnosed in late-stage disease. Currently, the goal of standard therapy for Stage IV lung cancer is palliation of symptoms and prolongation of survival, 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:

- Lobby 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

**Strategy:**

- (LU-5.1.1) Develop educational programs to promote participation and enhance public visibility and understanding of important lung cancer clinical trials.

**GOAL LU-6:**

**To increase research activities for establishing reliable methods for the early detection of lung cancer and precancerous lesions.**

**Objective LU-6.1:**

To promote research on early detection of lung cancer and precancerous lesions.

**Strategies:**

- (LU-6.1.1) Assess the current numbers of studies and the total in the area of early detection of lung cancer and precancerous lesions.
- (LU-6.1.2) Support existing research projects and fund additional pilot projects for early detection of lung cancer and precancerous lesions.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

Cancer Institute of New Jersey: LU-3.1.1; LU-3.1.4; LU-4.1.1; LU-5.1.1; LU-6.1.1; LU-6.1.2

Communities Against Tobacco Coalitions: LU-1.1.1; LU-1.1.3; LU-1.1.4

New Jersey Breathes Coalition: LU-1.1.1; LU-1.1.2; LU-1.1.4

New Jersey Department of Health and Senior Services, Division of Addiction Services: LU-1.1.1; LU-1.1.4; LU-2.1.1; LU-2.2.1; LU-2.2.1; LU-2.2.2

New Jersey QuitCenters: LU-1.1.4

University of Medicine and Dentistry of New Jersey/School of Public Health, Tobacco Dependence Treatment Program: LU-2.1.1; LU-2.1.1; LU-2.2.1; LU-2.2.2; LU-3.1.2; LU-3.1.3

## LUNG

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Adopt goals of the Comprehensive Tobacco Control Program (CTSP)	1.1: Support long-term goals of CTSP	LU-1.1.1 LU-1.1.2 LU-1.1.3 LU-1.1.4						
2. Increase provider utilization of tobacco dependency treatment guidelines	2.1: Increase provider knowledge of standards of care 2.2: Increase provider knowledge of resources 2.3: Reduce barriers for insurance providers	LU-2.1.1 LU-2.1.2 LU-2.2.1 LU-2.2.2 LU-2.3.1						
3: Increase earlier stage lung cancer detection	3.1: Monitor effective screening methods	LU-3.1.1 LU-3.1.2 LU-3.1.3 LU-3.1.4						
4: Improve quality of life through early detection and treatment	4.1: Develop Centers of Excellence	LU-4.1.1						
5: Increase clinical trials	5.1: Support NCI's Clinical Trial Implementation Goals	LU-5.1.1						
6: Increase research activities	6.1: Promote research	LU-6.1.1 LU-6.1.2						

**Target Completion Date**

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## CHAPTER 10. Melanoma

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## MELANOMA

### IMPORTANCE OF MELANOMA 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 persons with a nonmelanoma skin cancer are at higher risk for developing additional skin cancers (1-3). Melanoma of the skin<sup>§</sup> 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;4). It should be noted that nonmelanoma skin cancers are also important and should not be neglected. Many of the recommendations offered in this report 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 annually (4) at a rapid pace. In the United States alone, the lifetime risk for developing cutaneous melanoma is approximately 1 in 80 persons, an almost 200% increase in incidence since 1930. Persons born prior to 1930 have experienced the sharpest increases (5). In the U.S., about one-fourth of melanoma patients are diagnosed before age 40 (6). Thus, the years of life lost from cutaneous melanoma are higher than for most other forms of cancer. In 2002, it is estimated that 30,100 new cases of cutaneous malignant melanoma will be diagnosed in males and

23,500 in females (7). Approximately 4,700 men and 2,700 women will die from cutaneous melanoma in 2002 (7). In recent years, melanoma is one of the cancer sites showing the most marked increases nationally (8). The American Cancer Society estimates that, in 2002, melanoma of the skin will be the fifth leading new cancer site in the U.S. for men and the sixth leading new cancer site in the U.S. for women, accounting for 5% and 4% of all cancers, respectively (7).

Exposure to solar ultraviolet radiation (UV light) is well established as a major risk factor for melanoma (9-11). Other risk factors include skin coloring (11;12), geographic location (10;11), sunburn history (9;10;12), and melonocytic nevi (10). 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

**Incidence.** New Jersey cutaneous melanoma incidence rates reflect the national trend of increasing incidence (8). The stage at which melanoma is being diagnosed in New Jersey is improving. In 2000\*, 88% 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 consistently from 1979, peaking at 21.6 per 100,000\*\* in 1997 and decreasing to 18.5 in

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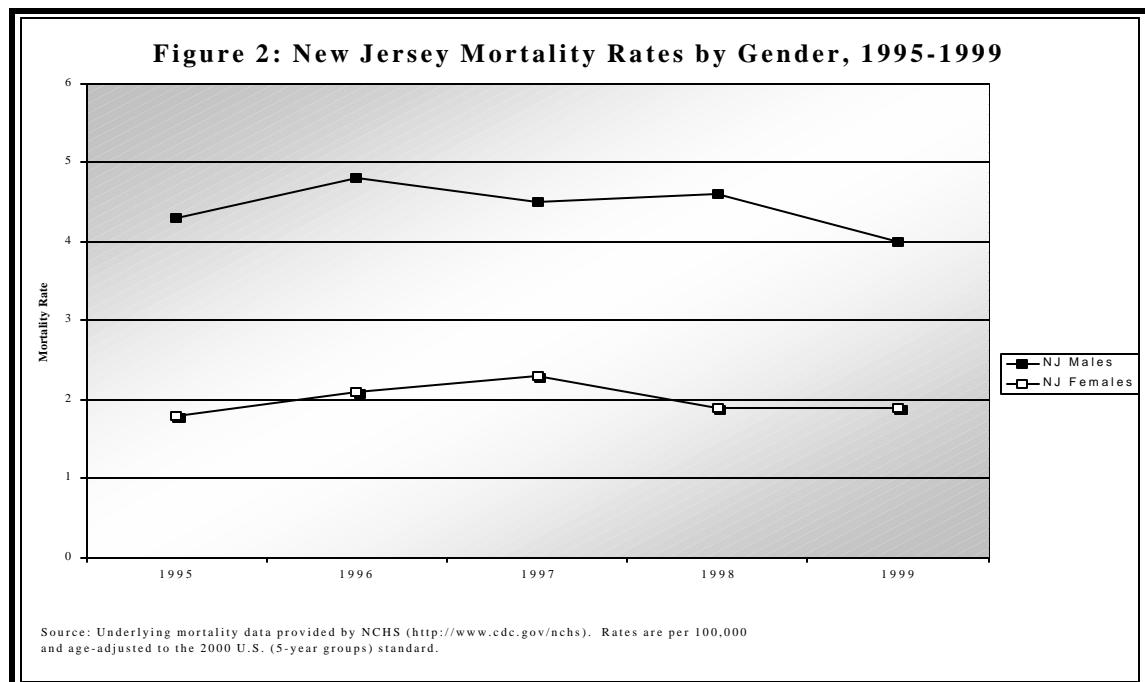
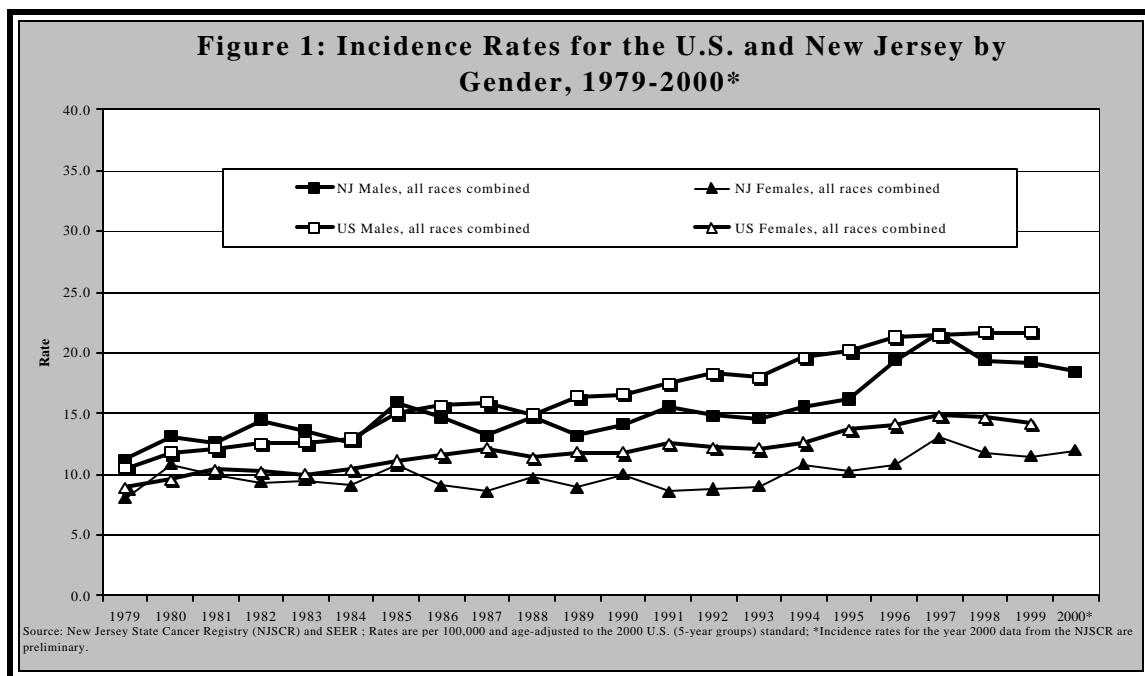
\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

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

<sup>§</sup>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.

2000\* (Figure 1). The American Cancer Society estimates that, in 2002, 1,800 new melanoma cases will be diagnosed in New Jersey (7). Melanoma incidence rates

increase as age increases. The highest rates of melanoma in New Jersey are in males, age 80-84 (incidence rate = 99.8 per 100,000)\*\* for the years 1995-2000\* combined.



\*Incidence rates for the year 2000 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.** Data from the National Center for Health Statistics reveal that cutaneous melanoma mortality rates for New Jersey males and females remained relatively stable between 1995 and 1999 (4.3 in 1995 versus 4.0 per 100,000\*\* in 1999 for males and 1.8 in 1995 versus 1.9 per 100,000\*\* in 1999 for females. This is consistent with rates for the U.S. (Figure 2).

### **Behavioral Risk Factor Surveillance**

**System Data.** According to the stratified estimates from the 1999 New Jersey Behavioral Risk Factor Surveillance System, more males than females (30.6 % compared to 21.7%) answered 'yes' to the question 'Did you have a sunburn in the past 12 months?'

for all ages combined. When broken down by age, the subgroup of 18- to 34-year-olds had the highest percentage of sunburns within the past year (40.2 %).

Cutaneous melanoma is a serious threat in New Jersey in particular, where melanoma incidence rates are the eighth highest in the nation. In New Jersey, approximately 1,800 melanoma cases are estimated to be diagnosed in 2002 (7). 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.

Below is the Healthy New Jersey 2010 goal related to melanoma.

**Healthy New Jersey 2010 Goal: Reduce the age-adjusted incidence rate of invasive melanoma per 100,000 to 7.0 for the total population, 8.0 for whites, and 0.3 for blacks.**

**Table 1. Baseline data and projected target rates to reduce the rate of invasive melanoma.**

<b>Populations</b>	<b>1998 Baseline Data</b>	<b>Target</b>	<b>Percent Change</b>	<b>Preferred 2010 Endpoint</b>	<b>Percent Change</b>
Total age-adjusted	12.4	7.0	-43.5	6.2	-50.0
White age-adjusted	14.5	8.0	-44.8	7.3	-49.7
Black age-adjusted	0.8	0.3	-62.5	0.2	-75.0
Asian/Pacific Islander Age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#

*Source: Healthy New Jersey 2010*

*#Data are statistically unreliable*

In support of the Healthy New Jersey 2010 goal for melanoma cancer, the recommendations of the Melanoma Workgroup are summarized below for the following three topic areas in priority order:

- Awareness
- Education
- Treatment

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

## GOALS, OBJECTIVES AND STRATEGIES

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### 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 (14). These low percentages clearly demonstrate the need to make the public more aware of UV exposure as a risk factor for cutaneous melanoma.

The Centers for Disease Control and Prevention (CDC) is developing several population-based interventions to prevent skin cancer. The national campaign “Choose Your Cover” increases awareness about skin cancer, while also influencing social norms regarding sun protection and tanned skin. Additionally, the CDC has convened the National Council on Skin Cancer Prevention; the Federal Council on Skin Cancer Prevention; and other 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. (For additional information on these programs, please visit the CDC website: [www.cdc.gov/cancer/nsccep/skin.htm](http://www.cdc.gov/cancer/nsccep/skin.htm))

The most common public awareness message is that of the “ABCD’s of Melanoma (15),” which describes suspicious lesions as those that are Asymmetrical, have an irregular Border, have Color variegation, and have a Diameter greater than 6 millimeters.

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, not early warning signs.

Despite these national efforts, New Jersey is still estimated to rank 8<sup>th</sup> in the nation for cutaneous melanoma incidence for 2002 (7). 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 has remained steady from 1994 through 1998 (8). This presents clear evidence that early detection and screening efforts must be improved.

The fact that melanoma is a life-threatening disease must be communicated effectively to the public and to healthcare professionals in order to increase melanoma diagnoses in the early stages and decrease melanoma diagnoses in the late stages. The Melanoma Workgroup recommends the development of awareness campaigns that target early diagnosis. Awareness issues must be addressed on four 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, patients must be made aware of the treatment regimens that are available immediately after diagnosis. Third, 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. Fourth, 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 being 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 that target 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 New Jersey Centers of Excellence for 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.
- (ME-1.1.4) Encourage New Jersey primary healthcare providers to send their patients to New Jersey Centers of Excellence for melanoma and skin cancer care.

#### **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 organizations such as the American Cancer Society.

- (ME-1.2.2) Collaborate with pharmaceutical industries 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.

## EDUCATION

**School-based education.** New Jersey school districts must be committed to the promotion of comprehensive school health education in the form of Kindergarten through 12<sup>th</sup> 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. According to the American Cancer Society Sun Safe Community Project, 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.

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.

Schools can promote sun safety through updated policies and by providing environmental support. School policies may address issues such 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. Many publications have demonstrated a dramatic rise in the proportion of thin melanomas, particularly after educational campaigns. A 600% increase in the diagnosis of in situ melanoma in the United States between 1973 and 1987, although the incidence of invasive melanoma increased by 52% nationally, is additional evidence for the earlier detection of malignant melanoma.

In an ideal world, early detection and excision of premalignant melanoma and thin melanomas would decrease both melanoma incidence and mortality associated with the disease. Berwick et al. has demonstrated that early detection through self-examination could have this effect (16). Berwick's study showed a decrease in the incidence of invasive melanoma associated with self-examination that might be associated with

earlier detection of premalignant skin lesions. Berwick further refers to 3,142 patients analyzed by MacKie, first diagnosed between 1979 and 1993, in a study demonstrating that age-standardized incidence was highest among the most affluent men and women as was five-year disease-free survival, which, in turn, implies that greater access to early detection and medical care reduces the mortality rate of melanoma.

### **GOAL ME-2:**

**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-2.1:**

To include in the curriculum of all public schools, and enhance where necessary, instruction on prevention, detection, and screening of melanoma and other skin cancers. This is supported by New Jersey Statutes, Title 18A:40-32, Cancer Awareness Week and 18A:40-33, Cancer Awareness Program for School-aged Children.

#### **Strategies:**

- (ME-2.1.1) Train representatives from school districts about melanoma and skin cancer prevention, detection, and screening.
- (ME-2.1.2) Implement incentives for training by providing professional development hours or continuing education credits relating to skin cancer.
- (ME-2.1.3) Partner with the American Cancer Society and other healthcare organizations to train appropriate professionals in school districts on proven skin cancer prevention programs, e.g., Sun Safe Communities.
- (ME-2.1.4) Educate parents at PTO/PTA meetings regarding prevention, detection, and screening for melanoma and other skin cancers.

- (ME-2.1.5) 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-2.1.6) 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-3:**

**To increase the proportion of school districts that provide structural sun protection and have sun-safe environmental policies.**

**Objective ME-3.1:**

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.

**Strategies:**

- (ME-3.1.1) Establish a baseline of school districts that have sun-safe policies and encourage improvement of their sun-safe policies where necessary.
- (ME-3.1.2) Build relationships with organizations with programs that can assist the school districts regarding the sun-safe environment, such as local shade tree commissions to provide trees for schools.

**GOAL ME-4:**

**To promote worksite education by employers to employees on prevention, detection, and screening for melanoma and other skin cancers.**

**Objective ME-4.1:**

To partner with employers in providing employee education on prevention, detection, and screening for melanoma and other skin cancers.

**Strategies:**

- (ME-4.1.1) 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-4.1.2) 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-5:**

**To identify champions in the hospitality, recreation, and entertainment industries that provide public education to develop presentations on prevention, detection, and screening for melanoma and other skin cancers.**

**Objective ME-5.1:**

To survey the hospitality, recreation, and entertainment industries regarding their policies of providing public skin cancer education.

**Strategies:**

- (ME-5.1.1) Develop and implement a survey of the hospitality, recreation, and entertainment industries to learn how they educate their customers about proper sun care while visiting or enjoying entertainment at that establishment.
- (ME-5.1.2) Partner with identified industries to develop public education programs on prevention, detection, and screening for melanoma and other skin cancers.

**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

**S**urgery remains the most effective treatment for melanoma. Radiation and chemotherapy have proven ineffective. Interferon is the only FDA-approved treatment for melanoma; however, it is generally used as an adjuvant therapy to surgery.

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 (17). 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 have centered on immunotherapy and bio-therapy (18-28). Both have shown measurable success. Autologous, polyvalent, and peptide vaccines have shown promise at

different disease stages and are being tested in clinical trials throughout the world (29-33).

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 (17). 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 identify New Jersey Centers of Excellence in the diagnosis and treatment of melanoma.

**Strategies:**

- (ME-7.1.1) Determine what criteria will distinguish a Center or Provider as meeting Standards of Excellence for melanoma, whether it is existing criteria established by organizations such as the American College of Surgeons Commission on Cancer or developing new criteria.
- (ME-7.1.2) Promulgate a list of centers and healthcare providers who meet the Standards for Excellence for melanoma for public use, through such measures as a website, addendum to the existing Cancer Resource Guide, and a toll-free telephone number, etc.
- (ME-7.1.3) Provide recognition for those centers and providers meeting the Standards of Excellence for melanoma.
- (ME-7.1.4) Encourage those meeting the Standards of Excellence for melanoma to advertise their accomplishments.

**Objective ME-7.2:**

To develop resource material discussing melanoma treatment options and clinical trial information for patients.

**Strategies:**

- (ME-7.2.1) Promulgate state-of-the-art treatment options as essential considerations in the treatment of melanoma, such as sentinel node biopsy, interferon alpha-2b, and vaccine therapy.
- (ME-7.2.2) Encourage participation in clinical trials for melanoma.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

Melanoma and Skin Cancer Coalition: ME-1.1.1; ME-1.1.2; ME-1.1.3; ME-1.1.4; ME-1.2.1; ME-1.2.2; ME-1.2.3; ME-2.1.1; ME-2.1.2; ME-2.1.3; ME-2.1.4; ME-2.1.5; ME-2.1.6; ME-3.1.1; ME-3.1.2; ME-4.1.1; ME-4.1.2; ME-5.1.1; ME-5.1.2;

ME-6.1.1; ME-6.1.2; ME-7.1.1; ME-7.1.2; ME-7.1.3; ME-7.1.4; ME-7.2.1

New Jersey Department of Health and Senior Services: ME-3.1.1; ME-4.1.1; ME-6.1.1; ME-6.1.2; ME-7.1.1; ME-7.1.2; ME-7.1.3; ME-7.1.4

Schering-Plough: ME-1.1.2; ME-1.1.3; ME-1.2.2; ME-2.1.2; ME-2.1.6; ME-5.1.2

## MELANOMA

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Awareness of diagnosis	1.1: Promote state-of-the-art diagnosis and treatment 1.2: Develop an alliance with businesses and organizations to develop media campaigns	ME-1.1.1						
		ME-1.1.2						
		ME-1.1.3						
		ME-1.1.4						
2: Increase prevention behaviors among youth	2.1: Enhance School Curriculum	ME-1.2.1						
		ME-1.2.2						
		ME-1.2.3						
		ME-2.1.1						
3: Provide structural sun protection and sun-safe environmental policies	3.1: Survey/evaluate policies	ME-2.1.2						
		ME-2.1.3						
		ME-2.1.4						
		ME-2.1.5						
4: Promote worksite education	4.1: Partner with employees	ME-2.1.6						
		ME-3.1.1						
		ME-3.1.2						
		ME-4.1.1						
5: Identify Champions	5.1: Survey public education in the hospitality, recreation and entertainment industries	ME-4.1.2						
		ME-5.1.1						
6: Educate community	6.1: Provide public health education	ME-5.1.2						
		ME-6.1.1						
		ME-6.1.2						
		ME-7.1.1						
7: Treatment	7.1: Identify Centers of Excellence	ME-7.1.2						
		ME-7.1.3						
		ME-7.1.4						
		ME-7.2.1						
	7.2: Develop resource materials	ME-7.2.2						

**Target Completion Date**

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## CHAPTER 11. Oral and Oropharyngeal Cancer

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## ORAL AND OROPHARYNGEAL CANCER

### IMPORTANCE OF ORAL AND OROPHARYNGEAL CANCER FOR CANCER PREVENTION AND CONTROL

**A**t 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 limitations on 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. It is estimated that oral and oropharyngeal cancer will account for up to 31,000 new cancer cases and 8,000 to 9,000 deaths (1-3), representing 2% to 3% of all cancer deaths (1;4;5). Males are approximately twice as likely as females to be diagnosed with and to die from oral and oropharyngeal cancer (3;4;6). Approximately 95% of oral and oropharyngeal cancer cases occur among persons over 45 years of age, and the average age of diagnosis is 60 years (5). Oral and oropharyngeal cancers are the sixth most common cancer among white males and the fourth most common among black males (1;7). From 1974 through 1997, trends in five-year relative cancer survival rates fluctuated around 56% for whites, 35% for blacks, and 54% for all races (3).

More than 90% of oral cancers are squamous cell carcinoma. About 5% are salivary gland malignancies, and smaller percentages are melanomas, sarcomas, and lymphomas. The primary focus of a cancer control program for oral and oropharyngeal cancers must, therefore, be on 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 known risk factors for oral and oropharyngeal squamous cell carcinoma are long-term tobacco use (1;5;7-16) alcohol use (1;5;7-14), immunosuppression (17), use of the betel (areca) quid popular in the Asian population (5;15;16;18) and in the case of lip cancer, long-term sun exposure (1;8-10). Evidence for consumption of fruits and vegetables as a protective factor is contradictory (1;10) and will thus not be addressed in this report. Immunocompetent 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's sarcoma, and non-Hodgkin's lymphoma. Approximately 25% of patients diagnosed with oral and oropharyngeal cancers have none of these risk factors (14). Recent studies indicate that infection with human papillomavirus, particularly genotypes 16 and 18, may represent another independent risk factor (1;7;19;20).

The most significant indicator in predicting survival is stage of disease at time of diagnosis. Cases diagnosed in the early stages have a five-year survival rate of more than 75%, while cases diagnosed in the late

stages have a poor five-year survival rate of less than 25% (7)(11;12). According to National Cancer Institute (NCI) 1995 surveillance data, only one-third of cases are diagnosed in the early stages (5), whereas two-thirds have already spread regionally or have metastasized. For blacks, the statistics are far worse than for the population as a whole – over 80% of oral and oropharyngeal cancers in this segment of the population have regional or distant spread at the time of diagnosis (5).

In a recent study, approximately 81% of dentists said they provided an oral cancer examination for 100% of their patients 40 years of age or older at their initial appointment, and only 78% indicated they provided this examination at recall appointments (1). This study confirmed similar findings in a previous survey (10). It is clear that too few people have regular oral and oropharyngeal cancer examinations and that too few dentists and physicians are performing routine oral and oropharyngeal cancer exams.

A national strategic planning conference was recently held to begin addressing oral and oropharyngeal cancer (5). 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. Maryland was the first state to pilot a state model (10). The goals, objectives, and strategies in this Plan are based on those developed by the national oral cancer group (21).

## ORAL AND OROPHARYNGEAL CANCER IN NEW JERSEY

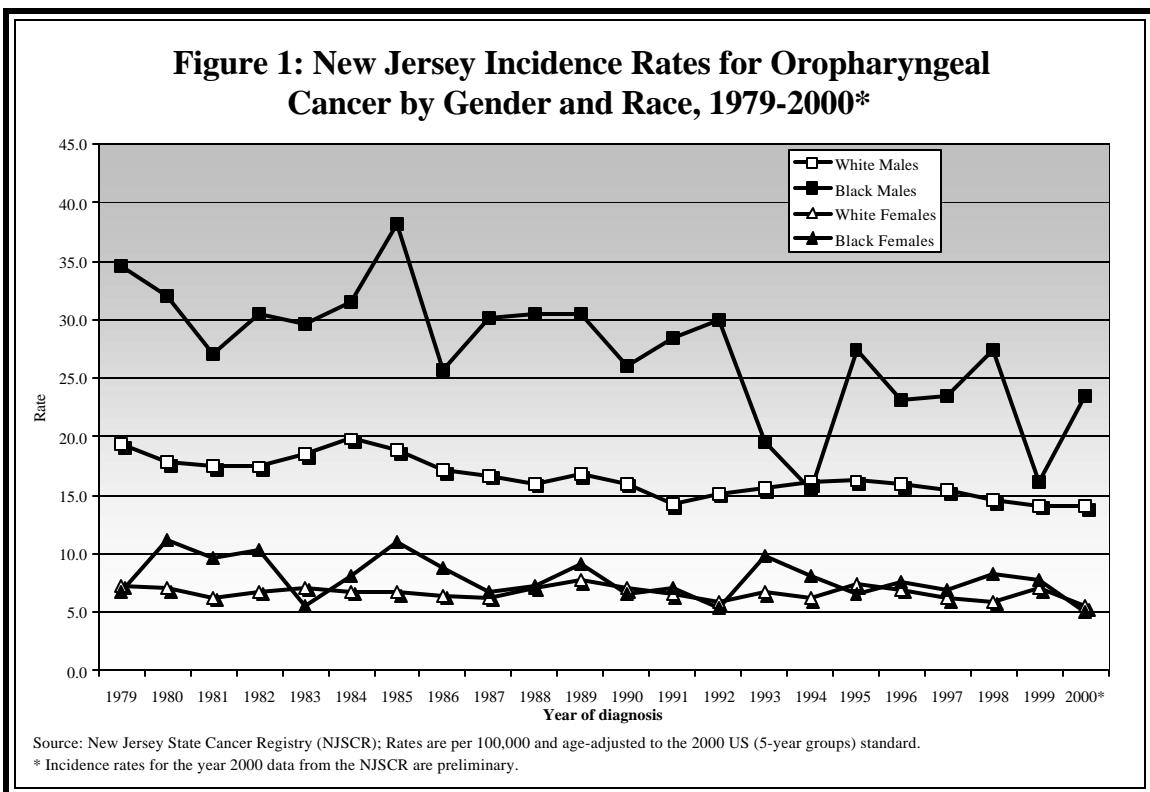
**Incidence.** New Jersey mirrors the national average for oral and oropharyngeal cancer incidence. Since the mid-1980s, New Jersey and US incidence rates for oropharyngeal cancer have been declining. For New Jersey males, incidence rates are higher among blacks than whites. In 2000\*, the incidence rate for black males was 23.5 per 100,000\*\* compared to 14.0 per 100,000\*\* for white males. Males have traditionally had higher incidence rates than females in New Jersey, although in recent years the gap is narrowing due to the increasing number of women who began smoking over the past three decades (Figure 1). Incidence rates for females in New Jersey have generally been similar among races. In 2000\*, black females had an incidence rate of 5.1 per 100,000\*\* compared to 5.5 per 100,000\*\* for white females (Figure 1).

For all stages combined, the five-year relative survival rate for oral and oropharyngeal cancer is 53% (22). With early detection, survival rates are considerably higher. The five-year survival rate for oral and oropharyngeal cancer diagnosed with localized disease is 81% (22). In 2000\*, approximately 54% of those with oral and oropharyngeal cancer were diagnosed in the late stages according to the New Jersey State Cancer Registry. Dentists and primary care physicians can recognize abnormal tissue changes and detect cancer at earlier stages during regular checkups.

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\*Incidence rates for year 2000 data from the New Jersey State Cancer Registry are preliminary.

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



In a study of New Jersey patients with AIDS, approximately 6% also had a cancer. Of these, 50% had Kaposi's 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 (17).

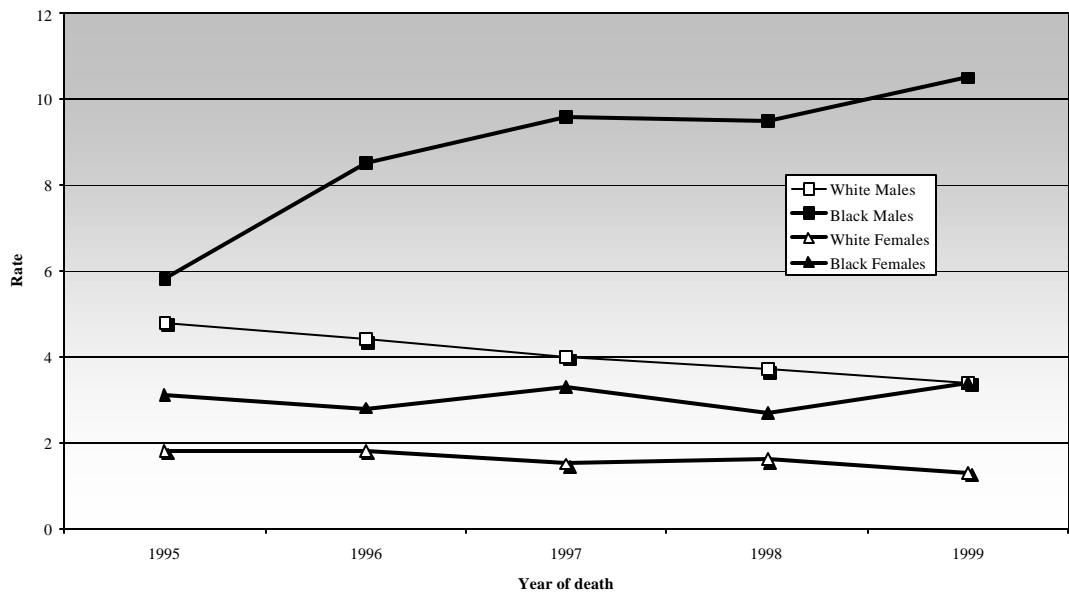
**Mortality.** Overall, oral and oropharyngeal cancer deaths in New Jersey mirror the decrease seen in the U.S. In 1999, New

Jersey males (all races combined) had a mortality rate of 4.0 per 100,000\*\* and New Jersey females had a mortality rate of 1.5 per 100,000\*\*. However, mortality rates differ dramatically by race. Mortality rates for New Jersey black males increased from 5.8 per 100,000\*\* in 1995 to 10.5 per 100,000\*\* in 1999; mortality rates for white males declined consistently from 4.8 per 100,000\*\* in 1995 to 3.4 per 100,000\*\* in 1999 (Figure 2). The mortality rates for females in New Jersey remained relatively stable between 1995 and 1999 (Figure 2).

\*Incidence rates for year 2000 data from the New Jersey State Cancer Registry are preliminary.

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

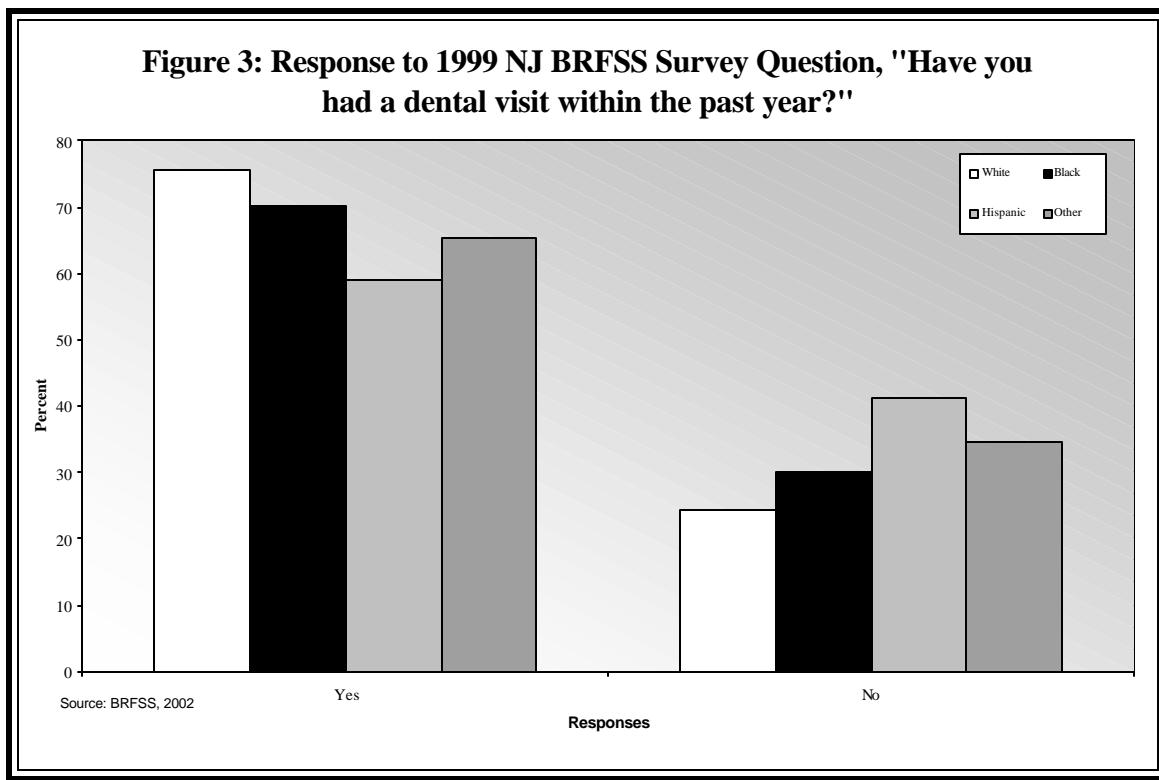
**Figure 2: New Jersey Mortality Rates for Oropharyngeal Cancer by Race and Gender, 1995-1999**



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

According to the 1999 Behavioral Risk Factor Surveillance System (BRFSS), 72.3% of New Jersey residents visited a dentist or dental clinic in 1999. Since a majority of residents are already visiting dentists, an opportunity exists to increase the number of routine oral cancer examinations in this setting. No differences are observed for gender or age, and dental visits are positively

associated with education and income level. When these data are analyzed by race, a disparity in dental care in New Jersey becomes evident (Figure 3). Among respondents who answered ‘no’ to the question, “Have you had a dental visit within the past year?”, 24.4 % were white, 29.9% were black, 41.1% were Hispanic and 34.7% were ‘Other’.



To target oral and oropharyngeal cancer in the New Jersey 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 will emphasize 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.

Below is the Healthy New Jersey 2010 goal relating to oral and oropharyngeal cancer.

**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. Baseline data and projected target rates to reduce the diagnosis of oral cancer in the late stages of disease.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
White Males	51.2	40.0	-21.9	20.0	-60.9
Black Males	58.5	40.0	-31.6	20.0	-65.8
White Females	39.0	35.0	-10.3	15.0	-61.5
Black Females	41.9	35.0	-16.5	15.0	-64.2

*Source: Healthy New Jersey 2010*

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 four topic areas in priority order:

- Public Awareness
- Public Access
- Professional Awareness and Education
- Research and Surveillance

## GOALS, OBJECTIVES AND STRATEGIES

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### 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 highly successful in reducing the morbidity and mortality from oral and oropharyngeal cancer (23). It is therefore essential to raise public awareness about lifestyle behaviors that put them 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.

A large segment of the public is unaware of the early signs of oral and oropharyngeal cancer, and the population at highest risk is least aware (24)(25;26). Most adults are also poorly informed about risk factors and the need for ongoing screening to detect early lesions. The 1990 National Health Interview Survey, Health Promotion and Disease Prevention Supplement, found that this general lack of knowledge and misinformation was common among U.S. adults, regardless of age, race, or ethnicity (25). Of the adults surveyed, 40% did not know any of the signs of oral and oropharyngeal cancer; another 25% correctly identified only one. Only 13% of those surveyed identified regular alcohol drinking as a risk factor for oral and oropharyngeal cancer. Even though two-thirds of respondents cited tobacco use as a risk factor for oral and oropharyngeal cancer, a greater number of respondents correctly identified smoking as a risk factor for heart disease, emphysema, or lung cancer than for oral and oropharyngeal cancer. Similarly,

few respondents recognized heavy drinking as a risk factor for throat and mouth cancer, although 83% knew heavy drinking increases risk for cirrhosis of the liver (25).

Oral and oropharyngeal cancer questions included in a pilot study about general oral and oropharyngeal health among 700 adults once again uncovered the fact that respondents were not well informed about risk factors (27). When asked, ‘Which of the following are early warning signs of mouth or lip cancer?’, only 63% correctly identified ‘a white or red patch in the mouth that does not go away’, and 20% responded ‘don’t know/not sure’ on the question. Only 49% indicated that regular use of both tobacco and alcohol were risk factors; 29% incorrectly responded that having a relative who has had mouth or lip cancer was a risk factor. These studies clearly demonstrate the need for improved public education and awareness efforts for oral and oropharyngeal cancer.

Although the overall level of knowledge about risk factors for oral and oropharyngeal cancer is low, adults who had a higher level of knowledge of risk factors for oral and oropharyngeal cancer were more likely to have had an oral and oropharyngeal cancer examination (28). 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 (29). The 1992 National Center for Health Statistics Cancer Supplement Survey found that only 14% of the public responded that they had been examined for oral cancer (30), indicating the need for increased awareness of risk factors of oral cancer and the importance of

screening. This survey also revealed that the groups least likely to have been examined were blacks or Hispanics, those with low levels of education, persons 65 years of age or older, current users of tobacco products (30), and respondents with a low level of knowledge about risk factors for oral and oropharyngeal cancer (28).

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 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 New Jersey Breathes Tobacco Control Coalition, a statewide 47-member agency, is to alter the social norm of tobacco acceptance fostered by the tobacco industry. Through awareness and education, New Jersey Breathes is 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. Any new tobacco control and oral health programs should build on existing activities, such as those of the New Jersey Comprehensive Tobacco Control Program (31-33). Existing activities are insufficient, as oral and oropharyngeal cancer incidence and mortality have remained steady over the past several years (Tables 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 (24). Targeting high-risk segments of the population for educational programs can be done 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, American Dental Association, 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 to work on strengthening laws and regulations concerning tobacco and alcohol, the two primary risk factors for oral and oropharyngeal cancer. Tobacco and alcohol exposure can be limited by promoting no-smoking laws and by making the public more aware of the direct association between use of these substances and oral cancer. Additionally, more stringent regulation would decrease accessibility of these substances.

Without accurate and appropriate information about oral and oropharyngeal cancer, New Jerseyans, 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 (26;34). 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 (24). 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 to begin this endeavor with 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) Review 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, the Oral Cancer Consortium, and the New Jersey Dental Association 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) Place a member of the Oral and Oropharyngeal Cancer Implementation Workgroup on New Jersey Breathes in order to collaborate with leading tobacco control advocates and to support Oral Health Funding from a larger collaborative.

### 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) Expand 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.
- (OR-1.2.7) Work with the National Council on Alcohol and Drug Dependency (NCADD) of New Jersey to incorporate oral and oropharyngeal cancer issues in alcohol control advocacy standards.

## PUBLIC ACCESS

The chapter on Access and Resources clearly demonstrates the need for better access and resources for cancer screening, early detection, and treatment in New Jersey. 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 (Goal OR-1) and even if dentists and physicians can be better educated and motivated (Goal OR-3), access issues are likely to persist as obstacles to early detection of oral and oropharyngeal cancer (35).

The incidence and mortality data presented earlier in this chapter demonstrate that disparities exist in race and gender. 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 must be considered as a possible factor.

For oral and oropharyngeal cancer in particular, two underlying problems directly affect access and resources for cancer control in New Jersey. First, a comprehensive oral and oropharyngeal cancer needs and capacity assessment does not exist. Without a needs

and capacity assessment, it is difficult to determine why New Jersey residents are not receiving the oral and oropharyngeal cancer care they need and which populations are most affected. Barriers, such as socio-economic and attitudinal, exist and many segments of the population do not benefit from existing programs in the state. Second, not enough dentists serve the high-risk population. The lack of availability of dentists in specific urban and rural areas in New Jersey is demonstrated by several areas of the state being designated as Dental Health Professional Shortage Areas (36;37).

The Oral Cancer Consortium, described earlier in this chapter, has recognized these problems as well. Currently, the 22 member organizations of the Oral Cancer Consortium are conducting and promoting free oral and oropharyngeal cancer screening events 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 partner to begin centralizing the oral and oropharyngeal cancer efforts within New Jersey.

Second, we propose 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 routinely visit a primary care physician and/or dentist. 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 widespread oral cancer screening also requires a multidisciplinary protocol involving the Emergency Department and the medical and surgical services at these hospitals. Therefore, funding is needed to increase the number of residents to provide essential professional human resources in order to deliver 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 to increase screening without creating substantial cost fluctuation, by using the following venues: mobile units, outpatient facilities run by medical center, 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.

- (OR-2.1.4) Partner with New Jersey Department of Health and Senior Services Division of Addiction Services and addictions providers to disseminate oral and oropharyngeal cancer education to “12 Step” groups.

## **PROFESSIONAL AWARENESS AND EDUCATION**

**M**ortality from oral and oropharyngeal cancer has remained high and, in contrast to nearly every other form of cancer, survival has not improved over the last 40 years, despite significant advances in cancer treatment. 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 (12). (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 (11). Studies have shown that dentists are not as knowledgeable about oral cancer prevention and early detection as they could be and that they recognize these deficiencies (8). As noted earlier, many dentists do not provide annual oral cancer examinations, even though they recognize their importance (1;10). Furthermore, preliminary oral cancer training in medical schools lacks both adequacy and comprehensiveness (9).

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 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 awareness and education 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. Education should particularly focus on lower socio-economic status populations and populations residing in areas with limited access to oral health services. Additionally, blacks with oral and oropharyngeal cancer have significantly more advanced disease at the

time of detection and a higher mortality rate after detection; therefore education and awareness efforts should target this population. Over the last 40 years, the proportion of oral and oropharyngeal cancer patients who are women has more than doubled, now comprising approximately one-third. The education of clinicians who focus

on women's issues should, therefore, not be overlooked.

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.

#### **Strategies:**

- (OR-3.1.1) Develop a core curriculum for physicians, dentists, and hygienists on the primary prevention and early detection of oral and oropharyngeal cancer including alcohol and tobacco studies.
- (OR-3.1.2) Promote the adoption of this oral health program in New Jersey's medical and dental schools and in medical primary care residency programs and dental residency programs throughout the state.
- (OR-3.1.3) Support advanced training programs in Oral Medicine.

#### **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.

**Strategies:**

- (OR-3.2.1) Develop a continuing education program for dentists, hygienists, and interested physicians on the primary prevention and early detection of oral and oropharyngeal cancer.
- (OR-3.2.2) Introduce the continuing education (CE) program on oral and oropharyngeal cancer through existing, already funded CE providers (see below).

**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.

**Strategies:**

- (OR-3.3.1) Recommend to the New Jersey Board of Dentistry that oral and oropharyngeal cancer education be part of the 40-hour requirement for license renewal every two years.
- (OR-3.3.2) Partner with organizations, such as the Oral Cancer Consortium, the New Jersey Dental Association, University of Medicine and Dentistry of New Jersey, Seton Hall University, among others, to gain support for licensure requirements for oral and oropharyngeal cancer education.

## RESEARCH AND SURVEILLANCE

Research needed on oral and oropharyngeal cancer centers on both public health issues and basic biomedical research. Included in public health issues are studies to better understand the epidemiology of this disease and outcomes assessments 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 prime targets.

New Jersey, while experiencing lower incidence of the disease than the nation as a whole, nevertheless has a higher mortality, with cases being diagnosed at later stages, as

demonstrated earlier in this chapter. Epidemiological research will identify the populations at higher risk and will help target susceptible populations for early detection and intervention. Research into the outcomes assessment of risk reduction interventions and early detection in oral and oropharyngeal cancer will guide 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 development of frank carcinoma, a progression of lesions from hyperplastic to dysplastic to carcinoma-in-situ is believed to be the common pathway leading to squamous cell carcinoma. Little is understood of the genetic events leading to

the development of squamous cell carcinoma. Efforts should be directed toward understanding basic biologic processes that lead to development and progression of this entity. Identification of reliable biomarkers that influence prognosis and response to treatment, as seen with many other cancers, is lacking in oral and oropharyngeal cancer. Within the state are significant resources for biologic research in both our public and private universities and other entities. No known effective chemotherapy exists for this disease. New Jersey is a powerhouse in the pharmaceutical industry, which represents a

potent resource for exploitation of discovery of new biologic information.

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, chemo-prevention of oral and oropharyngeal cancer, and the development of improved technologies in identifying and characterizing oral and oropharyngeal cancer.

#### **GOAL OR-4:**

**To identify target groups for oral and oropharyngeal cancer that maximize interventional and educational impact while permitting cost-effectiveness evaluation.**

#### **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.
- (OR-4.1.3) Evaluate practitioners' competency in performing oral and oropharyngeal cancer examinations regarding detection of premalignancies and oral and oropharyngeal cancer and treatment using the protocol for training in the Consortium for the Prevention and Detection of Oral Cancer.

**Objective OR-4.2:**

To document prevalence of risk factors for oral and oropharyngeal cancer in New Jersey.

**Strategies:**

- (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.
- (OR-4.2.2) Conduct a scientific research study to measure the correlation between outcomes and factors required for optimal management of patients with oral and oropharyngeal cancer.
- (OR-4.2.3) Work with the Oral and Oropharyngeal Cancer Implementation Workgroup to distribute recommendations for optimal treatment to healthcare professionals, New Jersey Department of Health and Senior Services, and involved public health organizations.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

New Jersey Dental Association: OR-3.3.1; OR-3.3.2

New Jersey Department of Health and Senior Services: OR-1.1.1; OR-1.1.2; OR-1.1.3; OR-1.1.4; OR-1.2.1; OR-1.2.2; OR-1.2.3; OR-1.2.4; OR-1.2.5; OR-1.2.6; OR-2.1.4; OR-4.1.1; OR-4.2.1; OR-4.3.1; OR-4.4.1; OR-4.4.2; OR-4.4.3

Oral Cancer Consortium: OR-1.1.1; OR-1.1.2; OR-1.1.3; OR-1.1.4; OR-2.1.1; OR-2.1.2; OR-2.1.3; OR-3.3.1; OR-3.3.2; OR-4.1.1; OR-4.2.1; OR-4.4.1

Seton Hall University: OR-1.1.5; OR-2.1.2; OR-2.1.3; OR-3.1.1; OR-3.1.2; OR-3.1.3; OR-3.2.1; OR-3.2.2; OR-3.3.1; OR-3.3.2

University of Medicine and Dentistry of New Jersey – Dental School: OR-1.1.1; OR-1.1.2; OR-1.1.3; OR-1.1.4; OR-1.1.5; OR-2.1.1; OR-2.1.2; OR-2.1.3; OR-3.1.1; OR-3.1.2; OR-3.1.3; OR-3.2.1; OR-3.2.2; OR-3.3.1; OR-4.1.1; OR-4.2.1; OR-4.3.1; OR-4.4.1; OR-4.4.2; OR-4.4.3

## ORAL AND OROPHARYNGEAL

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Heighten public awareness and knowledge	1.1: Increase direct public education to high-risk groups	OR-1.1.1 OR-1.1.2 OR-1.1.3 OR-1.1.4 OR-1.1.5 OR-1.1.6						
	1.2.: Strengthen tobacco/alcohol laws and regulations	OR-1.2.1 OR-1.2.2 OR-1.2.3 OR-1.2.4 OR-1.2.5 OR-1.2.6 OR-1.2.7						
2: Increase access to screening	2.1: Increase community outreach	OR-2.1.1 OR-2.1.2 OR-2.1.3 OR-2.1.4						
3: Increase involvement of healthcare providers through education	3.1: Provide education for training	OR-3.1.1 OR-3.1.2 OR-3.1.3						
	3.2: Update knowledge of practicing clinicians	OR-3.2.1 OR-3.2.2						
	3.3: Assure baseline knowledge by licensees	OR-3.3.1 OR-3.3.2						
4. Identify groups that maximize impact while cost effective	4.1: Assess knowledge in public/private sectors	OR-4.1.1 OR-4.1.2 OR-4.1.3						
	4.2: Document prevalence of risk factors	OR-4.2.1 OR-4.2.2 OR-4.2.3						

**Target Completion Date**

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## PROSTATE CANCER

### IMPORTANCE OF PROSTATE CANCER FOR CANCER PREVENTION AND CONTROL

Prostate cancer is the second leading cause of cancer deaths in U.S. men, and the number one type of new cancer cases in U.S. men (1). Evidence suggests, through autopsy studies, that a substantial number of men have prostate cancer that is undiagnosed (2;3). Cancer of the prostate is the most prevalent of all cancers in men because of slow tumor growth rate and improved survival rate.

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) (4). According to the American Cancer Society, about 70% of all men with clinically diagnosed prostate cancer are aged 65 years or older (5). 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. 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 1992-1998, 53.1 of every 100,000 black men died of prostate cancer compared with 22.4 of every 100,000 white men, 15.9 of every 100,000 Hispanic men, 14.0 of every 100,000 American Indian men, and 9.8 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 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). 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.

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 (4). 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.

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, Digital Rectal Exam (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.

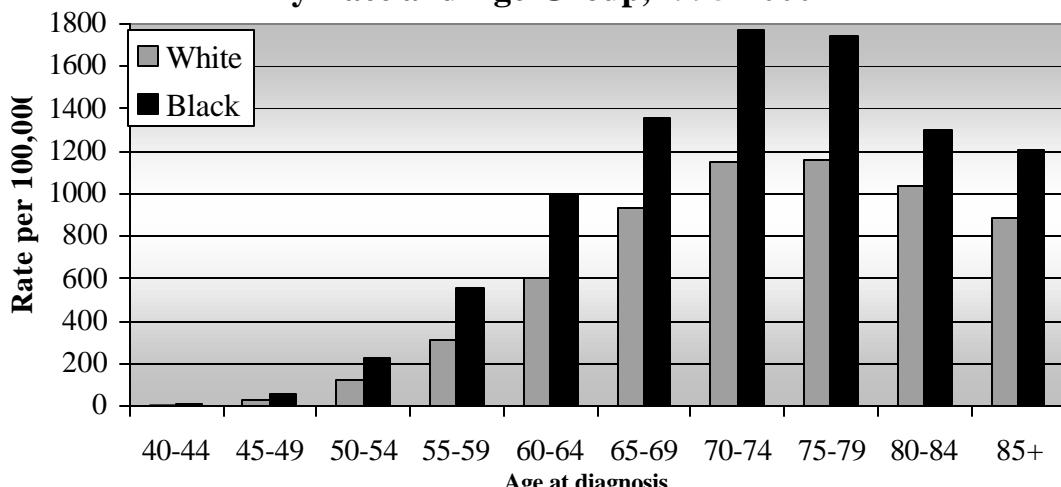
The Centers for Disease Control and Prevention (CDC) does not recommend prostate cancer screening, but does recommend that men be provided with up-to-date information about screening, including the potential harms and benefits. Several organizations – including the American Cancer Society, American Urological Association, National Cancer Institute, and 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.

For all of these reasons, it is important to educate the public and healthcare professionals about these issues concerning prostate cancer. Then, individuals will be able to make informed decisions about their prostate health in consultation with their doctors and families.

## PROSTATE CANCER IN NEW JERSEY

**Incidence.** The American Cancer Society estimates that among men in the U.S., 189,000 cases of prostate cancer will be newly diagnosed in 2002 (1). Among New Jersey men, about 5,700 cases of prostate cancer will be diagnosed in 2002 (1). In 2000\*, 192.2 men per 100,000\*\* were diagnosed with prostate cancer in New Jersey; the rate was 179.9\*\* among white men and 266.8\*\* among black men\*\*. The highest incidence of prostate cancer in New Jersey occurred in men between 70 and 79 for both whites and blacks (Figure 1). Black males have consistently had a higher incidence rate than white males in New Jersey, as well as in the nation (Figure 2). Between 1985 and 2000\*, 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 76% in 2000 (7;8).

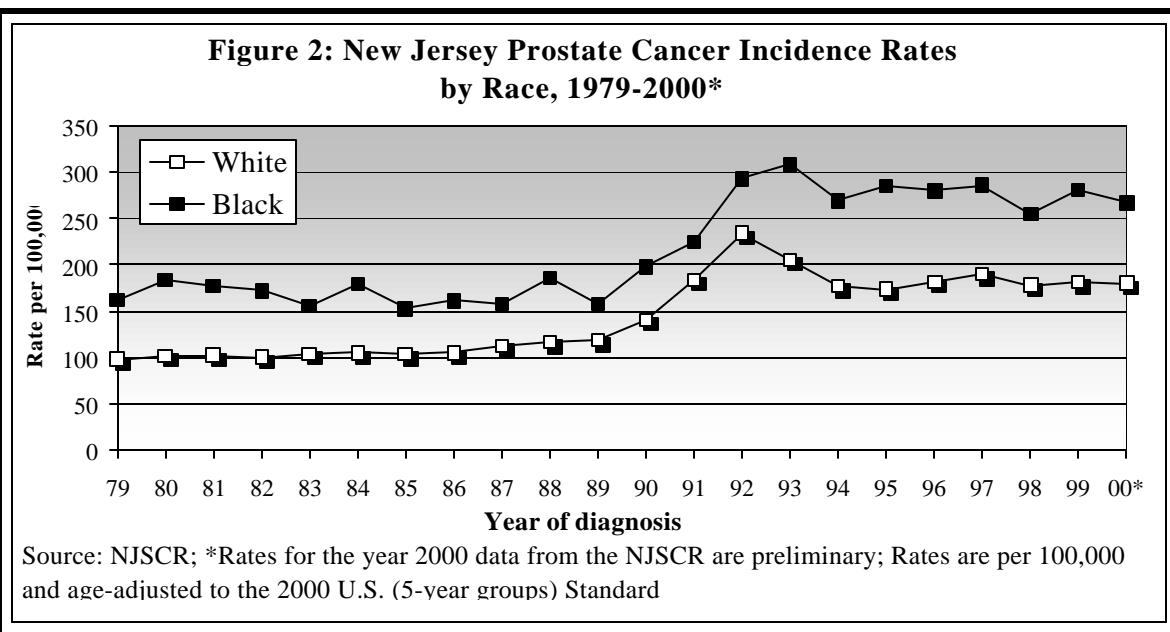
**Figure 1: New Jersey Prostate Cancer Incidence  
By Race and Age-Group, 1995-2000\***



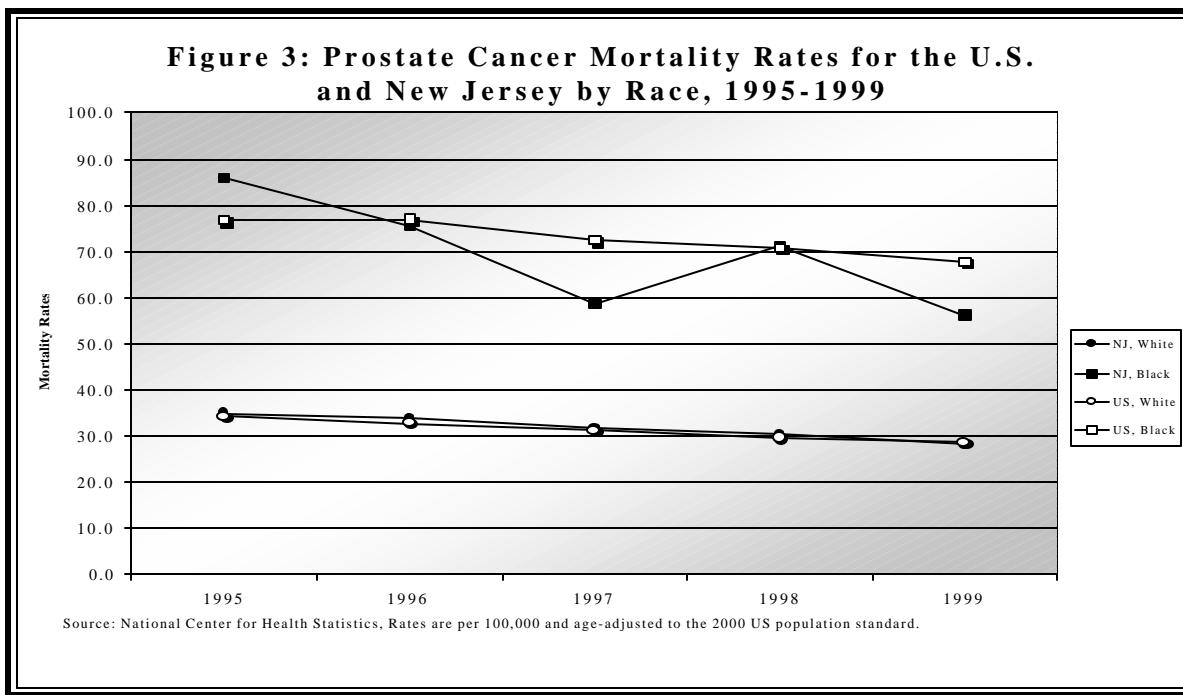
Source: New Jersey State Cancer Registry (NJSCR); Rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) standard. \*Incidence rates from NJSCR for 2000 are preliminary.

\*Incidence rates for year 2000 data from the New Jersey State Cancer Registry are preliminary.

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



**Mortality.** The American Cancer Society estimates that about 30,200 deaths due to prostate cancer will occur among men in the U.S. in 2002.(1) In New Jersey about 900 men will die of prostate cancer in 2002 (1). Prostate cancer mortality rates have decreased from 1995 to 1999; in whites in 1995 the New Jersey mortality rate was 35.0 per 100,000\*\* compared to 28.1 per 100,000 in 1999, for blacks the rate was 85.7 per 100,000 in 1995 compared to 56.2 per 100,000\*\* in 1999. This is consistent with decreases seen in the U.S. (9) (Figure 3).



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

Prostate Cancer Summits, most recently in April 2001, were held to gather New Jersey physicians, researchers, health professionals, patients, advocates and various organizations to address the serious healthcare crisis in prostate cancer. Three areas for action were identified for New Jersey: screening/early detection, public/professional/patient education, and research. Therefore, the Prostate Cancer Workgroup has used these three areas as a basis for addressing prostate cancer in this report.

Below is the Healthy New Jersey 2010 goal relating to prostate cancer.

**Healthy New Jersey 2010 Goal: Reduce the age-adjusted death rate of males from prostate cancer per 100,000 to 10.0 for total males, 10.0 for white males, and 25.3 for black males, ensuring that all efforts are appropriate culturally, linguistically, and at the proper literacy level, by 2010.**

**Table 1. Baseline data and projected target rates to decrease the death rate of males from prostate cancer.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	13.4	10.0	-25.4	6.2	-53.7
White age-adjusted	11.8	10.0	-15.3	5.4	-54.2
Black age-adjusted	32.0	25.3	-20.9	13.6	-57.5
Asian/Pacific Islander age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#

*Source: Healthy New Jersey 2010*

*#Data are statistically unreliable.*

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 five topic areas in priority order:

- Public Awareness and Education
- Patient/Client Education for Screening and Follow Up
- Access to Care
- Information for Medical Practitioners
- Research and Surveillance

## GOALS, OBJECTIVES AND STRATEGIES

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### PUBLIC AWARENESS AND EDUCATION

**A**s described earlier in this chapter, a 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 \$900,000 to provide education and outreach to men regarding prostate cancer and to offer screening for the disease (Appendix E). If the offer to screen is accepted, men are then given the PSA and DRE screening tests.

It is hoped that education and the offer of screening and treatment services will be instrumental in fighting prostate cancer in New Jersey.

However, the NJCEED program only targets a specific population. Dissemination of prostate cancer information should be broadened to reach all New Jerseyans in order to more widely influence knowledge, attitudes, and practice related to adherence to prostate healthy behaviors, prevention, and early detection. Public education programs should include a systematic design and sustained delivery of methods and messages.

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 fundamentally important to enhancing health promotion and quality of life for New Jerseyans. Interventions that will elicit and ensure participation from populations at high risk for prostate cancer should be a high priority.

#### GOAL PR-1:

**To promote a public health message regarding prostate cancer screening and the benefits and risk factors 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) Identify, or develop as needed, educational programs that comprehensively describe prostate cancer screening, the risk factors involved with screening, symptoms, follow-up, and treatment for all men, including participation in clinical trials.
- (PR-1.1.2) Ensure that the educational materials list the pros and cons of prostate cancer screening.
- (PR-1.1.3) Develop and test a standardized model informed consent form for prostate cancer screening.
- (PR-1.1.4) Identify, or develop as needed, educational programs that describe the issues related to barriers, myths, access, funding of prostate cancer screening, follow-up, and treatment for high-risk individuals, especially men of African descent.
- (PR-1.1.5) Identify and partner with community-based organizations for prostate cancer educational programs to further implementation.
- (PR-1.1.6) Provide prostate cancer educational programs throughout the age continuum through national, local, and statewide organizations, especially with high-risk populations.
- (PR-1.1.7) Develop a prostate cancer resource guide for New Jersey residents.
- (PR-1.1.8) Develop a distribution plan for the prostate cancer resource guide for New Jersey residents.
- (PR-1.1.9) Develop 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. Men should discuss an abnormal PSA or DRE 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 (10), many factors may cause an individual to refrain from seeking out available screening and educational programs. Personal beliefs and practices, 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.

To increase the number of New Jerseyans able to access screening, providing education is a first step. 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.

Currently, men in New Jersey who are eligible can be screened for prostate cancer through the NJCEED program (Appendix E). 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, and the general public.

#### **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) Investigate and distribute educational materials and resources that provide information on prostate health and screening. Develop these materials if needed.
- (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 (11).

In New Jersey, hassles within the healthcare delivery system have been identified as a major access issue, along with language and transportation barriers (11).

A variety of community-based organizations, especially faith-based organizations, specifically

design their programs for under-served 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. To improve access to care for prostate cancer, the Prostate Cancer Workgroup proposes the following goal, objective, 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 payors 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) Provide transportation to prostate cancer treatment services.
- (PR-3.1.9) 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-3.1.10) Develop 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.

## INFORMATION FOR MEDICAL PRACTITIONERS

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 and its treatment is constantly evolving. Physicians, particularly primary care doctors, may find it difficult to remain alert to new developments and subsequently advise or treat individual patients in an efficient and comprehensive manner. Various sources of information on prostate cancer are available nationwide but are not universally accessible. For example, Continuing Medical Education (CME) category 1 and 2 courses in prostate cancer are not always open to primary care physicians. A clearinghouse of data and information about prostate cancer and its treatment (located in and with data specific to New Jersey) would be advisable and should be located on the internet. The clearinghouse

should contain such information as a list of practicing clinicians (primary care physicians, urologists, oncologists, radiation oncologists, pathologists) in the state with medical biographies; a database of studies on both conventional and integrative treatments; and studies/information on screening tests. Furthermore, the clearinghouse should maintain a calendar of educational opportunities in the state for medical practitioners. Educational opportunities should include conferences, public, legislative, and government forums, as well as continuing education classes offered by medical schools and institutions, medical societies, and private entities. The calendar would serve as an additional source of information for practitioners who wish to keep pace with developments in prostate cancer and its treatment. The availability of this information, which may be included in medical publications and disseminated via professional organizations, should be forwarded to all primary care and specialty physicians in the state.

### GOAL PR-4:

**To improve professional education on symptoms, risk factors, screening, and follow-up care for prostate cancer.**

#### Objective PR-4.1:

To provide information and resources to medical professionals so they may discuss the pros and cons of prostate cancer screening with their patients and so that patients and providers together can make informed decisions about screening.

#### Strategies:

- (PR-4.1.1) Develop and implement an up-to-date database of prostate cancer educational opportunities for practitioners.
- (PR-4.1.2) Develop a communication plan for provider education on prostate cancer.

### Objective PR-4.2:

To provide information and resources to medical providers for prostate cancer follow-up care for high-risk and general populations.

### Strategies:

- (PR-4.2.1) Develop and implement an up-to-date database of prostate cancer educational opportunities for the public.
- (PR-4.2.2) Develop a communication plan for the database for prostate cancer.

## RESEARCH AND SURVEILLANCE

The American Cancer Society estimates that in New Jersey, 5,700 men will be diagnosed with prostate cancer and 900 will die of the disease in 2002. 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.

Currently, researchers at the Cancer Institute of New Jersey are studying the effects of alternative medicine, such as herbal medicine, in relation to prostate cancer (12). However, additional science- and evidence-based research and surveillance will provide the tools to direct resources to those with the greatest need and for whom intervention will bring the highest gains. By assessing the specific rates of prostate cancer, and stage at diagnosis by geographic and demographic information, specific interventions can be designed to address the needs identified.

### GOAL PR-5:

**To expand a research agenda specific to prostate cancer issues in New Jersey.**

### Objective PR-5.1:

To develop a plan to incorporate men, in demographic groups that are underrepresented, in prostate cancer screening and clinical trials.

**Strategies:**

- (PR-5.1.1) Identify and develop community leaders as intermediaries between organized medicine and the individual client concerned about prostate cancer.
- (PR-5.1.2.) Develop outreach programs with community leaders to improve client participation in screening and clinical trials.
- (PR-5.1.3) Increase the quality and the amount of information the patient receives to make an informed consent to prostate cancer screening.
- (PR-5.1.4) Partner with the New Jersey Commission on Cancer Research to encourage researchers to seek out grants in prostate cancer research.

**Objective PR-5.2:**

To support the evaluation of complementary alternative medicine (CAM) in relation to prostate cancer e.g., herbal preparations, vitamins, etc.

**Strategy:**

- (PR-5.2.1) Identify complementary alternative medicine (CAM) interventions being utilized by New Jersey residents for prostate cancer. Differentiate those patients involved in clinical trials.

**Objective PR-5.3:**

To facilitate the collaboration between institutions providing prostate cancer clinical trials and underrepresented populations.

**Strategies:**

- (PR-5.3.1) Encourage the physicians of underrepresented populations to refer their prostate cancer patients to clinical trials in New Jersey.
- (PR-5.3.2) Encourage the physicians of underrepresented populations to participate directly in clinical trials for prostate cancer in New Jersey.
- (PR-5.3.3) Educate physicians about clinical trials for prostate cancer so that this information can be disseminated to men who may be eligible to participate.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: PR-1.1.1; PR-1.1.2; PR-1.1.3; PR-1.1.4; PR-1.1.5; PR-1.1.6; PR-1.1.7; PR-1.1.8; PR-1.1.9; PR-2.1.1; PR-2.1.2; PR-2.1.3; PR-2.2.3; PR-2.2.4; PR-3.1.7; PR-3.1.8; PR-3.1.9; PR-3.1.10; PR-4.1.1; PR-4.1.2; PR-4.2.1; PR-4.2.1; PR-5.1.1; PR-5.1.3; PR-5.1.4; PR-5.2.1

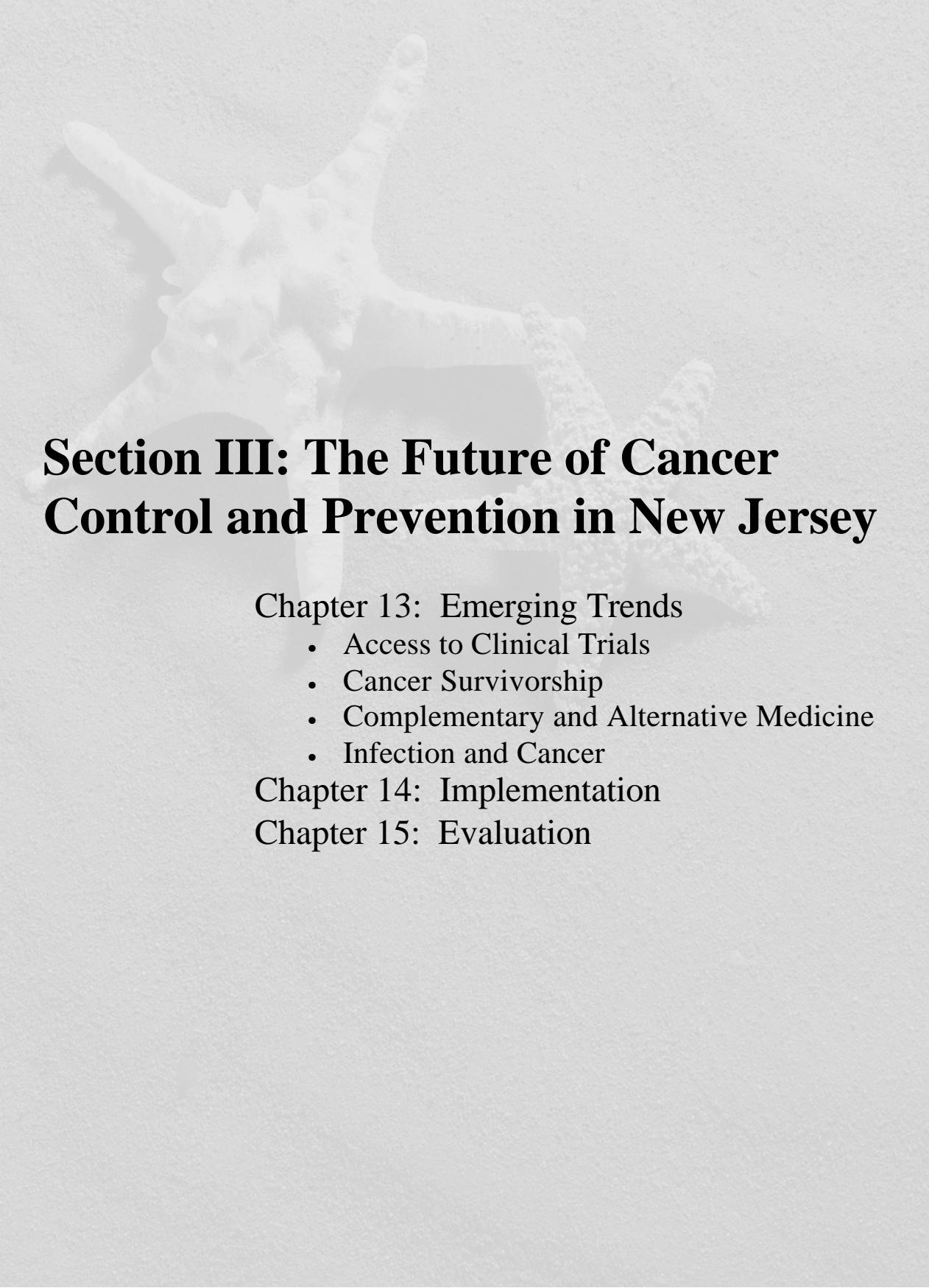
New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection (NJCEED): PR-1.1.1; PR-1.1.2; PR-1.1.3; PR-1.1.4; PR-1.1.5; PR-1.1.6; PR-1.1.7; PR-1.1.8; PR-1.1.9; PR-2.1.1; PR-2.1.2; PR-2.1.3; PR-3.1.1; PR-3.1.2; PR-3.1.3; PR-3.1.4; PR-3.1.5; PR-3.1.6; PR-3.1.7; PR-3.1.8; PR-3.1.9; PR-3.1.10

## PROSTATE

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Promote public health message	1.1: Increase public knowledge among all residents	PR-1.1.1 PR-1.1.2 PR-1.1.3 PR-1.1.4 PR-1.1.5 PR-1.1.6 PR-1.1.7 PR-1.1.8 PR-1.1.9						
2: Improve patient education	2.1: Increase knowledge among patients with normal screening results  2.2: Increase knowledge among patients with screening abnormalities	PR-2.1.1 PR-2.1.2 PR-2.1.3  PR-2.2.1 PR-2.2.2						
3: Increase access to services	3.1: Increase number of contacts	PR-3.1.1 PR-3.1.2 PR-3.1.3 PR-3.1.4 PR-3.1.5 PR-3.1.6 PR-3.1.7 PR-3.1.8 PR-3.1.9 PR-3.1.10						
4: Improve professional education	4.1: Provide information/resources to medical providers regarding screening  4.2: Provide information/resources to medical providers regarding follow-up care	PR-4.1.1 PR-4.1.2  PR-4.2.1 PR-4.2.2						
5 Expand research agenda	5.1: Develop plan for underrepresented groups regarding screening and clinical trials  5.2: Support evaluation of complementary alternative medicine  5.3: Facilitate collaboration regarding clinical trials	PR-5.1.1 PR-5.1.2 PR-5.1.3 PR-5.1.4  PR-5.2.1  PR-5.3.1 PR-5.3.2 PR-5.3.3						
<b>Target Completion Date</b>								

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## **Section III: The Future of Cancer Control and Prevention in New Jersey**

### **Chapter 13: Emerging Trends**

- Access to Clinical Trials
- Cancer Survivorship
- Complementary and Alternative Medicine
- Infection and Cancer

### **Chapter 14: Implementation**

### **Chapter 15: Evaluation**



## CHAPTER 13. Emerging Trends

### ACCESS TO CLINICAL TRIALS

Clinical trials are studies designed to answer a scientific question. This question may have been developed in carefully controlled laboratory research. Clinical trials are designed to bridge the gap between basic laboratory research and the patient by testing new treatments, investigating new means of prevention, improving early diagnosis, monitoring quality of life, and/or studying the psychological impact of cancer (1).

Clinical trial participants have historically been white with a middle or upper socioeconomic background. Researchers have long acknowledged the need to diversify clinical trial research (2). Barriers to inclusion of both culturally diverse patients and patients with lower socioeconomic status can be patient driven, physician driven, or system driven.

Many clinical trials have rigid inclusion criteria and complex testing regimes that can seem overwhelming to patients. Some patients feel that if they participate in clinical trials, they are no better than “guinea pigs”; others feel that only patients with no hope are placed on clinical trials. Patients may fear that participation in a clinical trial means being treated with an experimental therapy, or that they may not receive appropriate treatment, which may be a legacy of the Tuskegee Syphilis Study (3). A patient may not have the resources needed to travel to and from testing and treatments or may fear that a clinical trial will not be covered by insurance. Patients who are not fluent in English may have difficulty understanding the consents and the commitment needed to participate in a clinical trial.

Physicians may be reluctant to place patients on clinical trials for a variety of reasons. They may lack knowledge of clinical trials available in their area. Clinical trials take time, and physicians are not always willing to complete the paper work necessary to place a patient on a trial. Many physicians fear that by referring a patient to another doctor for a clinical trial, they will lose the patient (4).

If we examine one small aspect of clinical trials, we can begin to understand some of the barriers to recruitment (5). Some clinical trials “randomize”; that is, the patient is assigned by chance to either the treatment or a control group. Many patients are uncomfortable with this. They want to be in charge of their care and do not want their treatment left to chance. Many physicians are biased toward a particular type of treatment or dislike the treatment designated for the control group, which may keep physicians from suggesting clinical trials. An inherent conflict also exists between the physician, the caregiver, and the research physician. The allegiance of the caregiver and the physician is to the patient, while the scientist physician places the potential benefit to humanity and future generations first (4). This is just one aspect of the clinical trial process. So it is clear there is no simple answer to the problem of inclusion in clinical trials.

Education across the range of people and systems involved in clinical trials is needed to ensure that all New Jerseyans have access to the best possible care, and that care is often available through participation in clinical trials. The researcher, the physician, and the patient must understand what clinical trials can do and how to make informed decisions about participating in them. Issues specific to clinical trials have, therefore, been addressed throughout the chapters in the *Plan*.

## CANCER SURVIVORSHIP - CHALLENGES AND ISSUES FOR A GROWING POPULATION

**“W**ith communication comes understanding and clarity; with understanding, fear diminishes; in the absence of fear, hope emerges; and in the presence of hope, anything is possible.”

Ellen Stovall, Survivor  
National Coalition for  
Cancer Survivorship (NCCS)

The American Cancer Society estimates the number of Americans who will receive a cancer diagnosis this year to be 1,268,000. Statistics estimate the number of expected deaths from cancer this year to be 553,400 (6). While these are staggering figures, progress is being made in increasing cancer survival rates. For example, according to SEER data, the overall five-year survival rate for adolescents with cancer improved from 69% to 77% from the period 1975-1994 (7).

Dr. Harmon Eyre, Executive Vice-President of the American Cancer Society states, “It is a testament to the success of the American Cancer Society and other such organizations, as well as the countless researchers and clinicians who engage daily in the ongoing battle against cancer, that there are about nine million cancer survivors living in the United States today.” That is, the term cancer *victim* is being transformed into the term cancer *survivor* and includes representatives from all age groups (8). Yet the special needs of cancer survivors are not being adequately addressed. These needs include psychosocial needs, follow-up care, information needs, and legislative advocacy.

**Psychosocial Needs.** For most people, a diagnosis of cancer is an overwhelming experience. Fear of dying, worry about medical treatments, and concern over role changes at home or at work can make people

feel isolated and alone at a time when they most need others. Finding someone to talk to and share experiences with can ease the sense of isolation and reduce the stress (11). Since the psychosocial needs that arise from living through the cancer experience are not uniformly met in the healthcare system, more and more people with cancer are seeking groups to help them cope.

Realizing that others have experienced reactions and fears similar to their own reassures survivors that their reactions are normal. Research (9;10) underscores the positive effects of group participation on coping and on people's own evaluation of their quality of life. Some of this research also suggests that group participation increases post-treatment survival (11-13).

Existing support programs need to be continued, and new deliveries created, in response to the unique needs of survivors. In part this support is provided in groups – peer support – shared experience(s); educational programs delivered in the community or via toll-free teleconferences – facilitating learning and coping; website support through participation in chat and discussion groups; listening to and sharing personal stories; and accessing state of the art information, recommended books, and articles.

**Follow-up Care.** As we move into the 21<sup>st</sup> century, we are faced with an increasing number of childhood cancer survivors who are living into their middle adult years and beyond. Providing appropriate comprehensive follow-up care is a challenge for healthcare providers and one that can be met by developing quality follow-up programs for all childhood cancer survivors (14).

The future challenges and needs of survivorship for adult and child populations should address the impact of the lifetime effects of a cancer diagnosis. For example, who should monitor these various aspects of

survivorship - the primary care physician or the oncologist? Cancer treatment modes can and do affect other organ functions during survivorship. Survivors should be monitored continually during their lifetime to help reduce the chances of recurrence and late-term effects of treatments. Some examples include: fatigue, depression, psychosocial problems, and sexual dysfunction.

We should include a broader community service commitment to meet the needs of cancer survivors, concentrating on wellness and health maintenance issues rather than treatment. In fact, communities should be encouraged to create programs to address the needs of cancer survivors as contributing members of the community and include new and existing community support systems within the State of New Jersey.

**Information Needs.** Other survivorship services should include faster distribution and promotion of cancer resources to healthcare providers and to the public. The amount of new research data being generated is staggering, and our knowledge is constantly changing at a rapid pace. A dialogue between the media and healthcare representatives should be encouraged to help promote news of the latest in cancer treatment other survivorship issues for this population. Although researchers have begun to tackle these issues, the gaps in knowledge of the long-term effects of surviving cancer can be frustrating to survivors themselves and to their practitioners (15).

Childhood survivorship issues for the future must include better access to high-quality medical care in combination with a strong medical model concentration on wellness and prevention. Again, these wellness management issues should include ongoing dialogue between the primary care physician and the oncologist. Individualized cancer wellness programs need to be continually

developed and fine-tuned to meet the challenges of legal, psychosocial, emotional, and late-term treatment effects of the patient. For example, lifestyle choices such as nutrition, weight management, exercise, and reduced stress management have been proven to contribute to quality of life, along with positive approaches to living a more productive life.

**Legislative Advocacy.** Finally, legislative support for quality care issues is essential if quality of life is to be maintained throughout the lifetime of the survivor. In 1998, legislation was passed earmarking \$15 million for the National Cancer Institute to better understand the issues cancer survivors face. Appropriations must continue and grow to meet research demands and provide necessary tools to the medical and survivor communities. For example, according to American Cancer Society data for 1999, 16% of Americans under 65 have no health insurance and about 26% of older persons have only Medicare coverage; 18% of Americans aged 18 to 64 years do not have a regular source of healthcare.

There is a critical need to understand the issues of the growing survivor population. Existing and future outreach into research and partnerships will be essential for the collection of data and for programming efforts within New Jersey as well as from all across the country.

In summary, cancer survivorship concerns are myriad. The cancer experience will continue to challenge this population to regain control over their lives and to expect "a time of life as usual." It is critical that we understand the issues and provide resources for this ever-growing population. We must continue to provide the education, resources, and tools for self-advocacy and ensure a high quality of life (16).

## COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) - ITS EFFECTS ON CANCER TREATMENT

Complementary and alternative medicine (CAM) 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. Not only have surveys documented CAM's widespread use, but also its increasing use in the past decade. Using the results of a population-based survey, Eisenberg et al. extrapolated that in 1990 an estimated 61 million Americans used at least 1 of 16 unconventional therapies and approximately 22 million Americans saw providers of unconventional therapy for a principal medical condition. Repeating this survey in 1997 found that the use of 1 of 16 alternative therapies during the previous year increased from 34% in 1990 to 42% in 1997. Further, this increase was attributable primarily to an increase in the proportion of the population seeking alternative therapies, rather than increased visits per patient (17;18).

CAM has been defined as medical interventions not taught widely at U.S. medical schools or generally available at U.S. hospitals (17). However, this definition may no longer be satisfactory, since some forms of CAM are now taught in medical schools, and hospitals and health maintenance organizations now offer it (19). Laws in some states require that health plans cover it (20). CAM is identified with the following types of therapies: acupuncture, biofeedback, chiropractic, commercial weight-loss programs, energy healing (including magnets), folk remedies, herbal medicine (including teas), homeopathy, hypnosis, imagery, lifestyle diets (e.g., macrobiotics), massage, megavitamins, relaxation techniques (including meditation), self-help groups, and spiritual

healing. Cited as the types of therapy most used are relaxation techniques, herbal medicine, massage, and chiropractic. In both surveys referenced above, as well as others, respondents cited the following conditions that accounted for the most frequent use of CAM therapies: chronic conditions, including back problems, anxiety, depression, and headache. Also cited were chronic fatigue, muscle sprains, arthritis or rheumatism, digestive problems, and diabetes. Cancer was included in the 1990 survey among the conditions for which CAM therapies were most frequently used, but not in 1997 (17;18;21).

The funds expended for CAM have also increased and are significant. The estimated expenditures for alternative medicine professional services 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 (17;18).

The reasons why people with cancer use CAM are multiple. Many 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 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 and that they achieve a sense of contributing to the care of their malignancy (21-23).

Studies have shown that persons using CAM tend to be better educated 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. 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 (22).

Of respondents to the Eisenberg et al. survey done in 1990, 83% reported having one or more principal medical conditions, and close to 60% of these with at least one principal medical condition saw a medical doctor but not a provider of unconventional therapy; 3% saw only a provider of unconventional therapy; 7% saw both a medical doctor and a provider of unconventional therapy; and 33% saw neither for at least one principal medical condition (17).

Among respondents in the 1990 survey who reported a principal medical condition and used unconventional therapy for that condition, only 4% saw a provider of unconventional therapy without also seeing a medical doctor. No respondent saw a provider of unconventional therapy but not a medical doctor for the treatment of cancer, diabetes, lung problems, skin problems, high blood pressure, urinary tract problems, or dental problems (17). However, Gertz, in an article published in 2001, states that it is estimated that fewer than one-half of patients with cancer receive only conventional therapy; approximately 44% combine conventional and alternative methods; and 10% of patients with cancer use unorthodox therapy only and forgo any form of conventional anticancer treatment (21).

Close to 90% of respondents who saw a provider of unconventional therapy in 1990

did so without the recommendation of their medical doctor. More than 70% of users of unconventional therapy did not inform their medical doctor of this use. This pattern of nondisclosure persisted in the 1997 survey (17;18).

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. This permits a lack of quality control in the products, and misleading labeling that can lead to patients thinking they are taking a certain amount, when in reality they are receiving excessive amounts of potent or harmful substances. For example, the herbal combination PC-SPES, containing eight herbs, has potent clinical effects inpatients with prostate cancer. This product is considered a dietary supplement and can be found in many health food stores. Because of the need for close monitoring and regulation of dosage, it is not recommended that patients use PC-SPES outside clinical trials (23). Other examples cited in the literature are of patients receiving chemotherapy or radiation who consume herbs, high-dose vitamins, or supplements before or during treatment. These substances may, hypothetically, inhibit or enhance the activity of conventional therapeutic agents. Further harm can be done when substances such as shark cartilage, bee pollen, and vitamin E affect laboratory studies, such as transaminase, used to monitor malignancies (22;24).

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 (25). Although most CAM therapies are relatively low risk, any therapy that results in a delay of a proven

therapy indirectly causes harm. An example of this is a recommendation against a biopsy of a potentially malignant site by a promoter of analysis of heavy metals in the blood, hair or nail analysis, and iridology. Particularly troublesome to conventional providers are the alternative therapies that espouse a simple etiology to explain all cancers. This thinking progresses to include using natural methods to treat cancer and cites the role of the bowel in contributing to malignant disease (21). It is generally agreed that there is inconclusive evidence about the safety, efficacy, mechanism of action, and cost-effectiveness of individual alternative treatments (22;24). 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 (26-28).

A systematic analysis of published articles on CAM was performed on reports of trials, surveys, and systematic and traditional reviews. This analysis excluded articles of a subjective nature, such as editorials, commentaries, and book reviews and indicated that there is a “relative paucity of evidence from randomized controlled trials and systematic reviews...”. More studies are needed in order to make informed decisions on the value of integrating CAM into conventional healthcare (29).

It is expected that as the public’s interest in CAM increases, the numbers of conventional schools offering courses in CAM will continue to grow. Centers in medical schools and schools of public health to study CAM are also being established (30;31). 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 increasingly aware of both conventional and CAM modalities, healthcare providers should include asking their patients about their use of CAM. In order to safeguard the patients’ 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.

## INFECTION AND CANCER

### *EPSTEIN-BARR VIRUS*

**E**pstein-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 nasopharyngeal carcinoma (NPC) and Burkitt's lymphoma (33). There are varying degrees of evidence linking EBV to Hodgkin's disease, gastric carcinoma, lung carcinomas, and neoplasms of smooth muscle origin (34). It has long been suspected that EBV acts in concert with other co-factors in the development of cancer, but those putative co-factors currently remain unidentified (33). 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 have 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, it is rare in Western countries with an annual incidence of less than 0.5 cases per 100,000 (34). 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 are linked with EBV. It is important to note that another infectious agent, human papillomavirus (HPV), has been implicated in the pathogenesis of squamous cell NPCs (34). Proposed risk factors for development of NPCs include exposure to salted fish at an early age and certain tumor-producing compounds, such as nitrosamines, which are found in some food products (35). Further, smoking has been established as a major risk factor for development of squamous cell NPCs (but not of non-keratinizing NPCs). It

has been suggested that smoking may account for up to two-thirds of squamous cell NPCs (34).

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 (36). 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 (36). Baumforth and others have hypothesized that perhaps the low percentage of EBV-associated cases in the U.S. is related to a loss of EBV at some point in tumor development (35).

Approximately 10% of gastric carcinoma cases (e.g., more than 50,000 cases per year) worldwide have EBV integrated into the cancer cells. Germany (18%) and the U.S. (16%) have the highest proportions of gastric carcinomas positive for EBV (37). 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 (37).

The development of Hodgkin's disease, a relatively uncommon cancer in the U.S., has long been thought to be associated with EBV. It has been reported that when 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 (38). 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 patients (39).

It has been suggested that 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 (39). 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 (36). EBV may be involved in the development of oral squamous cell carcinomas, especially since a proportion of patients with the disease do not smoke or consume alcohol (36). EBV has been associated with lymphoepithelioma-like carcinoma of the lung in Asian populations, but not in Western patients (40). The first report of an EBV-associated smooth muscle tumor of the kidney occurred in 1998 (41). EBV-associated smooth muscle neoplasms arising at other locations have been reported previously in patients with AIDS and in recipients of organ transplants (41).

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 (36).

In the future, if national clinical trials of treatments for EBV-positive gastric carcinoma commence, we should encourage participation in these trials of New Jersey institutions and of 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. As smoking appears to further increase the risk from Epstein-Barr virus for the development of squamous cell nasopharyngeal 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 (42-45). The human immunodeficiency virus (HIV) is the etiologic cause of AIDS (46). 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 their 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 individual's mortality and cancer risk (47), which raises the issue that smoking cessation programs need new emphasis among IDUs (47). 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") (45) might be involved (48). Although a herpes-like virus was linked with Kaposi's as long ago as 1972 (49;50), 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 (51;52). Almost all HIV-associated KS has occurred among men who have sex with men (MSMs). However, the evolving epidemiology of HHV-8 has demonstrated evidence of this virus in other risk groups, so the puzzle remains partially unresolved.

Non-Hodgkin's lymphoma (NHL), including primary brain lymphomas, also emerged early on as linked with the AIDS epidemic. The Epstein-Barr virus (EBV) 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 United States surveillance, newly include the occurrence of invasive cervical cancer (ICC) in an HIV-infected woman as a sufficient condition (53). The change was supported by data strongly linking cervical dysplasia with HIV infection (54), and by the finding by one group in New York City of an association with ICC (55). Thus, since that time, any woman infected with HIV who has ICC is automatically defined as having AIDS

(56). This led to an increase in the number of women defined as having AIDS, especially in New Jersey (57). However, later data has raised some questions about the nature of the association (58;59). Anal carcinoma and squamous dysplasia both appear to have increased among MSMs. Both anal carcinoma and cervical carcinoma are strongly associated with certain types of human papillomavirus (HPV). 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 MSMs and others at high risk warrants further clarification (60;61).

The New Jersey Department of Health and Senior Services recently reviewed the New Jersey experience concerning the occurrence of cancers among persons with AIDS (59). 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 (62;63) 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 (59;64-67).

A prospective cohort study in New Jersey of men and women at high risk for HIV was begun in 1984 (68). The increased risk of lung cancer (69), when examined in terms of New Jersey yearly incidence data by age, gender, and race for lung cancer (70), remains: 8.4 fold increased in HIV+ compared to expected, 2.7 fold increased in those HIV negative. The 3.1 fold higher rate among 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 (71-74), as well as with neurologic disease. Both HTLV-I and human T-cell lymphotropic virus type II (HTLV-II) are associated with immunologic abnormalities (75-78). It remains uncertain whether HTLV-II is linked to an increased risk for cancer (79). 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 (80;81). Current screening of blood donors has nearly eliminated the former risk of transfusion-related acquisition.

Hepatitis B and C viruses are discussed in the section on liver cancer. Human papillomavirus is discussed in further detail in the section on cervical cancer and below.

Steps that can be taken in the future to address issues in HIV and cancer include: monitoring cancer incidence trends in New Jersey among persons at increased risk for HIV and among those with HIV-infection; encouraging development of clinical trials that seek to improve survival in HIV-infected persons diagnosed with a malignancy; encouraging recruitment of persons for these trials, in light of many eligible persons being from groups that are historically less likely to participate in trials; 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; 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 (54); and, develop programs targeted to IDUs to reduce excessive use of tobacco products.

#### *HELICOBACTER PYLORI*

*Helicobacter pylori*, a type of bacteria that colonizes human stomachs, has been associated with an increased risk for development of peptic ulcer disease and gastric cancers, in particular non-cardia gastric adenocarcinoma and gastric non-Hodgkin's lymphomas of B cell type (82). 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 (83). Patients with chronic atrophic gastritis tend to have a particularly high risk of developing gastric carcinomas (83). 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 (83). 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 (84).

Meta-analyses have reported that *H. pylori* infection increases risk two-fold for gastric cancer development (85). More specifically, *H. pylori* infection is associated with a nearly six-fold increased risk of developing non-cardia gastric cancer (86). 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 adeno-carcinoma in the Western world (82).

It has been hypothesized that the cohabitation of humans and *H. pylori* for millions of years implies that some type of symbiotic relationship may exist (82). 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), and 2) increased antibiotic utilization (82). The fall in *H. pylori* colonization has been mirrored by a decrease in the incidence of gastric cancers.

However, there have been increasing rates of various esophageal diseases (i.e. gastroesophageal reflux or GERD, Barrett's esophagus, and adenocarcinomas of the lower esophagus) as well as gastric cardia adenocarcinomas (82). 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 (87). Infection with Cag+ strains is significantly associated with a reduced risk for adenocarcinomas of the esophagus and gastric cardia (88). These results suggest that eradication of *H. pylori* may be harmful, as protective effects may be lost.

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 nine-fold increased risk in developing non-cardia gastric cancer, while smokers infected with CagA+ *H. pylori* strains have a 17-fold increased risk for non-cardia gastric cancer (89).

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 (90). 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 (90).

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 (91). A strong association exists between the *H. pylori* infection status of parents and preschool-age children, suggesting that transmission may occur from parent to child. Specifically, as compared to children with uninfected mothers, preschool-age children of mothers infected by *H. pylori* have an almost eight-fold risk of being infected. As compared to children with uninfected fathers, children of infected fathers have nearly a four-fold risk (92). Further, infected individuals of higher birth order or from larger families may be at increased risk for developing gastric cancer (93).

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 (94). It has been estimated 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 has suggested that, once an effective vaccine for *H. pylori* is developed, vaccination might be considered for reducing gastric cancer (94).

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 (95). 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 (96) as well as other equally effective combinations, such as esomeprazole, clarithromycin, and amoxicillin (97) - 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 estimates that *H. pylori* screening may remain cost-effective at rates of cancer risk reduction of less than 30% (98). However, controlled studies are needed to prospectively confirm, and determine the amount of, noncardia gastric cancer risk reduction associated with *H. pylori* eradication. 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 (98).

Future considerations 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); 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; 4) providing funding for a research study led by

cancer epidemiologists in conjunction with local cancer registrars and the New Jersey State Cancer Registry to 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, and assess its utility for prospective surveillance. This study should be undertaken in the near term, before further advances in therapy or the development of a vaccine for *H. pylori*, so that adequate baseline data may be assessed.

#### *HUMAN PAPILLOMAVIRUS*

**H**uman papillomaviruses (HPVs) are DNA viruses that have been associated with the development of warts and a variety of cancers. HPVs can be separated into three categories based upon the risk of malignancy: low risk (including types 6, 11, 42, 43, 44), intermediate risk (including types 31, 33, 35, 51, 52, 58), or high risk (including types 16, 18, 45, 56) (99). Low-risk types are associated with benign lesions, which rarely become malignant, while intermediate-risk types are found in high-grade intraepithelial lesions. High-risk types are associated with intraepithelial and invasive cancers (99).

HPVs are very strongly linked to cervical cancer (100). HPVs are also associated with oral squamous cell carcinoma (OSCC), anorectal dysplasia and cancer, nasopharyngeal carcinoma (NPC), esophageal cancer, and squamous cell carcinomas of the larynx, vulva, and penis. HPV is transmitted by close contact of skin or mucosal surfaces to an infectious source. Genital HPV infection is sometimes observed in young children and among persons who deny ever having had sexual contact, raising the question whether transmission from environmental surfaces or transplacental transmission may sometimes take place (101).

Cervical cancer is the second most common cancer among women worldwide. In the U.S., the incidence of cervical cancer is nearly 9.8 per 100,000 women. Of the 15,700 new cases diagnosed annually, 4,900 result in death (102). The mean age for developing cervical cancer is 52, and the frequency of cases is highest for women 35-39 and 60-64 (103). While HPV (especially types 16 and 18) is the most strongly associated etiologic cause of cervical cancer, other factors such as smoking, tar-based vaginal douching, oral contraceptive use, inadequate nutrition (e.g., insufficient vitamins A, C, and E), age at first intercourse, number of partners, and possibly HIV or herpes simplex virus type 2 infection may be involved (102). Further, HPV infection is independently associated with number of sex partners, oral contraceptive use, younger age, and black race (104). Almost 90% of cervical cancers worldwide are attributed to HPVs, and HPV type 16 accounts for one-half of these cases (105). HPV type 16 predominates in squamous cell tumors, while HPV type 18 predominates in adenocarcinomas and adenosquamous tumors (105).

The mainstay for screening for cervical cancer in the United States has been the Papanicolaou (“Pap”) smear, a test that involves examining cells collected from the vagina and cervix for cancer detection. The American Cancer Society and the American College of Obstetricians and Gynecologists have recommended pelvic exams and Pap smears for women beginning at age 18 (99), and other groups additionally recommend screening for any woman who is, or may be, sexually active (106), independent of her partner’s gender(s) (54;107). Annual screening has been common practice in the United States for many years, although evidence to suggest that outcomes are substantially better with annual than with

biennial or triennial screening is limited at best (106). Although the screening interval may now be somewhat controversial, the need for regular screening is not. There still remain major gaps in New Jersey in the delivery of routine gynecologic care, including screening (54;108). The advent of newer methods of HPV detection and innovations in cervical cancer screening, including ThinPrep Papanicolaou tests, are leading to reassessment of screening guidelines (106).

Vulvar carcinoma has been associated with HPV infection, but this association is not as strong as it is for cervical cancer. The highest incidence of vulvar carcinoma occurs at age 80, and most women with this cancer are between the ages of 65 and 80 (109). It has been reported that up to 60% of vulvar carcinomas may be associated with HPV, but results vary depending on the method used for detecting HPV (110). HPV type 16 is the predominant type found among the cases of vulvar carcinoma (110).

Penile cancer is rare in the Western world with an incidence of less than 1 per 100,000. Common risk factors for penile cancer include phimosis, lack of circumcision (although this has recently again become controversial), balanitis, lichen sclerosus et atrophicus, smoking, UV light irradiation, number of sexual partners, and HPV infection (111;112). Approximately 40% of penile cancer cases are associated with HPV, and HPV type 16 is the predominant type found in these cases (111).

Anal dysplasia is common in biopsy specimens from homosexual men with visible HPV-associated internal anal abnormalities. Natural history studies are needed to better determine the clinical significance of anal dysplasia, rates of progression to cancer, and the role of screening and therapy (60;113).

Women who have anal sex may also be at increased risk for anorectal dysplasia (114).

Oral cancer, a common cancer in the U.S. (e.g., over 30,000 cases diagnosed each year), leads to 7,800 deaths per year (115). Risk factors for OSCC, the most common type of oral cancer, include diets low in fruits and vegetables, smoking, and alcohol consumption (116). Recently, HPV has been suggested as a possible risk factor for OSCC. One meta-analysis suggests that HPV is more than five times more likely to be detected in patients with OSCC than in patients with normal, noncancerous oral mucosa (115). Furthermore, up to 60% of OSCC cases may be associated with HPV infection (116). Specifically, HPV types 16 and 18 were present at higher rates than other HPV types among patients with OSCC (116).

Laryngeal cancer, which accounts for 1.2% of cancer cases in the U.S., may be associated with HPV. More than 90% of laryngeal cancers are squamous cell carcinomas (SCCs). Risk factors for laryngeal cancer include alcohol and tobacco use (117). HPV type 16 was the most commonly found type in patients with laryngeal cancer. However, there are no definitive data concerning the percentage of laryngeal SCCs associated with HPV (117). Estimates vary from 8% to 54% (117).

Esophageal cancer is known to be caused by smoking and alcohol consumption, but there is conflicting data concerning its association with HPV (118). Nearly 287,000 deaths due to esophageal cancer occur each year. Incidence of this cancer is higher among men (118). Several studies have suggested that an association exists between HPV infection and development of esophageal cancer. HPV types 16 and 18 are detected at higher rates in patients with esophageal SCC, and HPV type 16 has been associated with an increased risk

for esophageal cancer (119). However, Lagergren has recently reported that infection with HPV types 16 or 18 is not associated with higher risk for esophageal adenocarcinoma or esophageal SCC (118).

Nasopharyngeal cancer (NPC) is a relatively uncommon cancer with a worldwide incidence of 1 in 100,000, but the incidence is higher in certain areas, such as Southeast Asia and North Africa (120). The possible relationship between EBV and squamous cell NPCs is not fully clear (see section on EBV). There is evidence of an association between HPV and squamous cell NPCs. Preliminary findings suggest that up to 50% of NPC cases in American Caucasians may be associated with HPV (120). Proposed risk factors for development of NPCs include exposure to salted fish at an early age, nitrosamines (which are found in some food products), and smoking (35). Smoking may account for up to two-thirds of all squamous cell NPC cases (34).

Recommendations with respect to specific cancers noted above, and especially regarding cervical cancer, may be found in their respective chapters.

#### *LIVER CANCER*

**P**rimary 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 (121). Cases are usually rapidly fatal.

Infection with either hepatitis B virus (HBV) or hepatitis C virus (HCV) are important risk factors for the development of HCC (122-124). Infection with HBV early in life appears to be a much stronger risk factor for HCC than acquisition of HBV in adulthood

(121). 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 (125). Chronic infection with HBV has been associated with HCC even in the absence of detectable serum HbsAg (126). It has been suggested that the use of a hepatitis B virus vaccine, which provides durable immunity in very young children, will probably prevent most cases of HCC (127). Vaccination against HBV is currently recommended for all children in the United States (128;129).

Worldwide, exposure to aflatoxins is also a major risk for HCC (130). 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) (130-132).

HCC incidence in the United States has recently been rising (133), with HCV the suspected cause (134). 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) (70). 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 (70).

HCV is believed to have spread extensively among injection drug users (IDUs) in the United States during the 1970s and early 1980s, with particularly high rates in New Jersey that reach 99% in one statewide cohort (135). 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 human immunodeficiency virus [HIV] negative and positive persons)

(135;136). 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) (137;138). In the United States, about 2.7 million persons are chronically infected with HCV (139). Among United States' 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 (139). However, tattooing and body piercing are risk factors for HBV and HCV (140), as well as other parenterally transmissible pathogens such as human immunodeficiency virus (HIV). HIV infection appears to worsen this natural history of chronic parenterally acquired hepatitis C, leading to an unusually rapid progression to cirrhosis (141;142).

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 (143). These data reinforce the importance of prevention measures, including the primary prevention approach of vaccination.

Future steps in liver cancer should include: continuing support for vaccination of New Jersey children against HBV in accordance with CDC guidelines; increasing efforts to identify and vaccinate adults at risk for HBV and HCV; continuing epidemiologic studies examining HCC risk and efforts to explore whether there are predictive markers or co-factors amongst HCV-infected persons; monitoring HCC incidence trends in New Jersey; encouraging clinical trials that seek to improve survival in persons diagnosed with HCC; and considering establishing regulations to reduce HBV, HCV, and retroviral transmission that can occur in establishments engaged in tattooing, body piercing, or similar practices (144;145).

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## CHAPTER 14. Implementation

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## IMPLEMENTATION

The next step for the *New Jersey Comprehensive Cancer Control Plan* is implementation. Submission of the Task Force report to the Governor benchmarks not the end of the process but rather a beginning. Critical to the success of implementation will be the essential elements as identified by the Implementation Ad Hoc Committee and briefly discussed below – assessment, funding, and coordination.

### ASSESSMENT

Although some new programs and services may arise from recommendations of the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey, comprehensive cancer control planning is not only about creating new programs and services, but also first and foremost about coordinating and integrating what is already there. New Jersey is fortunate to have many resources to draw upon, and the Task Force and its workgroups and subcommittees have spent many months familiarizing themselves with some of these resources. However, a number of recommendations in the *Plan* address the importance of learning what capacity currently exists throughout the state – and where the need for services is greatest – before forging ahead to develop new programs. Without a baseline capacity and needs assessment, we run the risk of overlooking major gaps in some parts of the state and of duplicating efforts in other parts of the state.

North Carolina, one of the earliest states to develop and implement a comprehensive cancer control plan, recognized that a comprehensive inventory would promote information sharing and communication among diverse groups (1). Conducting a Capacity and Needs Assessment should thus be an early step in the implementation process. A Capacity and Needs Assessment will provide information on the best approach to implementing the *Plan*, help keep the implementation process on target, and provide

both baseline and (over time) follow-up information for evaluation purposes (2).

Conducting a Capacity and Needs Assessment will bring together the efforts of both public and private agencies that have already begun to inventory the many cancer control activities in our state. From this baseline, ongoing identification of organizations and programs and a dissemination of the information will be undertaken. Individual capacity and needs assessment strategies have been built into separate chapters of the *Comprehensive Cancer Control Plan*. However, by designating assessment as an overall implementation strategy and setting it as our first implementation objective, we stress the importance the Task Force assigns to developing a centralized cancer resource for New Jersey's many constituents.

### FUNDING

Funding sources are extremely critical to successful implementation. The Implementation Ad Hoc Committee recommends that an action group be dedicated to identifying and obtaining funding for plan implementation, as well as for administrative support to further this initiative. However, as the Centers for Disease Control and Prevention (CDC) points out in its *Guidance Document*, this ongoing activity of mobilizing support involves more than merely securing funding. It requires a broad campaign that will provide visibility, develop political good will, and enhance awareness of community leaders who may become advocates for both

funding and implementing portions of the *Plan* (2).

## **COORDINATION**

Finally, all of these efforts cannot be accomplished without coordination and communication. Designating an agency to coordinate and monitor plan implementation is one of the CDC building blocks for comprehensive cancer control that become the foundation for implementing the plan and institutionalizing the initiative (2). The coordinating agency will facilitate the process of achieving unity of effort among diverse participants and diverse activities so that the goals and objectives in the *Plan* are attained (3). Successful implementation will depend on effective coordination and communication among the many committed organizations and the myriad rich resources here in New Jersey. The Implementation Ad Hoc Committee recognizes the many facets necessary for coordination. Committee members further believe that internally monitoring plan

implementation and communicating with partners about programs, resources, and best practices through multiple media will assist in guiding joint efforts and benchmarking progress. Coordination and communication will not only foster synergy among the stakeholders but will also ultimately benefit all the citizens of New Jersey through enhanced cancer prevention and control.

The Task Force on Cancer Prevention, Early Detection and Treatment and its workgroups and subcommittees has 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 Jerseyans. Recognizing that coalition building, partnerships, and education are essential to fruition of the *Plan*, the Implementation Ad Hoc Committee presents the following goal, objectives, and strategies for implementation.

## GOALS, OBJECTIVES AND STRATEGIES

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### GOAL IM-1:

To implement the *New Jersey Comprehensive Cancer Control Plan*.

#### Objective IM-1.1:

To conduct a Cancer Capacity and Needs Assessment for New Jersey.

##### Strategies:

- (IM-1.1.1) Identify and develop a database inventory of those organizations and programs that engage in or support cancer control-related activities.
- (IM-1.1.2) Partner with key stakeholders to identify gaps in cancer control-related program and activities.
- (IM-1.1.3) Disseminate results of the Capacity and Needs Assessment using multiple media, especially the internet.

#### Objective IM-1.2:

To identify funding streams for implementation of the *New Jersey Comprehensive Cancer Control Plan*.

##### Strategies:

- (IM-1.2.1) Create a Funding and Resources Action Group to identify and obtain funding for the *New Jersey Comprehensive Cancer Control Plan*.
- (IM-1.2.2) 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) Transition Task Force workgroups and subcommittees into Action Groups.
- (IM-1.3.2) Empower Action Groups to prioritize strategies and obtain commitments from respective organizations and agencies.

**Objective IM-1.4:**

To develop a framework for the assessment of progress made toward achievement of goals, objectives, and strategies for the *New Jersey Comprehensive Cancer Control Plan*.

**Strategies**

- (IM-1.4.1) Internally monitor implementation activities of the Action Groups.
- (IM-1.4.2) Share programs, resources, and best practices through such means as a newsletter, website, and/or annual conference.
- (IM-1.4.3) 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*.

**Strategies:**

- (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.
- (IM-1.5.2) Honor survivors and memorialize those who have been part of the battle against cancer in New Jersey.

- (IM-1.5.3) Investigate further solicitation of agencies for partnering with the *New Jersey Comprehensive Cancer Control Plan* through strategies such as an implementation website.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

New Jersey Department of Health and Senior Services: IM-1.1.1; IM-1.1.2; IM-1.1.3; IM-1.2.1; IM-1.2.2; IM-1.3.1; IM-1.3.2; IM-1.4.1; IM-1.4.3; IM-1.5.1; IM-1.5.2; IM-1.5.3

New Jersey Department of Health and Senior Services, Office of Cancer Control and Prevention: IM-1.1.1; IM-1.1.2; IM-1.1.3; IM-1.3.1; IM-1.3.2; IM-1.4.1; IM-1.4.2; IM-1.4.3; IM-1.5.1; IM-1.5.2; IM-1.5.3

## IMPLEMENTATION

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Implement the Comprehensive Cancer Control Plan	1.1: Conduct capacity and needs assessments	IM-1.1.1						
		IM-1.1.2						
		IM-1.1.3						
	1.2: Identify funding streams	IM-1.2.1						
		IM-1.2.2						
		IM-1.3.1						
	1.3: Coordinate/mobilize key stakeholders	IM-1.3.2						
		IM-1.4.1						
		IM-1.4.2						
	1.4: Develop framework for assessment	IM-1.4.3						
		IM-1.5.1						
		IM-1.5.2						
		IM-1.5.3						

**Target Completion Date**

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## CHAPTER 15. Evaluation

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Office of Cancer Control and Prevention

## EVALUATION

Evaluation is critical to ongoing success and utility of the *New Jersey Comprehensive Cancer Control Plan*. Charged by Executive Order 114, the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey is responsible not only for reporting initial findings to the Governor, but thereafter for submitting biennial reports (1). Recognizing the importance of obtaining data on implementation progress over time for the biennial reports to the Governor, the Task Force charged an Ad Hoc Committee with development of an Evaluation Chapter for the *Plan*. In preparing this chapter, the Committee reviewed best practices by the comprehensive cancer control model planning states and the comprehensive cancer control implementation grantees funded by the Centers for Disease Control and Prevention (CDC), especially the states of Kentucky, Maine, Michigan, and North Carolina. The Committee also considered recommendations by Battelle Centers for Public Health Research and Evaluation, a consultant to the Task Force throughout the planning process.

The conceptual model developed by Battelle for CDC's Division of Cancer Prevention and Control presents an outcomes-based planning and implementation process, the long-range goal of which is to achieve significant reductions in the incidence, morbidity, and mortality of cancer among all citizens (2). In this model, Evaluation is considered as one of the six "building blocks" of comprehensive cancer control – 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 has built evaluation into its *Plan* to assist Task Force members in visualizing what success will look like and in documenting that success over time. Evaluation has been part of New Jersey's

planning process from the outset. For example, evaluation activities were conducted after each Task Force and workgroup meeting to benchmark participant satisfaction and to guide "continuous quality improvement" in process and procedures.

CDC and Battelle recommend evaluating the comprehensive cancer control process as a whole as well as each respective phase – planning, implementation, and institutionalization – while also preparing to measure long-term health outcomes. Comprehensive cancer control is a highly complex and dynamic initiative, and many of its outcomes are relatively intangible and difficult to "measure", such as improved working relationships among partners (2). Attempting to measure health outcomes prematurely (such as decreases in morbidity and mortality or reductions in disparities) can lead to disappointing results. While the health outcomes remain always in view as the ultimate outcome desired, they will not be achieved until some years hence. Task Force efforts are currently concentrated on building an implementation infrastructure able to put into action the statewide cancer plan that New Jersey cancer experts believe will lead to the desired health outcomes. It is documenting success in this aspect of the endeavor that should be the initial evaluation focus, while systems are established to eventually measure long-term health outcomes.

A number of states have already developed feasible approaches to evaluating their comprehensive cancer control initiatives. North Carolina, for example, recognized the critical need for evaluation in its 1996 – 2001 *Plan* and realized that without monitoring and documentation, the effectiveness of their efforts would be unknown, state resources would be less than wisely utilized, and the

development of future plans might be hindered (3). Michigan, in the case study of their comprehensive cancer control planning process, set short- and long-term goals to assess outcomes of the implementation process, while monitoring the process as a whole in an ongoing manner (4).

Availability of adequate evaluation data is critical for the effective implementation of the *New Jersey Comprehensive Cancer Control Plan*, as well as for the development of future plans (3). While the Ad Hoc Committee realizes that incidence and mortality change is a long-term goal, measurement of the ongoing process to achieve that change is also essential.

The Evaluation Ad Hoc Committee has determined that convening an Evaluation Planning Workgroup and identifying and

securing funding for evaluation represent critical first steps in developing an evaluation strategy for the New Jersey comprehensive cancer control process. The Committee also recognized the importance of utilizing an outside agency to develop and implement an Evaluation Plan, based on the 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 a professional evaluator (5).

Below the goal, objective, and strategies developed by the Task Force's Evaluation Ad Hoc Committee to initiate development of an evaluation design for New Jersey's comprehensive cancer control process are presented.

## GOALS, OBJECTIVES AND STRATEGIES

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### GOAL EV-1:

To evaluate the *New Jersey Comprehensive Cancer Control Plan* by assessing the implementation and effectiveness of its strategies, by determining its impact on the knowledge and behavior of the citizens of New Jersey, and by measuring resultant changes in health outcomes.

### Objective EV-1.1:

To develop and implement an Evaluation Plan for the *New Jersey Comprehensive Cancer Control Plan*.

### Strategies:

- (EV-1.1.1) Identify members of an Evaluation Planning Workgroup.
- (EV-1.1.2) Identify and secure funding for evaluation of the *Plan*.
- (EV-1.1.3) Identify, through an RFP process, a New Jersey academic institution to develop and implement an Evaluation Plan in partnership with the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey,  
Evaluation Ad Hoc Committee: EV-1.1.1; EV-1.1.2; EV-1.1.3  
University of Medicine and Dentistry of New Jersey – School of Public Health:  
EV-1.1.3

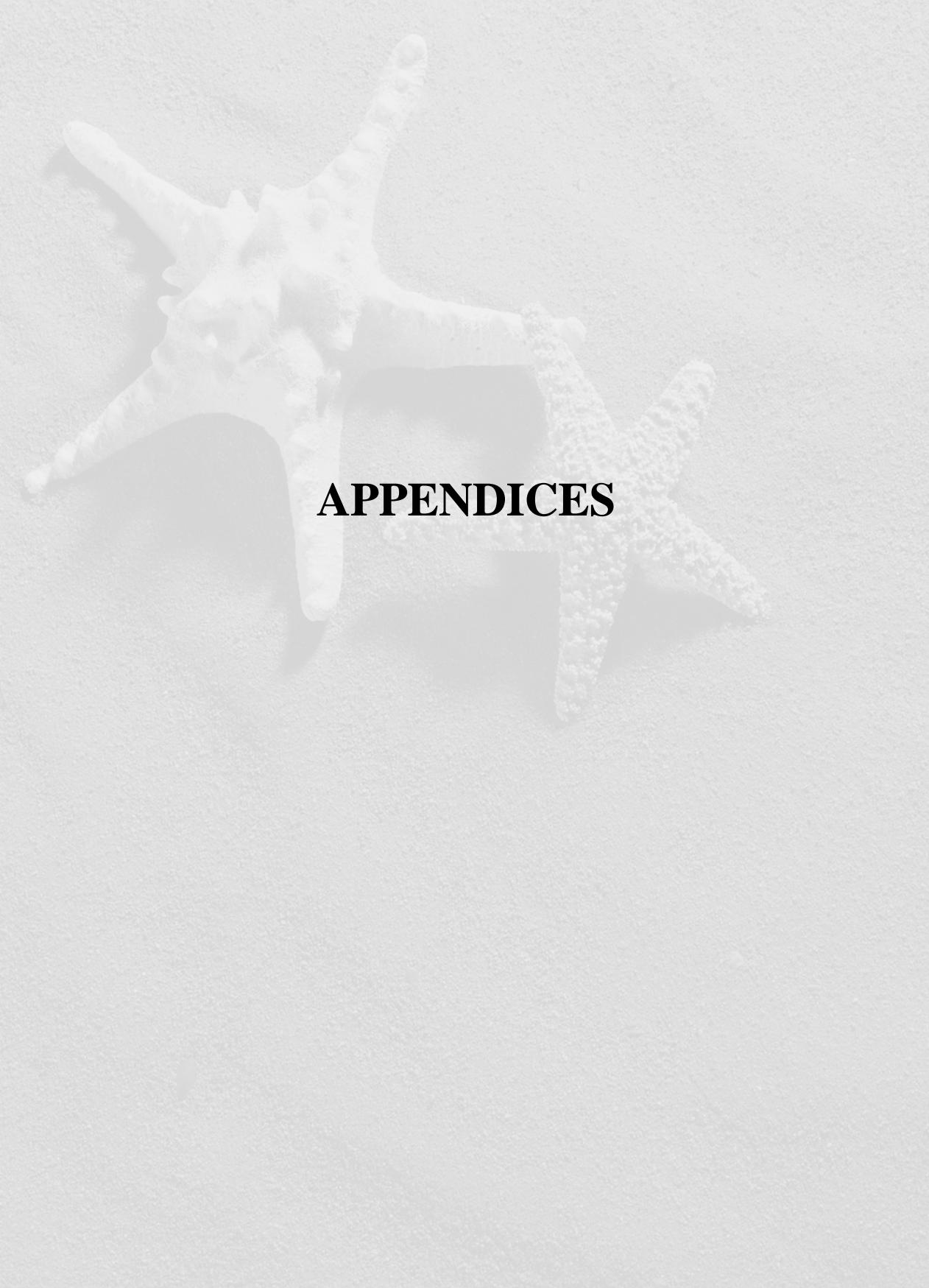
## EVALUATION

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Evaluate the Comprehensive Cancer Control Plan	1.1: Develop/implement an Evaluation Plan	EV-1.1.1						
		EV-1.1.2						
		EV-1.1.3						

Target Completion Date

## **References**

- (1) State of New Jersey Executive Department. Executive Order 114. 5-9-2000. Governor Christine Todd Whitman.
- (2) Abed, J. Establishing feasible priorities: A model for the collaboration and integration of cancer control and prevention. Presentation at Battelle Centers for Public Health Research and Evaluation, 2000.
- (3) Advisory Committee on Cancer Coordination and Control. North Carolina Cancer Control Plan 1996-2001. Raleigh, NC: North Carolina Department of Environment, Health, and Natural Resources, 1996.
- (4) Abed J, Kasprzyk D, Butler MO. Case study of Michigan Comprehensive Cancer Initiative. Arlington, VA: Battelle Centers for Public Health Research and Evaluation, 1998.
- (5) Centers for Disease Control and Prevention, Battelle Centers for Public Health Research and Evaluation. Guidance for Comprehensive Cancer Control Planning. Atlanta, GA: Centers for Disease Control and Prevention, 2002.



## **APPENDICES**



## APPENDIX A: MISSION STATEMENT

### **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:** **CHAPTER CONTRIBUTORS**

The Task Force on Prevention, Early Detection and Treatment in New Jersey gratefully acknowledges the workgroup and subcommittee members who have collaborated on developing language for major section of the *Plan*:

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### **THE BURDEN OF CANCER IN NEW JERSEY**

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- Stanley H. Weiss, MD, FACP

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## **SECTION III: THE FUTURE OF CANCER CONTROL AND PREVENTION IN NEW JERSEY**

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- Linda Johnson

### **CHAPTER 15: EVALUATION**

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## **APPENDICES**

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- Susie S. Ahn
- Anna Ruth Thies, MA, RN

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## **BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM**

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- Georgette K. Boeselager
- Kenneth J. O'Dowd

## APPENDIX C: GLOSSARY

- Advanced Practice Nurse** - registered nurse with master's level nursing education who provides expert clinical care in settings including but not limited to acute and long-term care facilities and ambulatory care clinics.
- Aflatoxins** - group of toxic compounds produced by certain molds which is a powerful liver carcinogen
- Age-adjusted** - rates in which statistical procedures have been applied to remove the effect of differences in composition of the various populations
- Basal cell** - most common form of skin cancer
- Biological marker** - genetic, biological, chemical measurements taken from a sample of biological material used to detect preclinical disease
- Biotherapy** - treatment of disease with biologicals, such as certain drugs, vaccines, or antitoxins
- Body Mass Index** - weight in kilograms divided by height in meters squared
- BRCA-I** - breast cancer susceptibility gene localized to chromosome 13q12-q13 which influences vulnerability to breast and ovarian cancer
- BRCA-II** - breast cancer susceptibility gene localized to chromosome 17 q-linked which influences vulnerability to breast and ovarian cancer
- Breast Self-Exam (BSE)** - systematic method of self-inspection and palpation of the breast and axilla
- Cachexia** - a general wasting of the body during a chronic disease
- Carcinoma-in-situ** - cancer that involves only the cells in which it began and has not spread to other tissues
- Chemotherapy** - treatment used with anti-cancer drugs to achieve a cure
- Cholangiocarcinoma** - relatively rare cancer that arises from the cells of the bile duct (passages external to the liver)

<b>Cumulative risk</b>	- accumulated probability that an event will occur
<b>Cytology</b>	- the study of cells
<b>Cytotechnologist</b>	- individual that specializes in the study of cells
<b>Dendritic cell</b>	- branched protoplasmic extension of a nerve cell that conducts impulses from adjacent cells inward toward the cell body
<b>Disparities</b>	- condition or fact of being unequal, as in age or rank
<b>Etiology</b>	- study of medicine that deals with the causes or origins of disease
<b>False-negative rates</b>	- (in the cases of screening test results) the individuals who are screened as negative but truly have the condition or disease
<b>Hyperplastic</b>	- of or pertaining to abnormal increase in the number of normal cells
<b>Incidence</b>	- describes the number of newly diagnosed cases of a disease in a defined population in a specific time
<b>Immunotherapy</b>	- treatment to stimulate or restore the ability of the immune system to fight infection and disease
<b>Inpatient</b>	- patient temporarily confined to an institution such as a hospital or nursing home, where there is an overnight stay
<b>Latent</b>	- present or potential but not evident or active
<b>Malignant</b>	- cancerous
<b>Mammography</b>	- tool where the breast is compressed and two views are taken, plain film or xeromammography for the purpose of detecting abnormalities
<b>Managed Care</b>	- system that combines the functions of health insurance and actual delivery of care
<b>Molecular markers</b>	- molecules that identify physical location on a chromosome
<b>Mortality rate</b>	- describes the number of deaths that occur in a defined population in a specific time period

<b>Nutraceuticals/ functional foods</b>	- food or naturally occurring food supplement thought to have a beneficial effect on human health
<b>Nutrition</b>	- study that deals with food and nourishment
<b>Oncology</b>	- study of cancer
<b>Oropharyngeal</b>	- relating to the area of the throat at the back of the mouth
<b>Palliative care</b>	- enhancing the quality of life of patients with cancer and other illnesses by targeting physical and psychological symptoms and spiritual needs from the time of diagnosis to end of life care in all settings
<b>Papnicolaou test (Pap test)</b>	- method of examining stained cells in a cervical smear for early diagnosis of uterine cancer
<b>Photographic- mole mapping</b>	- procedure, through the use of a dye and radioactive tracer injection, that attempts to determine the presence or absence of spread of melanoma to the draining lymph nodes
<b>Preclinical</b>	- relating to the period of a disease before the appearance of symptoms
<b>Prevalence</b>	- refers to the number of existing cases of a disease or health condition in a population including incidence cases
<b>Registered Nurse (RN)</b>	- trained medical professional who has passed a state registration examination, has been licensed to practice nursing, and assists people in healthcare settings
<b>Squamous cell (carcinoma)</b>	- form of cancer that can be seen on the skin, lips, inside the mouth, throat, or esophagus
<b>Stage of diagnosis</b>	- stage at which a disease or health condition is identified; at diagnosis (from early to late) may be expressed as numbers (I, II, III, or IV, for example) or by terms such as “localized,” “regional,” and “distant”
<b>Ultraviolet (UV) light</b>	- solar ultraviolet radiation

## APPENDIX D: ABBREVIATIONS AND ACRONYMS

ACS	--	American Cancer Society
ACEs	--	Active Community Environments
ACoS	--	American College of Surgeons
AIDS	--	Acquired Immune Deficiency Syndrome
BCCEED	--	Bergen County Cancer Education and Early Detection Program
BMI	--	Body Mass Index
BRCA-I	--	Breast cancer susceptibility gene localized to chromosome 13q12-q13
BRCA-II	--	Breast cancer susceptibility gene localized to chromosome 17q-linked
BRFSS	--	Behavioral Risk Factor Surveillance System
BSE	--	Breast Self Examination
CAM	--	Complementary and Alternative Medicine
CBE	--	Clinical Breast Examination
CCSS	--	Childhood Cancer Survivor Study
CDC	--	Centers for Disease Control and Prevention
CME	--	Continuing Medical Education
CNS	--	Central Nervous System
COBRA	--	Consolidated Omnibus Budget Reconciliation Act
CT	--	Computer Tomography (scan)
CTCv2	--	Common Toxicity Criteria, version 2 of NCI
CXR	--	Chest X-ray
DCBE	--	Double Contrast Barium Enema

DME	--	Direct Medical Education
DRE	--	Digital Rectal Exam
DTC	--	Direct-to-consumer
EBV	--	Epstein-Barr Virus
ELCAP	--	Early Lung Cancer Action Project
ETS	--	Environmental Tobacco Smoke
FDA	--	United States Food and Drug Administration
Flex Sig	--	Flexible Sigmoidoscopy
FMLA	--	Family Medical Leave Act
FOBT	--	Fecal Occult Blood Test
GASP	--	New Jersey Group Against Smoking Pollution
GIS	--	Geographic Information System
HBV	--	Hepatitis B Virus
HCC	--	Hepatocellular Carcinoma
HCFA	--	Health Care Finance Administration
HCV	--	Hepatitis C Virus
HHV-8	--	Human Herpes Virus Type 8
HIV	--	Human Immunodeficiency Virus
HMO	--	Health Maintenance Organization
HP2010	--	Healthy People 2010
HPV	--	Human Papilloma Virus
HSNE	--	Healthy Schools Nutrition Environment
HTLV-1 & 2	--	Human T-cell Lymphotropic Virus type 1 & 2

ICC	--	Invasive Cervical Cancer
IDU	--	Injection Drug User
IME	--	Indirect Medical Education
KS-HV	--	Kaposi's Associated Herpes Virus
LINCS	--	Local Information Network and Communication System
MCO	--	Managed Care Organization
MSM	--	Men Who Have Sex with Men
N/A	--	Not Applicable
NCDB	--	National Cancer Data Base
NCHS	--	National Center for Health Statistics
NCI	--	National Cancer Institute
NHANES	--	National Health and Nutrition Examination Survey
NHIS	--	National Health Interview Survey
NHL	--	Non-Hodgkin's Lymphoma
NJCEED	--	New Jersey Cancer Education and Early Detection Program
NJCCR	--	New Jersey Commission on Cancer Research
NJCPFS	--	New Jersey Council on Physical Fitness and Sports
NJDHSS	--	New Jersey Department of Health and Senior Services
NJDOE	--	New Jersey Department of Education
NJDOT	--	New Jersey Department of Transportation
NJSCR	--	New Jersey State Cancer Registry
HPDP	--	Health Promotion and Disease Prevention
OCCP	--	Office of Cancer Control and Prevention, New Jersey Department of Health and Senior Services

PHS	--	Public Health Service
PRONJ	--	Peer Review Organization of New Jersey
PSA	--	Prostate Specific Antigen
PTSD	--	Post Traumatic Stress Disorder
QALY	--	Quality Adjusted Life Year
RCE	--	Rutgers Cooperative Extension
RFP	--	Request for Proposal
SCCA	--	Squamous Cell Carcinoma
SEER	--	Surveillance, Epidemiology, and End Results
SES	--	Socioeconomic Status
SMN	--	Second malignant neoplasms
SNB	--	Sentinel Node Biopsy
SPOHNC	--	Support For People With Head Neck Cancer, Inc. < <a href="http://www.hncancer.com">http://www.hncancer.com</a> >
UMDNJ	--	University of Medicine and Dentistry of New Jersey
WHO	--	World Health Organization
WIC	--	Women, Infants, and Children Program

## **APPENDIX E:** **THE NEW JERSEY CANCER EDUCATION AND** **EARLY DETECTION SCREENING PROGRAM (NJCEED)**

The New Jersey Cancer Education and Early Detection (NJCEED) Screening 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 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 25 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.

### **References**

- (1) Lee NC. The national breast and cervical cancer early detection program: 10 years of progress. *Chronic Disease Notes and Reports* 2000; 13(3):5-23.
- (2) Centers for Disease Control and Prevention. The National Breast and Cervical Cancer Early Detection Program 2001. Atlanta, GA: Centers for Disease Control and Prevention, 2001.
- (3) New Breast and Cervical Cancer Treatment Option Adopted by States. Issue Brief 01-42. Washington, D.C., Federal Funds Information for States, 2001.
- (4) NJCEED. New Jersey Cancer Education and Early Detection (NJCEED) Program Annual Report. Trenton, NJ: New Jersey Department of Health and Senior Services, 2001.

## **APPENDIX F:** **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 organization 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.

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#### **For more information:**

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

**National Cancer Institute:** [www.nci.nih.gov](http://www.nci.nih.gov)

**National Guideline Clearinghouse:** [www.guideline.gov/NAVBARs/top\\_home.asp](http://www.guideline.gov/NAVBARs/top_home.asp)

**U.S. Preventive Services Task Force:** [www.ahcpr.gov/clinic/uspstfix.htm](http://www.ahcpr.gov/clinic/uspstfix.htm)