New York State Comprehensive Cancer Control Plan

Strategic Directions for New York State

2003-2010

Dear Reader:

The New York State Department of Health and the American Cancer Society are very pleased to present the first-ever *New York State Comprehensive Cancer Control Plan*. The plan is a collaborative effort intended as a road map for the years 2003-2010, to achieve reductions in cancer rates and improve outcomes for people with cancer in New York State.

This plan is unprecedented in the level of collaboration involved in its creation. Experts from across the state participated in the plan development process. Community Forums were held to collect ideas from advocacy groups, survivors, and additional experts. Finally, a Leadership Summit brought together additional stakeholders to refine cancer control strategies. The insights garnered from all of these dedicated individuals were the fabric of the final document.

New York is a large culturally, ethnically, and geographically diverse state. The challenge of our diversity is also our strength. Optimal health for all New Yorkers and care provided in a culturally sensitive manner is dependent on the commitment of individuals and organizations throughout the state. As we implement this Plan, the community of cancer control professionals and advocates and other interested parties will be critical to the success of our joint undertaking.

The Department and ACS would like to thank the many committed individuals who came together to create our vision: to reduce the burden of cancer in New York. We welcome your comments and participation as we continue our work in cancer control.

Sincerely,

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Foreword

Comprehensive cancer control is achieved through a partnership of public and private stakeholders whose common mission is to reduce the overall burden of cancer. These stakeholders review epidemiological data and research evidence (including program evaluation data) and then jointly set priorities for action. This partnership mobilizes support for implementing these priorities, puts in place coordinated activities, monitors progress over time, and reassesses priorities periodically in light of emerging developments in cancer and related fields.

Cancer is the second leading cause of death in New York State as well as the nation. An estimated 86,000 people will be diagnosed with cancer in New York State in 2003 — nearly 235 people each day of the year. An estimated 36,000 New Yorkers will die from cancer — about 100 individuals each day. Four cancer sites account for 56% of the total cancer burden — lung, colorectal, breast and prostate cancers. These same four cancers are responsible for 51 percent of all cancer deaths in New York State.

While we have made significant progress over the last decade, primarily in reducing cancer mortality, much remains to be done to better prevent and control cancer. The New York State Comprehensive Cancer Control Plan (NYSCCCP) outlines the steps to be taken. Individuals and people representing organizations from across the State have collaborated to put together this Plan. It offers a collective, statewide vision to advance, accelerate, and focus on the war on cancer over the next seven years, from now until 2010.

The process undertaken to develop the Plan occurred over a period of about 18 months. That process is perhaps unprecedented in its effort to be inclusive. The plan development process was coordinated through the combined leadership of the American Cancer Society and the New York State Department of Health; and it is a plan that has been developed through a partnership of hundreds of people and organizations.

A Core Work Group helped coordinate the many facets of the Plan and ensured broad-based participation. Other state plans were reviewed and referenced. Stakeholder Surveys were sent to approximately 400 organizations and individuals to seek their ideas on the key issues and solicit input on suggested goals and strategies. Nine Goal Development Teams were created, comprised of 65 experts and advocates, around the nine goal areas of the Plan, and they identified a preliminary set of goals and strategies. Ten Community Forums were conducted across the State in which over 300 people reviewed and commented on a draft of the Plan. The forum comments were then incorporated into the Plan.

A two day Leadership Summit was held where experts and advocates met to provide final review and comment on the Plan and to indicate their commitment once the implementation phases begin.

This Plan focuses on the multiple areas related to the burden of cancer in New York State.

The magnitude and scope of this Plan is notable. It covers the spectrum of issues and concerns regarding cancer control, prevention, and quality of life. This Plan focuses on the multiple areas related to the burden of cancer in New York State. The Plan is a vehicle for consensus building about goals and strategies among the many stakeholders, and it also offers several other benefits. It gives us the opportunity to create partnerships for collaboration to implement the Plan, necessary since no single organization or agency has the capacity to address all the cancer control needs within a state. It promotes a public health approach to addressing cancer through activities such as monitoring and surveillance, public education, and outreach. The Plan helps us determine where and how health care providers deliver services in a coordinated, integrated manner. A comprehensive approach to cancer prevention and control will enable stakeholders to continue to address disparities among racial and ethnic minority groups and medically underserved populations.

We are witnessing a series of exciting developments in the war on cancer that serve to further enhance the impact of the Plan. These include promising developments in the field of treatment; historic efforts in prevention, from tobacco cessation to diet, to avoidance of sun exposure; multiple data sources that can provide more information than ever before; increasing emphasis on pain management, quality of life, and psychosocial support services; and, the growing recognition of the effect cancer has on family and other loved ones and the need to develop services accordingly.

The characteristics of the New York State Comprehensive Cancer Control Plan — its goals and strategies, magnitude and scope, broad participation and commitment to implementation, and the promising developments in addressing cancer — give all of us a collective means to reduce the burden of cancer. We intend to make the most of it.

Next Steps

No one organization can hope to undertake all of the goals and strategies developed within this Plan. Implementation will be the responsibility of all partners. Linkages and partnerships between groups involved in Plan activities will be vital to implementing this Plan and ensuring its success over time.

An Implementation Advisory Committee, comprised of stakeholders who have participated in the development of the plan, is charged with identifying priorities and moving the plan into action. Contributions from multiple parties and coordination of their efforts are critical to addressing cancer control needs within the State. Not all goals and strategies can be undertaken simultaneously. Thus, the goals and strategies that will be implemented initially are those that partners are poised to put in place and that affect the most common types of cancer. Over time, the intention is to implement all the goals in the Plan.

An Evaluation Committee will be convened to monitor the implementation of Plan goals and strategies. The Evaluation Committee members will design an evaluation, collect data on implementation progress, and determine the need for any “mid-course” correction and how that correction might be achieved.

Our expectations are to implement a plan over the next several years for the citizens of New York State that continues to move our State into a leadership position nationwide in cancer prevention, control, and quality of life.

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A Core Work Group was developed to help coordinate the many facets of putting the Plan together and to ensure broad-based participation.

National Overview

Every day 1500 Americans die from cancer.[1] In 2003, it is estimated that cancer will claim another 556,500 US lives.[1] At the same time, an additional 1.3 million persons will be diagnosed with cancer. The overall cost to the nation from this assault, estimated by the National Institute of Health (NIH), is $189.5 billion in 2003.[2]

For all of its consequence in terms of human suffering and economic cost, there is reason for hope. Cancer is no longer the out-of-control, stealth disease it once was. Scientific investigators are unlocking its mysteries at the molecular level. The combined enterprise of the public and private health, medical, educational, bio-pharmaceutical and allied health community has made significant progress. Some people are predisposed by lifestyle or familial susceptibility, and have a higher risk for developing the disease and are being more carefully monitored. Cancer screening protocols have proven their benefit as agents of prevention and early detection. Treatment options are less severe and the data on long-term outcomes is encouraging. Ironically, the management of survival has become an essential element in the life cycle of cancer, suggesting that what was once considered an acute disease, must now be viewed from the perspective of chronic disease.

As much as some cancers appear to be genetically predisposed, DNA is not always destiny. Increasingly, medical scientists appreciate the role of environmental factors and human behaviors as negative triggers that influence the development of cancer. Some in the medical community have been willing to state that as many as half of all cancers can be prevented through a commitment to healthier living. Self-determinism reinforced through life choice is a central factor in cancer prevention. This is particularly true with lung cancer and its link to persons who smoke; to certain breast cancers and their incidence among post- menopausal women with high fat diets and sedentary lives; or to inactive men with high fat diets who develop colon cancer. Studies indicate that high exposures to some chemicals can increase the risk of developing cancer. The cancer prevention evidence supports tobacco avoidance, limited use of alcohol, good nutrition, weight management, age-appropriate physical activity and reducing exposures to elevated levels of known and likely human carcinogens. [3-9]

Thus, the opportunity to reduce cancer incidence, morbidity and mortality is striking given the advances made in the overall understanding of the disease. Existing discoveries from basic and applied research inform a wide range of options in prevention, screening, detection, treatment, palliative and end-of-life care. The dynamic advance of molecular biology and systems biology is laying the foundation for future targeted therapies. At the same time, there are hundreds of clinical trials of new drug compounds being conducted by bio-pharmaceutical companies across the globe.

Against this background, the need for a coordinated, comprehensive and integrated approach to cancer control has been emerging since the early 1990s. This has been spearheaded by the Division of Cancer Prevention and Control (DCPC), National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) of the Centers for Disease Control and Prevention (CDC). For many years, public policy and federal and state appropriations produced categorical funding in cancer for site-specific programs (i.e. breast, colon). The CDC has begun to encourage the development of comprehensive cancer control plans at the state level. These plans were to evolve from creative stakeholder dialogues in which the ideal was ultimately transformed into grounded, feasible objectives that could be measured over time. A framework for developing comprehensive cancer control plans, for identifying their goals and prioritizing their strategies emerged. The framework presumes that decisions are evidence-based, informed by data, supported by science, and directed at improved outcomes.[10]

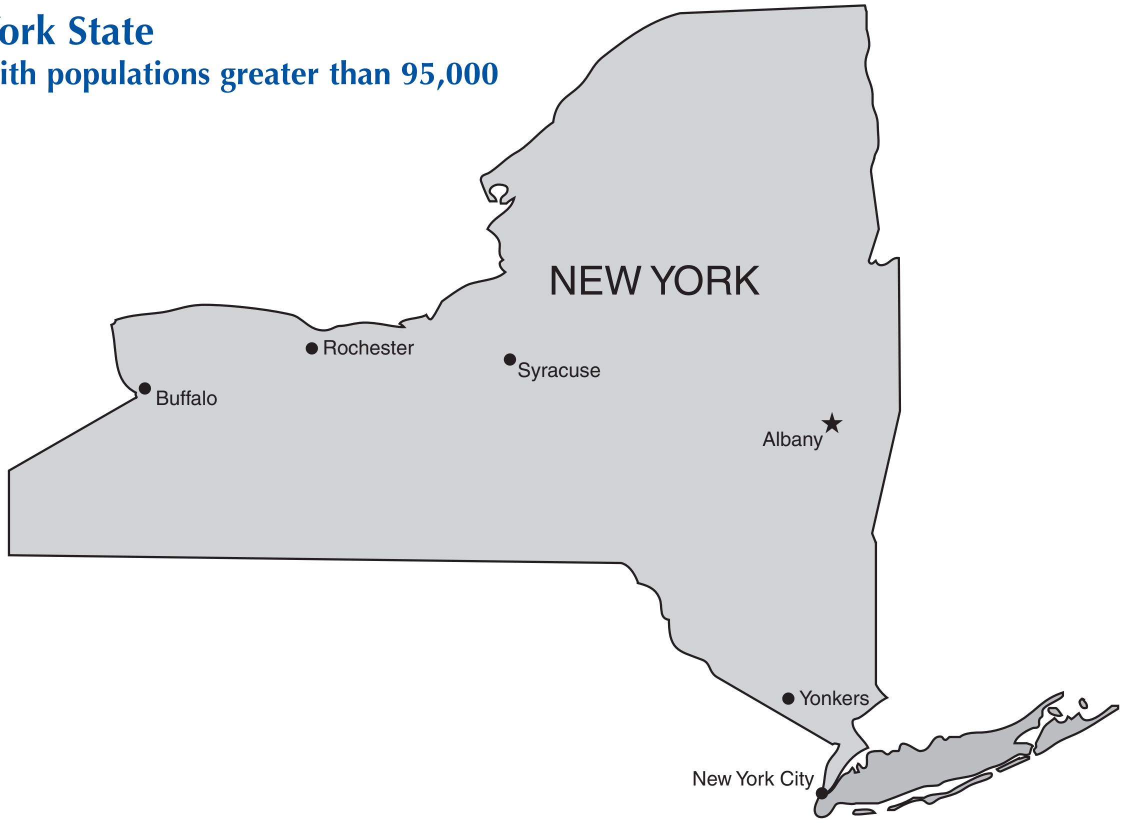
New York Demographics & Geography

New York State's population of more than nineteen million[11] is comprised of geographically, culturally and ethnically diverse groups. New York City comprises about 40 percent of the state's population and the counties immediately north of New York City (Orange and Westchester Counties) and on Long Island (Nassau and Suffolk Counties) comprise an additional 21 percent of the state's population. Twenty-six percent of New Yorkers live in rural areas. The vast and diverse demographics of the state are noted by the range of population density, from an average of 52,808 individuals per square mile in New York County (Manhattan) to only three people per square mile in Hamilton County in the Adirondacks.

Although non-Hispanic Whites remain the largest racial group, three out of every ten persons belong to one of the state's racial or ethnic minority groups. According to the 2000 US Census, NYS has the largest population of Blacks in the United States (3,014,385), is among the top eight states with Hispanic residents (2,867,583), and includes more than one million Asian/Pacific Islanders (1,053,794). Thus, inherent to all assessment, strategic planning and program development activities is the recognition of the importance of the cultural and linguistic diversity of the state.

The racial and ethnic diversity of the people of New York State, as well as the varied geography and disparate population density pose special challenges to cancer control planning and implementation. The New York State Comprehensive Cancer Control Plan, via the goals identified on the following pages, will focus strategies to address the cancer burden and lay out a coordinated and cohesive course to reach these goals by 2010.

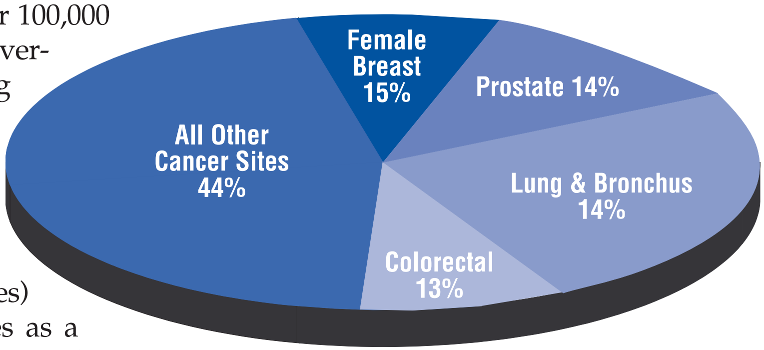
New York State
Cities with populations greater than 95,000



Cancer in New York State

Morbidity

New York State Cancer, 1999
Cases by Site

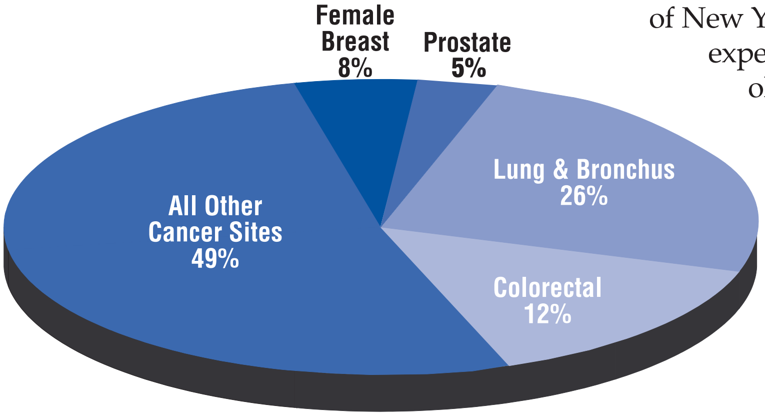


In 1999, almost 89,000 invasive, malignant tumors were diagnosed among NYS residents (534.5 per 100,000 males and 427.5 per 100,000 females). On average, 10,717 cancers are diagnosed among Blacks (564.4 per 100,000 males and 357.0 per 100,000 females), 5,509 among Hispanics (390.4 per 100,000 males and 273.5 per 100,000 females), and 1,844 among Asian/Pacific Islanders (320.1 per 100,000 males and 256.5 per 100,000 females) per year. As is true for the United States as a whole, cancers of the lung, colon and rectum, breast, and prostate account for the majority of cancers in NYS. Excluding skin cancers, these four sites account for 55.5% of all incident cancers and 50.9% of cancer deaths.[12] Black males have a higher rate for all cancers combined than do White males, attributable to the higher prostate cancer rate among Black males. Black females, in general, have lower cancer rates than do White females. As is seen nationally, the overall rates for Hispanics and Asian/Pacific Islanders are lower than the rates for Whites and Blacks.

Mortality

New York State (NYS) faces a large cancer burden. In 1999, nearly 37,600 individuals died of cancer (237.5 per 100,000 males and 172.5 per 100,000 females). Of this total there were 2,051 prostate cancer deaths (28.6 per 100,000) and 9,638 lung cancer deaths (66.6 per 100,000 males and 39.7 per 100,000 females), 4,330 colorectal cancer deaths (26.8 per 100,000 males and 19.8 per 100,000 females), and 3,113 breast cancer deaths (28.7 per 100,000).[12] In 2003, it is estimated that there will be 85,900 new cases of cancer diagnosed, and 35,800 New Yorkers will die of cancer.[13] As the population of New York continues to age, these figures can be expected to increase. Individuals age 65 and older are one of the fastest growing population groups in New York, expected to reach 2.5 million by 2010. In New York State, nearly $11 billion per year in costs, either through direct medical care or lost productivity, can be attributed to cancer.[14]

New York State Cancer, 1999
Deaths by Site



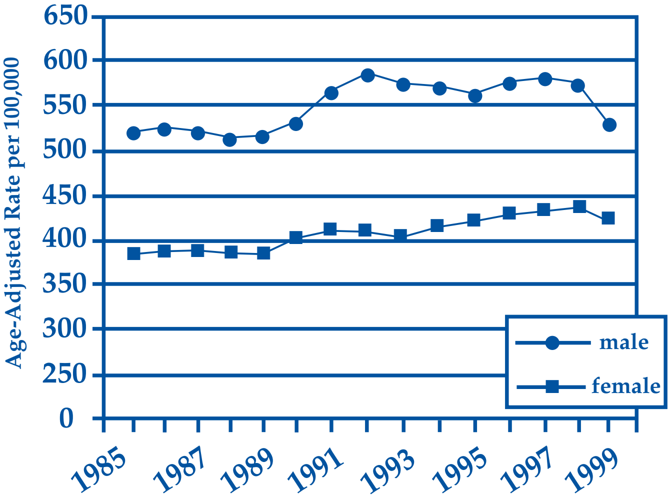
A Note About Age, Gender and Race

Age is the most important factor in the occurrence of cancer. Generally speaking, as individuals age, their chance of being diagnosed with cancer increases, although the frequency of different types of cancer among age groups changes. For example, in New York State the incidence rate for all cancers combined for males under 15 is 17.0 per 100,000, but increases to 2,488.0 per 100,000 by the 65-74 age group. [12]

Other important factors in the occurrence of cancer are gender and race. At all ages, women have lower incidence and mortality rates than men in the same age group, and this gender difference has remained fairly stable over time.[12] The average annual 1995-1999 incidence rate for all invasive malignant cancers combined for males is 557.3 cases per 100,000, and for females is 435.0 cases per 100,000. The mortality rate is 247.3 and 174.6 per 100,000 for males and females, respectively.[12]

The distribution of stage at diagnosis is important for cancer control. For each anatomical cancer site, the percent of Black males diagnosed at later stage is higher than for White males. This is also true for Black females when compared to White females, except for cervical and ovarian cancers, for which the percent diagnosed at a localized stage does not vary by race. The reasons for these differences are not well understood. It is likely that some of this effect is caused by societal issues such as the differences in access to prevention, screening and treatment. Lifestyle factors such as diet, in combination with environmental and genetic factors may also play a role.[15]

Trends in New York State Cancer Incidence Rates
1985 to 1999, All Invasive Cancers, Male and Female



Source: New York Cancer Registry.
Rates are age-adjusted to the 2000 Standard US Population

For more detailed information on cancer sites, incidence, and mortality in New York State, please contact your American Cancer Society at 1-800-ACS-2345 and request a copy of the current "Cancer Facts and Figures". This document incorporates information from the New York State Cancer Registry with prevention information from the American Cancer Society, as well as site-specific information for the major cancers affecting New Yorkers, and a well-developed resource section.

The percent of Black males diagnosed at a later stage is higher than for White males.

Prevention of Cancer: Current Knowledge

Many cancer deaths — perhaps as many as 12,000 annually in New York State — are preventable. Important and significant steps must be taken to help people prevent cancer through the adoption of healthy lifestyles, reduction of exposure to high risk environmental factors and better understanding of cancer genetics.

Healthy Lifestyles

Cigarette smoking is the leading preventable cause of cancer. For the majority of Americans who do not use tobacco products, dietary choices and physical activity are the most important modifiable determinants of cancer risk demonstrated to date.[3,5,6,7,8,9] It is clear that there are certain behavioral changes individuals can make that will help reduce their cancer risk. An added benefit is the effect of healthy life-styles on reducing the risk of cardiovascular disease, lung disease, and diabetes. By adopting healthy lifestyles that include tobacco avoidance, not drinking alcohol excessively, eating a variety of fruits and vegetables, whole grains and lower fat food choices, and engaging in moderate physical activity most days of the week, individuals are becoming empowered in the fight to prevent cancer.[16, 17] In order to assist in making better lifestyle choices, societal support structures must be in place. Tobacco-free environments; nutritious, low fat school lunches; vaccination programs for Hepatitis B and, in the future, Human Papilloma Virus; and provision of well-lit, well-maintained sidewalks and public walking areas to encourage outdoor activity, are examples of the ways healthy behaviors are supported by environments. In addition, educational information and materials that are culturally and linguistically appropriate enable individuals to make healthy behavior choices within the values and personal frameworks of their lives.

Environment

In addition to lifestyle factors, there are external or environmental considerations that play a role in increasing the likelihood of cancer. Research into the environmental risk factors for cancer continues to be conducted, for example by programs within the Department of Health, the National Cancer Institute, and others as well as in academic and health care institutions across the state. People are exposed to many different substances in the air they breathe and the food and water they ingest. One of the most important of these exposures is second hand tobacco smoke. In addition, workers are exposed on the job to substances or other circumstances known to be risk factors, such as radiation or certain chemicals. For example, there is considerable evidence demonstrating an association between diesel exhaust exposure and increased cancer risk among workers in occupations where diesel engines have been used historically.[18] Exposure to arsenic in drinking water has been shown to increase cancer risk.[19] It is clear that additional research is needed to better understand the risks from environmental exposures. New findings will continuously be reviewed for consideration as strategies in implementation of the Comprehensive Cancer Control Plan.

Genetics

As the Human Genome Project progresses, we are learning more about genetic factors which may predispose some persons to develop cancer. Specific mutations, groups of mutations, and interactions between genes and environment may help to explain some of the variance in cancer risk among individuals and groups. This information is beginning to influence cancer prevention, diagnosis and treatment. The role of genetic testing is expected to become more important in coming years.

Background of the Plan Development Process

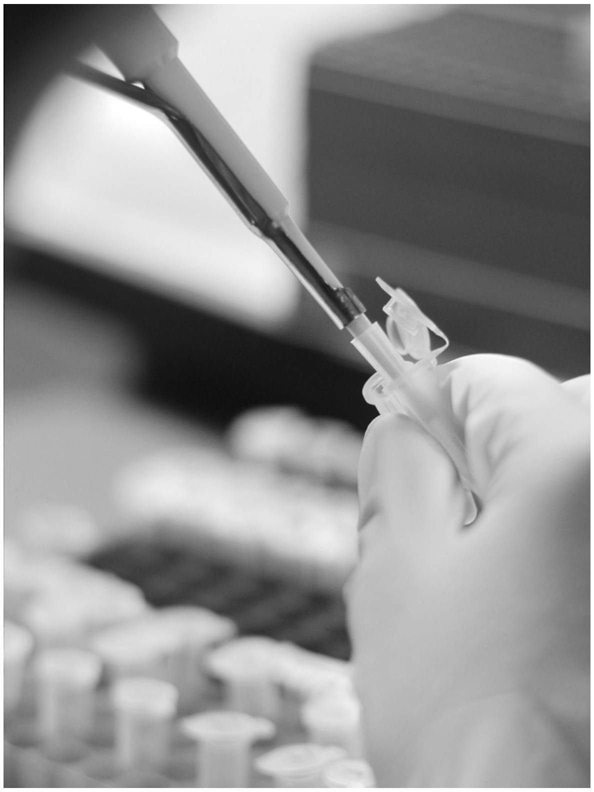
The Centers for Disease Control and Prevention (CDC) has been a driving force in encouraging states to develop cancer control plans that incorporate the voices of cancer stakeholders through partnerships and outreach to the community. This is in recognition of the importance of coordinating services for prevention, detection and treatment. To assist states, the CDC has provided guidance and support in many forms, including the creation of a Toolkit for Comprehensive Cancer Control Planning. For information on the CDC's Comprehensive Cancer Control activities, access their website at http://www.cdc.gov/cancer/ncccp/index.htm.

In the fall of 2001, a group of individuals from the New York State Department of Health, American Cancer Society-Eastern Division, and other health and policy-related organizations, including Memorial Sloan-Kettering Cancer Center, the Schuyler Center for Analysis and Advocacy, Harlem Hospital and New York University Medical Center, met to discuss the process for developing a New York State Comprehensive Cancer Control Plan (NYSCCCP). From this initial group, the Core Work Group (CWG) was formed, the collaborative team responsible for planning and development of the NYSCCCP. The CWG members reached out to experts in nine cancer-related areas, requesting that they come together in Goal Development Teams (GDTs) to discuss the state of cancer control in New York and develop Goals and Strategies for the Plan.

The nine GDTs, comprised of between five to fifteen individuals each, focused on the following areas:

- ✔ Health Promotion and Disease Prevention
- ✔ Early Detection
- ✔ Treatment
- ✔ Palliative Care
- ✔ Quality of Life
- ✔ Health Personnel
- ✔ Research
- ✔ Data and Surveillance
- ✔ Policy Review

Over the course of several months during the summer and fall of 2002, these experts were interviewed individually, met in work groups, and participated in teleconferences and videoconferences. After the first draft of the Plan was created, the Core Work Group continued to reach out for further community input, in the form of Community Forums, which occurred during the month of January 2003. Over one thousand people throughout the state were invited to participate in one of ten events offered across New York, to review the initial goals and offer comments and suggestions for revisions. Over three hundred fifty people did participate in one of these events. The information provided by the GDTs and the Community Forum participants was used to create draft goals and strategies. This draft was then presented at a Leadership Summit, where additional feedback and input was solicited, and reviewed and incorporated into this Plan. The goal of this participation has been to ensure that the New York State Comprehensive Cancer Control Plan is truly a statewide undertaking, involving input from



citizens, cancer survivors, advocacy groups, health care providers, researchers, service delivery organizations, policy makers, planners, and the state government. Involving all communities who have a role in preventing cancer and caring for those with cancer, and obtaining community commitment to expanding, refining, and implementing the recommendations set forth in this plan will move toward meeting the needs of the diverse populations of this state in a culturally sensitive, competent manner.

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> Ultimately, the goal of this participation is to ensure that the New York State Comprehensive Cancer Control Plan is truly a statewide undertaking, involving input from citizens, cancer survivors, advocacy groups, health care providers, researchers, service delivery organizations, policy makers, planners, and government.

I. Health Promotion and Disease Prevention

Environmental and behavioral factors, including smoking, diet, infectious diseases, as well as chemicals and radiation, are estimated to cause three-quarters of all cancer deaths in the United States. Consider this alarming fact: Every day in the United States, another 6,000 youth under age eighteen try cigarette smoking. Of this number, over half become daily smokers.[1] Approximately half of the youth who become daily smokers will eventually die from tobacco-related diseases.[2]

This chapter provides a comprehensive set of goals and strategies that will help reduce the incidence of cancer. The potential of preventive actions is compelling. In many cases, knowledge of what needs to be done to reduce the risk of cancer is straightforward. On the other hand, achieving cancer prevention is dependent upon successful changes in the way people live. At the heart, behavior change is largely self-driven, coming from individual actions that do not rely, for the most part, on complex or expensive interventions. In order to successfully engage individuals in behavior change, organizations and agencies seeking to reduce cancer risk behaviors must attend to cultural beliefs and their affect on lifestyle and individual choices, and to engage individuals to become more pro-active in making individual cancer prevention decisions.

Environmental and structural enhancements support healthy choices where adults and children live, work, receive healthcare and go to school. These improvements and community initiatives can serve to invite and even stimulate change. At the same time, regulatory bodies should continue their oversight and regulation of occupational and environmental (e.g. air, drinking water and ambient water standards, pesticides and consumer products) exposures to known and likely human carcinogens, and continue surveillance and follow up of individuals who have been exposed to high levels of these agents in the work place or in their air, water, or food.[3] Finally, it is critical to understand more about the relationship between environmental substances and cancer, and to decrease known environmental exposures to carcinogens.

Preventing cancer spares people its consequences: human suffering and premature death, decreased quality of life, psychological pain, loss of income and treatment costs. Scientific research has established an indisputable link between lifestyles and cancer risks. Similarly, research has demonstrated that almost two-thirds of all cancers could be prevented by eliminating the use of tobacco, improving nutrition and reducing alcohol consumption, increasing physical activity and engaging in sun safe behaviors.[4-10]

Passive smoking is the third leading preventable cause of death in the United States today, behind active smoking and alcohol.[12] In March, 2003, the New York State Legislature enacted, and Governor Pataki signed into law, one of the most sweeping Clean Indoor Air measures in the United States that will effectively protect all workers from exposure to toxic second-hand smoke. Tangible effects include elimination of exposure for hundreds of thousands of people employed in these settings. This measure follows enactment of similar laws at local levels in Long Island, New York City, Westchester and Duchess counties, and represents a significant step forward in cancer prevention.

Importantly, tough tobacco control programs are directly credited with a decline in certain cancer rates. In those states where such programs have been implemented, for example California, Massachusetts and Florida, lung and bronchus cancer rates decreased by 14.0% from 1988 through 1997. By contrast, these same rates only declined 2.7% in other regions of the country where no comparable program existed.

Prevention strategies aimed at lifestyle modification can work. For example, striking smoking rate declines have occurred in California, where an aggressive, statewide Tobacco Control Program has been implemented. As a result of interventions and communications carried out in this program, adult smoking prevalence changed from 11% lower than the rest of the nation in 1988 to 20% lower by 1996. Additionally, the same study revealed that overall per capita cigarette consumption in California had fallen by more than 50% for this same time period.[11]

TOBACCO IMPLICATIONS: Context and Challenge

Tobacco use, especially cigarette smoking, is the single most preventable cause of unnecessary mortality in the United States. Each year, more people die prematurely from smoking than die from automobile accidents, drug abuse, AIDS, suicides and alcohol combined.[13]

Smoking by women increased between 1935 and the early 1960s, resulting in a greater than 600% increase in female lung cancer mortality since 1950. Lung cancer is now the leading cause of cancer death in women.[14, 15]

A worksite smoking cessation program at fifteen manufacturing firms in Eastern Massachusetts proved successful when integrated into an overall occupational health and safety program directed at blue-collar workers. At the end of two years, investigators found that more than two times as many workers quit smoking in the group where smoking cessation messages were integrated into a larger occupational health and safety program than in the group where the smoking cessation messages stood alone.[16]

The CDC estimates that as many as 70% of all smokers want to quit each year, but only 2.5% are able to do so. Nicotine's addicting properties cannot be ignored. A mix of intervention strategies may be indicated that includes pharmacological interventions.

GOAL 1: TOBACCO

By 2010, reduce tobacco use by adolescents to 12%.

By 2010, reduce tobacco use by adults to 15% for cigarette use, 0.4% for spit tobacco use, and 1.2% for cigar use.

STRATEGIES

- Decrease the number of individuals who initiate smoking.
- Work with colleges and universities to encourage adoption of smoke-free campus and dormitory policies.
- Through a combination of federal, state and local funding, fund the tobacco control program interventions in proportion to CDC recommendations or greater in order to implement effective comprehensive tobacco control.
- Continue to implement the recommended strategies of the Community Preventive Services Task Force and the CDC to reduce tobacco use and exposure to environmental tobacco smoke: increase awareness to reduce initiation of tobacco use and increase cessation; reduce out of pocket costs for effective therapies to stop using tobacco; promote provider reminders systems and provider education to assess all patients for tobacco use and intervene accordingly; implement community-based partnerships that work to change local tobacco-related policies and change social norms regarding tobacco use.

New York State Tobacco Use Baseline Data:

Percent who smoke:

High School Youth – 2002:	21.3%
Adults – 2002:	22.3%

Smokeless tobacco use:

Adults – 1999:	0.7%

Cigar use:

Adults – 1998:	1.8%

Sources: NYS Youth Tobacco Survey 2002, BRFSS 2002

- Expand access to cessation assistance including increased use of telephone and web-based cessation help lines for people who want to stop using tobacco.

ENVIRONMENTAL IMPLICATIONS: Context & Challenge

Some chemicals in the environment and the workplace cause cancers in humans or are thought likely to cause cancers in humans based on animal tests. The degree of risk from these chemicals depends on the amount of chemical to which an individual is exposed and the duration of exposure. The risks may also be influenced by an individual's age, sex and general health. Occupational exposures to high concentrations of ionizing radiation and some chemicals (e.g. benzene, vinyl chloride, dioxin and chromium) have caused cancers in some workers. Also, non-occupational exposures to radiation and arsenic have caused cancer in some people exposed to relatively high levels of these compounds in the environment. Other chemicals (e.g. trichloroethene and diesel emissions) are considered likely to cause cancer in humans because of findings in animal studies or limited information in humans.

Low-dose exposures that pose a small risk to an individual can still cause substantial ill health across an entire population if the exposures are widespread. For example, low level exposure to diesel emissions increases the cancer risk in large numbers of people even though the increased risk to an individual may be small.

Reducing exposures through regulatory control (e.g. environmental standards, product restrictions, required product modifications, etc.), occupational practices and individual efforts can play an important role in reducing risk of cancer. New York State has many programs that regulate environmental releases or people's exposure to chemicals as well as programs to inform people about chemical exposures and to help them make decisions about reducing exposures to chemicals in their homes. The state reviews toxicological and environmental information about pesticides before they can be registered for use in the state. Program staff investigate contaminated sites (superfund, brownfields, oil spills) to delineate environmental contamination and identify human exposures to chemicals from these sites and recommend actions to mitigate exposures. The state has adopted comprehensive drinking water standards and regulates public water suppliers to assure compliance with these standards to protect public health. The state has adopted federal air pollution control standards and continues to administer the state air toxics program to reduce chemical emissions from many sources of air pollution. State agencies provide the public with information to help them make informed decisions about eating contaminated fish, burning waste in burn barrels, and using pesticides, as well as many other environmental exposures. Both regulatory and educational efforts help to minimize exposures to chemicals that are known to cause cancers in people as well as those that are likely to cause cancer.

GOAL 2: REDUCE ENVIRONMENTAL EXPOSURE

By 2010, reduce population risks associated with environmental exposures to known or likely environmental risk factors for cancer.

STRATEGIES

- Continue the partnership of federal, state and local governments, businesses, and communities to reduce elevated exposures to known or likely environmental risk factors for cancer (e.g. elevated levels of known or likely human carcinogens at hazardous waste sites, in drinking water supplies, in indoor or outside air, etc.).
- Increase awareness and promote programs that help consumers decrease their use of chemicals in the home (e.g. promote principles of integrated pest management).
- Improve the public's understanding of the risks of exposures to chemicals in the environment and continue outreach efforts to promote the effective dissemination of information to the public.
- Enforce and increase compliance with environmental regulations to reduce exposures to known or likely human carcinogens (e.g. diesel engine

rule) and consider actions that further reduce exposures to elevated levels of known or likely human carcinogens.

- Expand research into the risks associated with environmental and occupational exposures and promote strategies to reduce elevated exposures.
- Develop techniques being created as part of environmental public health tracking programs to assist with cancer surveillance.
- Promote and enforce existing clean indoor air policies and continue the comprehensive, statewide, Clean Indoor Air Act.
- Increase awareness of the harmful effects of secondhand smoke to children and adults exposed in schools, daycare facilities, worksites, colleges, public places, homes, and automobiles.

GENETICS IMPLICATIONS: Context and Challenge

Real and measured progress has been made in identifying the genes that give rise to 'cancer families' even though the understanding of a genetic predisposition to certain cancers is still regarded as, at best, preliminary.[17]

The Harvard Center for Cancer Prevention points out that the greater challenge lies in unlocking the genetic causes of 'sporadic cancer' which are more common than cancers that present with a familial inheritance pattern. They cite the importance of better understanding how these genes influence individual response to environmental exposures and how lifestyle factors contribute to the total burden of cancer.[17]

Environmental risk factors, when combined with individual inherited cancer susceptibility, must be studied further in order to improve the effectiveness of cancer prevention, early detection and treatment approaches.[18]

GOAL 3: GENETICS

By 2010, increase public and provider awareness about prevention studies for persons at high risk of cancer due to family history or genetics to 85% of those surveyed.

STRATEGIES

- Determine knowledge of and attitudes toward use of prevention interventions for individuals considered at high risk of developing cancer.
- Encourage health care providers to query patients on family history of cancer to identify possible high-risk individuals.
- Identify prevention clinical trial activities within the state and increase awareness of health care practitioners of these opportunities for their patients.

- Encourage genetic testing reimbursement for proven genetic testing methodologies with implications for prevention and treatment by managed care plans, insurance plans, Medicaid, and other payors, and inform the public of the availability of this testing.

SUN EXPOSURE IMPLICATIONS: Context and Challenge

There is irrefutable evidence that ultraviolet (UV) light can cause DNA damage which is linked to both melanoma and non-melanoma skin cancer.[17] Approximately one million persons develop some form of skin cancer each year in the United States, making it the most common form of cancer. By age 65, it is predicted that nearly 50% of all Americans will have developed a form of skin cancer, some of it fatal.[19]

GOAL 4: SUN EXPOSURE

By 2010, increase the proportion of New Yorkers who use sun protective measures to prevent excessive sun exposure to 75%.

STRATEGIES

- Increase health care providers' awareness of the risks of sun exposure.
- Utilize existing, proven programs to promote and educate the public on the benefits of sun protection.

New York State Sun Exposure Baseline Data:

23.9% (1999)

Adults 18 and older who report having had a severe sunburn lasting 12 hours or more in the past 12 months.

Source: BRFSS 1999

- Increase awareness of the dangers of artificial sun tanning.
- Target educational programs to providers of services for young children, such as preschool and child care providers, camp directors, community recreation programs staff, educators and scout leaders.
- Increase awareness of sun protection needs of infants and young children among pregnant women and new parents.
- Increase the proportion of elementary schools, day care centers, and parks/recreation centers that have sun protection policies.

LIFESTYLE IMPLICATIONS: Context and Challenge

Women who are overweight and obese are at significantly increased risk for cancers of the esophagus, colon and rectum, liver, gallbladder, pancreas, kidney, and for non-Hodgkin's lymphoma and multiple myeloma, as well as cancers of the stomach, breast, uterus, cervix and ovaries. Such increased risk is not found only among the most obese women; for example, women with a Body Mass Index (BMI) of 25 to 30* were found to have a 34% higher risk for breast cancer.[20]

Overweight & obese men also have significantly higher risk of many cancers including: esophagus, colon and rectum, liver, gallbladder, pancreas, kidney, and for non-Hodgkin's lymphoma and multiple myeloma, as well as cancers of the stomach, and prostate. It is estimated that 14% of all cancer deaths in men are related to overweight or obesity and 20% of women's cancer deaths can be attributed to overweight or obesity.[20]

During the past decade, obesity rates have reached epidemic proportions, with 60% of American adults now considered to be overweight or obese.[20]

Lifestyle research is a challenge. Multiple variables may confound reaching one conclusion. For example, while higher physical activity levels have been linked to a relative risk reduction in colon cancer incidence by as much as 40-50%, other variables such as genetic predisposition and diet may also be likely influences.[21]

GOAL 5: HEALTHY LIFESTYLE

DIET/NUTRITION—By 2010, increase the proportion of New Yorkers age 2 and older who consume at least five servings of fruits and vegetables daily to 75%.

PHYSICAL ACTIVITY—Adults: By 2010, increase the proportion of adults who engage regularly, preferably daily, in moderate physical activity for at least thirty minutes per day to at least 30%.

PHYSICAL ACTIVITY—Children and Adolescents: By 2010, increase the proportion of children and adolescents who engage in moderate physical activity for at least thirty minutes on five or more of the previous seven days to 35%.

OBESITY—Adults: By 2010, decrease the proportion of adults who are clinically obese to 15%.

OBESITY—Children and Adolescents: By 2010, decrease the proportion of children and adolescents who are clinically obese to 5%.

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*In adults, <18.5 is underweight, 18.5-24.9 is considered a healthy weight, 25-29.9 is considered overweight, and a BMI of 30 or greater is considered obese.

Healthy Lifestyle Baseline Data:

Percent of teens eating five or more fruits/vegetables a day: 26.0% (1999)

Percent of adults eating five or more fruits/vegetables a day: 27.5% (2000)

Percent of teens participating in moderate physical activity: 25.1% (1999)

Percent of adults participating in moderate physical activity: 21.2% (2000)

Percent of teens that are overweight: 8.3% (1999)

Percent of the adult population that is obese: 17.7% (2000)

Sources: YRBSS, BRFSS

STRATEGIES

- Engage appropriate stakeholders in nutrition and physical activity interventions at a local level: school nutritionists, preschools/day care providers, physical educators, athletes, grocers, young adults, older adults, etc.
- Increase promotion of existing programs to increase the number of fruits and vegetables consumed daily.
- Promote low-fat, low-calorie, high-fiber foods.
- Increase the proportion of schools that provide access to their physical activity spaces and facilities for community members, outside of normal school hours.
- Increase the number of schools that provide quality instruction on nutrition and healthy eating and daily physical activity as a lifestyle choice.
- Increase the proportion of schools providing opportunities for nutritious meals and daily exercise, including review or modification of school policies related to lunch menu requirements and availability of non-nutritious foods on campus.
- By 2006, decrease proportion of overweight or obese adults to 45% (NYS Baseline 57.3%, 2002 BRFSS).
- Increase the availability of 100% fruit juice and low fat milk in place of soft drinks and other high sugar beverages in school systems.
- Encourage development of policies at the federal and state levels that offer guidelines for school breakfast and lunch programs, to facilitate school districts' ability to offer students healthier food options.
- Work with health insurance providers to offer preventive services, such as weight control programs.
- Increase worksites that support healthy eating, exercise and maintaining healthy weights.
- By 2006, decrease proportion of overweight youth to 7.5% (NYS Baseline 10.6%, 2001 YRBSS).
- Promote evidence-based methods for safe physical activity to communities, for all age groups.
- Promote strategies for more nutritious offerings within the "fast food" industry.
- Promote the concept of "walkable communities"to increase the availability of safe and attractive public areas and walkways where physical activity can take place (e.g., rails to trails, sidewalk construction, safer crosswalks, etc.).
- Provide increased opportunities for increased physical activity for children and adolescents.
- Promote policies and strategies that maximize the use of existing health and fitness facilities in communities.

GOAL 6: ASSIST HEALTH CARE PROVIDERS IN PATIENT COUNSELING

By 2010, increase the number of health care providers who report offering cancer prevention related counseling to their patients to 85%.

STRATEGIES

- Educate providers, specifically in specialty areas (primary care practitioners, dentists, nurses, etc.) on risk factors and counseling techniques to reduce health risk behaviors.

- Share proven prevention messages, health education materials and referral sources with health care providers on a regular basis.
- Develop and encourage the use of consistent messages in cancer prevention counseling.
- Determine providers' cancer prevention continuing education needs and develop methods to address those needs, including CME classes.
- Implement tools for providers to use in assessing patient risk of developing cancer.
- Implement tools providers can utilize as reminders to offer screening at appropriate times.
- Work with healthcare systems to develop quality improvement programs in medical settings to increase the number of patients receiving health assessment and counseling related to behaviors and lifestyles.

GOAL 7: FOCUSED COMMUNITY EDUCATION/OUTREACH

By 2010, develop and implement community-based strategies for public awareness activities.

STRATEGIES:

- Promote community-wide efforts toward comprehensive public outreach campaigns addressing all health promotion and prevention areas defined previously.
- Using principles of social marketing, encourage the partnering of community agencies and stakeholder organizations to develop professional and community conferences on health issues.
- Utilize existing messages and develop new materials, as needed, on prevention of lower incidence cancers, such as safe sex practices also reducing cervical cancer risk.
- Engage community partners and encourage the formation of community-based cancer prevention and control coalitions.
- Use materials and strategies that are age, culturally and linguistically appropriate.
- Encourage development of peer teaching modules in community education programs.

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II. Early Detection

For several types of cancer, detection at an early stage greatly increases the likelihood that treatment will be successful, and improves the treatment options that are available to persons with cancer. The five-year survival rate for breast cancer that is in its earliest stages is 97.0%, while at late stage it is only 23.3%. Similarly, colorectal cancer diagnosed in its earliest stage currently has a five-year survival rate of 90.1% as opposed to later stage disease, which has a five-year survival rate of 9.2%.[1]

Unlike prevention activities which seek to stop cancers before they ever develop, the goal of early detection is to identify cancers in people before they begin to experience clinical symptoms. Tests for cervical and colorectal cancer can even identify precancerous conditions that can be treated before they develop into cancer, essentially preventing disease from occurring.

In considering which cancers and screening methods to include in goals for the improvement of early detection in New York State, factors included the extent of the burden of disease for each cancer and the availability of evidence-based screening methods which yield a clinically significant benefit for population-based screening. Despite the difficulty in reaching widespread consensus about screening guidelines, there is solid evidence demonstrating the efficacy and cost-effectiveness of screening exams for the early detection of breast, cervical and colorectal cancer. There is some controversy regarding screening for prostate cancer and whether it results in decreased mortality from this disease. The cancers and methods described in the goals that follow were chosen because they represent the greatest opportunities to reduce the burden of cancer through early detection. In all cases, individuals should discuss the available screening tests with their health care providers. The New York State Comprehensive Cancer Control Plan recognizes the important role of primary care providers and has incorporated goals and strategies that reinforce this relationship. This includes efforts to improve access to those most at risk of developing cancer.

It is vital to recognize the diverse nature of our population, both geographically and ethnically. To achieve our goals in reducing the cancer burden, special recognition of this diversity must be taken into consideration. Certain populations suffer disproportionately from cancer, and reducing these disparities is a medical and societal challenge.[2]

The focus of early detection is, therefore, to increase access to and use of proven, existing screening methods, and to address disparities, especially for underserved populations.

GOAL 1: KNOWLEDGE, AWARENESS AND UTILIZATION

By 2010 enhance public and professional awareness, knowledge and utilization of age-appropriate, evidence-based comprehensive screening guidelines.

STRATEGIES

- Promote social marketing strategies that influence public acceptance of comprehensive risk assessment and screening guidelines.

- Encourage development of community-based, peer-to-peer educational programs to increase public awareness of the value of early detection.
- Target high-risk geographic areas and populations to increase access to screening programs.
- Promote cross-functional outreach (multiple cancer sites across multiple health profession disciplines) at the community level.
- Work toward measuring professional outcomes in the areas of age-appropriate comprehensive cancer screening, risk assessment and appropriate referral consistent with existing guidelines, and update as required.
- Explore the feasibility of utilizing non-physician personnel in providing cancer screening education and counseling to patients.
- Increase provider understanding of reimbursement mechanisms for screening activities.
- Reinforce workplace participation in achieving screening goals and work toward financial participation by health insurance plans.
- Engage the business and payor communities and other partners such as professional groups, hospitals, and community-based organizations, in developing collaborative strategies to enhance use of screening guidelines (incentives, reminders, time off for screening exams, etc.).
- Explore successful state programs (both within and outside of New York), to determine their replicability in New York.
- Review and consolidate recent research on cancer screening.
- Include oral cancer screening as part of a comprehensive cancer early detection examination.

BREAST CANCER IMPLICATIONS: Context and Challenge

Between 1973 and 1992, breast cancer incidence in the United States increased by 34%, partly as a result of increased screening.[3] About 80% of breast cancers occur in women aged 50 and older.[4] The risk of dying from breast cancer is reduced by nearly 30% among women who have regular mammograms beginning at age 50.[5] Nascent technologies such as digital mammography allow for easier sharing and accessing of breast images, thus facilitating long distance consultation with other specialists.[6] Early detection matters. Data support that when breast cancer is diagnosed at a local stage, 97% of women are still alive five years later.[1]

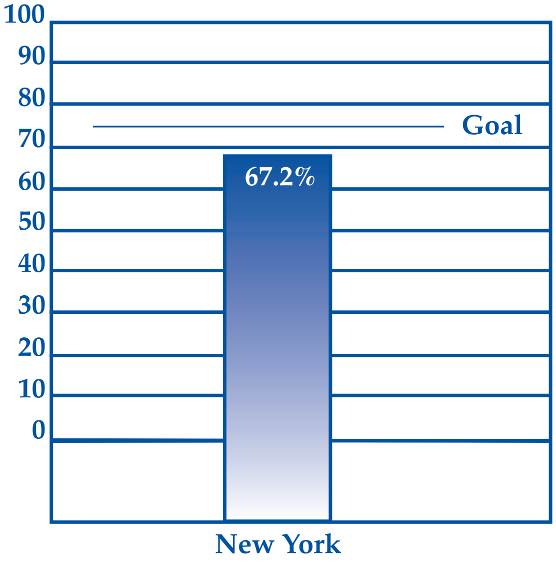
GOAL 2: BREAST CANCER EARLY DETECTION

By 2010, increase the proportion of breast cancers detected at an early stage to 75%. (NYS Baseline: 67.2% [1999])

STRATEGIES

- By 2006, increase breast cancer screenings for women over age 40 to 75% (NYS mammography Baseline 63.8%, 2002 BRFSS).
- Continue efforts to identify high-risk populations and refer for appropriate screening.
- Continue efforts to enhance access to high quality accredited mammography facilities statewide with reasonable waiting time for obtaining service.
- Assess appropriateness of existing consumer messages for age appropriateness and cultural/linguistic relevance and revise as needed to increase awareness of the need for screening.
- Conduct ongoing assessment of the populations of women receiving mammograms to determine changes in characteristics.
- Increase health care practitioners' use of American Cancer Society Clinical Breast Examination guidelines.

Breast Cancer: Percent Detected at an Early Stage, 1999



Source: NYS Dept. of Health, Cancer Registry

COLORECTAL CANCER IMPLICATIONS: *Context and Challenge*

Multiple studies provide evidence about the impact of screening on prevention and detection of colorectal cancer. The Minnesota Colon Cancer Control study found that the risk of dying from colon cancer was reduced by more than 33% among people over age fifty who were screened regularly with fecal occult blood testing (FOBT).[7] Further, annual FOBT screening has been found to reduce the incidence of colorectal cancer by nearly 20%.[8] Getting screened every five years with flexible sigmoidoscopy is associated with a 40% reduction in color cancer incidence.[9] The reduction of incidence of colorectal cancer, which is likely due to removal of precancerous polyps during screening,[8,9] extends the value of colorectal cancer screening from early detection (mortality reduction) to actual prevention of the disease.

GOAL 3: COLORECTAL CANCER EARLY DETECTION

By 2010, increase the proportion of colon & rectum cancers detected at an early stage to 50%. (NYS Baseline: Males 42.6%, Females 39.2% [1999])

STRATEGIES

- Increase the use of Fecal Occult Blood Test among New Yorkers over age 50.
- By 2006, increase colorectal cancer screenings for people over age 50 to 50% (NYS Baseline: 44.6%, 2002 BRFSS).
- Identify those at high-risk due to personal and/or family history and refer for appropriate screening.
- Create culturally, linguistically, and developmentally appropriate messages to increase awareness of the need for screening tests.
- Develop strategies to assess current capacity for provision of colorectal cancer screening tests and methods to increase capacity, where needed.

PROSTATE CANCER IMPLICATIONS: *Context and Challenge*

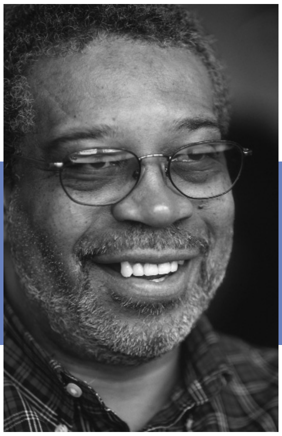
From 1989 to 1992, prostate cancer incidence rates in the United States rose more than 100%, likely as a result of increased screening.[10] Prostate cancer is the most common tumor in men, with nearly one in five American males expected to be so diagnosed in their lifetime.[1] Many prostate cancers may have a lower biological risk. Only 3% of men diagnosed with prostate cancer will die of the disease.[1]

GOAL 4: PROSTATE CANCER EARLY DETECTION

By 2010, increase the proportion of prostate cancers detected at an early stage to 95%. (NYS Baseline: 87.1% [1999])

STRATEGIES

- Increase opportunities for male New Yorkers ages 50+ to discuss PSA testing and digital rectal examination (DRE) with their providers.
- Educate men in high-risk categories (e.g., Black, strong family history of prostate cancer, and those in other high-risk categories) about PSA and DRE.
- By 2006, increase prostate cancer screenings for men over age 50 to 70% (NYS Baseline 55.4%, 2002 BRFSS).
- Develop methods to assist health care providers in communicating about prostate cancer and its screening tests with men, including materials targeting those at high risk.
- Develop culturally, linguistically, and developmentally appropriate messages to increase awareness of the need for screening tests.
- Review research to identify successful methods of increasing screening rates and consider the feasibility of implementing these strategies in New York State.
- Develop strategies to assess the current capacity for provision of prostate cancer screening tests and methods to increase capacity, where needed.



Prostate cancer is the most common tumor in men, with nearly one in five American males expected to be so diagnosed in their lifetime.

GOAL 5: CERVICAL CANCER EARLY DETECTION

By 2010, increase the proportion of cervical cancers detected at an early stage to 65%. (NYS Baseline: 55.2% [1999])

STRATEGIES

- Increase the number of women over age 21 or sexually active over age 18 receiving pap tests.
- Create culturally, linguistically, and developmentally appropriate messages to increase awareness of the need for screening tests.
- Develop targeted educational messages for populations (such as women over 65 and recently emigrated women who have the highest rates of cervical cancer in NYS) known to be less likely to receive pap tests on a regular basis.
- Increase the number of providers who discuss the importance of pap tests with their patients.
- Continue research and monitor results of Human Papilloma Virus vaccination trials. (Also a prevention strategy).

GOAL 6: SKIN CANCER EARLY DETECTION

By 2010, increase the proportion of cases of melanoma skin cancer detected at an early stage to 90%. (NYS Baseline: Males 80.1%, Females 85.5% [1999])

STRATEGIES

- Increase the number of health care providers who educate patients about the early signs of skin cancer and appropriate responses to such symptoms.
- Include early detection messages with skin cancer prevention messages.
- Increase the number of retail outlets selling sun protection products that place early detection messages with their displays.
- Create culturally, linguistically, and developmentally appropriate messages to increase awareness of the need for screening tests.

GOAL 7: LUNG CANCER EARLY DETECTION RESEARCH

By 2010, support research into early detection of lung cancer in New York State, including clinical trials.

STRATEGIES

- Promote clinical trials of screening methodologies to the public and to health care providers.
- Offer technical assistance and letters of support for grant applications.
- Provide assistance in recruitment efforts of participants for clinical trials.
- Assist in arranging access to health care systems where screening trials can take place.
- Promote the enrollment of diverse populations in clinical trials.

GOAL 8: OTHER EARLY DETECTION RESEARCH

By 2010, support ovarian, testicular and oral cancer early detection research in New York State, including clinical trials.

STRATEGIES

- Promote clinical trials to the public and to health care providers.
- Offer technical assistance and letters of support for grant applications.
- Provide assistance in recruitment efforts of participants for clinical trials.
- Assist in arranging access to health care systems where screening trials can take place.
- Promote the enrollment of diverse populations in clinical trials.

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III. Treatment

The ability to provide effective, high quality, accessible and affordable treatment to people with cancer is an essential component of cancer control, with profound implications that can include the difference between life and death, or temporary and permanent disability. Treatment is interwoven with many other areas of focus in this Plan, including quality of life, palliative care, and health personnel. An optimal treatment plan will incorporate all stages and levels of care and will be concerned with the coordination and integration of medical, social, psychological and community provider contributions. At the center of this is the person living with cancer.

In New York State, there is a large and sophisticated treatment system that expends approximately $4 billion annually.[1] The primary treatment modalities for cancer are surgery, radiation, and chemotherapy. Tens of thousands of doctors, nurses, radiologists, and others provide cancer-related care. Most of the 250 hospitals in NYS treat cancer patients in addition to numerous outpatient chemotherapy and radiation treatment sites. The dollars expended on cancer treatment services by the public far surpasses the expenditure of funds on preventive and early detection measures.

To further improve quality, this chapter advocates a system in which evidence-based standards of care are utilized in treatment decisions, clinical guidelines are revised and used as appropriate by health care providers as part of continuous quality improvement, cancer patients provide input about their satisfaction with the services they receive (this information will then be utilized to make changes, when needed), patients and primary care doctors have access to cancer care specialists, and updated information on the efficacy of treatments tested via clinical trials is available to providers and consumers, among others. Such a form of cancer control is fundamental to the principles established for clinical practice.[2,3]

Physicians, public health practitioners, policy makers and health care consumers are deluged with information about the best approaches to prevention, treatment and health care delivery. Evidence-based medicine has the goal of helping providers and consumers make informed decisions about prevention and treatment based on the best available scientific evidence. The strategies outlined in this chapter provide a basis for maximizing our efforts to address cancer through improved evidence-based medicine.

The National Cancer Institute (NCI) has also recognized the need to develop standards of care that acknowledge best practices and work toward national norms. To that end, NCI is working with other partners to track quality of care through a new initiative, the Cancer Care Outcomes Research and Surveillance Consortium. Policy and practice guidelines are expected to result when a link between care and outcomes can be better quantified and qualified.[4]

Many improvements in public health and health care delivery have been achieved, including increased professional expertise, improved understanding of the complexities of delivering community-based services and greater availability of program results through evaluation. Such improvements have reinforced the value of coordinated cancer control programs. As we continue our efforts in strategic directions for New York State, we recognize that coordination of cancer control activities is essential to maximize resources and achieve desired cancer control outcomes.

Treatment values also extend beyond standards of care and best practices. The non-clinical factors of socioeconomic status, age at diagnosis, body image concerns, financial eligibility considerations, and cultural mores all influence the potential for compromised outcomes. The literature has demonstrated, in particular, that African Americans are 33% more likely than Whites to die from cancer.[5] This appears to be associated with a lack of access to care and not to any higher predisposition to a negative cancer progression. A recent issue of the *Journal of the National Cancer Institute* indicated that "...when African-American and White patients receive the same basic treatment for colon cancer, i.e. surgery followed by chemotherapy, they fare equally well." The Black males had a 65% overall survival rate compared to 66% for the White patients. The recurrence-free survival rate for the Black cohort was 57% contrasted with 58% for White patients.[6]

Treatment services are extensive in New York and accessible to most of our population Nonetheless, some shortages in New York may exist in certain areas, particularly the rural regions of the state. Further research to characterize the healthcare cancer workforce is needed. Financial access may also need to be addressed. Although approximately 85% of our population has public or private insurance coverage that will pay for most surgical, radiation and chemotherapy services, about 15% of our population has no insurance coverage for cancer treatment and a significant additional percentage has inadequate coverage.[7]

GOAL 1: QUALITY OF CARE: CURRENT TREATMENT

By 2010, increase the availability of the best cancer care to all New Yorkers.

STRATEGIES

- Increase awareness among the public and providers of standards of care for effective treatment and quality cancer care.
- Make information on cancer site-specific treatment options, benefits and disadvantages, survivorship issues and other information easily available to consumers.
- Provide access to appropriate care for all age, racial, ethnic, geographic and socioeconomic groups.
- Encourage quality of care programs at all treatment sites including studying the feasibility of utilizing American College of Surgeons (ACoS) certification of hospitals as a quality of care tool.
- Test ways to increase use of clinical guidelines among providers and awareness of clinical guidelines among consumers.
- Conduct research on and assessments of the quality of cancer treatment in New York State.
- Identify and promote the use of age appropriate, culturally and linguistically appropriate information.
- By 2006, increase cancer survivors' satisfaction that cancer-related effects (e.g. pain, fatigue, nutrition) are managed effectively.

GOAL 2: COMPREHENSIVE SCOPE OF QUALITY OF CARE RESOURCES (see also Quality of Life Section)

By 2010, encourage best practice delivery systems recognizing the chronic nature of cancer, including ongoing supports and navigation for families, rehabilitation, education, social and legal services.

STRATEGIES

- Develop ways for cancer survivors to routinely rate their satisfaction with cancer treatment services.
- Engage cancer treatment facilities in plans to support and monitor cancer treatment across the continuum of cancer care.
- Encourage cancer treatment facilities to develop active quality of care programs that engage and support people being treated and their caregivers.
- Engage organizations to provide support for individuals without active caregivers who are under treatment for cancer.
- Enhance access to supportive services including transportation, housing, nutrition, outpatient treatment and wellness programs.

The ability to provide effective, high quality, accessible and affordable treatment to people with cancer is an essential component of cancer control . . .

- Disseminate materials relating to the short- and long-term effects of cancer treatment, targeting specific groups in need of this information (childhood cancer survivors, older women, etc.).
- Encourage research on survivorship issues and the impact of different factors on outcomes.

GOAL 3: QUALITY OF CARE: INTEGRATION OF SERVICES

By 2010, integrate existing cancer treatment services and develop strategies to reduce service gaps.

STRATEGIES

- In rural areas, explore increasing the use of telemedicine as a way to document cancer treatment, data, support services, and financial help to improve the quality of cancer treatments.
- Explore with managed care organizations, comprehensive case management to meet the range of patient needs.
- Explore patient navigator systems that utilize a variety of cancer professionals, e.g. oncology social workers to ensure the seamless transition between services and agencies, and assess the costs and benefits (both medical and social) of case management/health navigator models.
- Encourage integrative care networks that coordinate the range of services required by patients.
- Collaborate with health care providers throughout the state toward regional tumor boards and meetings of multidisciplinary teams to discuss treatment options for patients with challenging cancer cases.
- Develop methodologies to assess the need for cancer services by type.
- Review research findings and encourage the incorporation of evidence-based complementary and alternative therapies into cancer treatment plans.

GOAL 4: TREATMENT INFORMATION RESOURCES

By 2010, assess knowledge among, and information dissemination to, health providers and consumers.

STRATEGIES

- Determine the baseline number of contacts to cancer information services in New York and track contact rates on an ongoing basis.

> An optimal treatment plan will be concerned with the coordination and integration of medical, social, psychological and community provider contributions.

- Identify networks of cancer specialists who can provide diagnostic and treatment consultation to primary care physicians in medically underserved areas.
- Identify telecommunication systems among medical providers to facilitate their participation and collaboration in a provider network.
- Identify systems for up-to-date information on clinical trials for health care providers and consumers.
- Make available information related to age appropriate treatment, that is culturally and linguistically suited to target populations.
- Make available current regional or local cancer resource catalogs/directories that provide information on cancer institutions, specialists, providers, research, therapies, and support services, including financial.

GOAL 5: GEOGRAPHIC ACCESS TO CARE

By 2010, geographic access issues will be identified and reduced.

STRATEGIES

- Determine the capacity of cancer treatment services by type throughout New York State.
- Use existing data to evaluate cancer care by type of facility, geography, and other variables.
- Define the essential components of a delivery system for cancer care that assures certain basic services are available locally, and more specialized services are reasonably accessible.
- Assess regionalization of cancer services, beginning with treatment involving high risk, low incidence procedures.

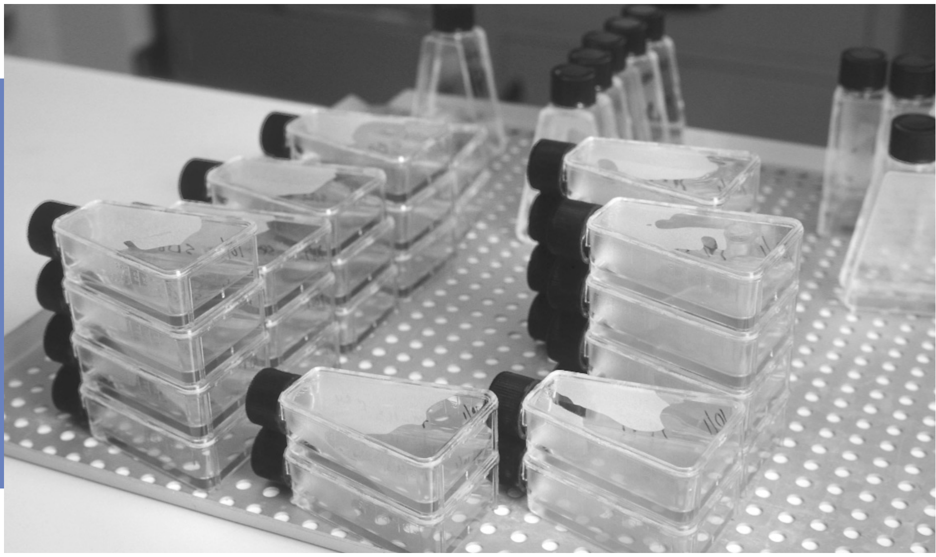
- Assess service availability and accessibility as related to the needs of vulnerable populations, such as immigrant populations, incorporating cultural sensitivity and ability to address language barriers effectively.

GOAL 6: FINANCIAL ACCESS TO CARE

By 2010, assure that high quality cancer treatment and services are accessible to New York State residents, regardless of socioeconomic status, geography or race/ethnicity.

STRATEGIES

- Assess the availability of insurance coverage for cancer treatment.
- Encourage health insurance and managed care plans to support prompt access to appropriate cancer treatment, supportive services and clinical trials.
- Encourage managed care organizations to remove barriers to timely referral to out-of-network providers for medically appropriate care when necessary.
- Promote reimbursement structures that facilitate access to multiple levels and loci of care, inclusive of all patient needs.
- Use existing data to evaluate cancer care by type of facility, geography, and other variables.
- Support educational and outreach efforts directed at prevention and early detection as promoted throughout this Plan.
- Identify and promote the use of culturally and linguistically appropriate information.



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IV. Quality of Life

A remarkable advance in the field of cancer is the increased 'cure' rate, which has led to lengthening the survival period (which starts at the point of diagnosis and continues through the remainder of the patient's life). Forty years ago, only 30% of people diagnosed with cancer lived five years after diagnosis. Now, more than 60% survive their disease for five years or longer.[1] At the same time cancer can impose physical limitations and leave emotional scars, affecting not only the survivor but also the family. The increased number of survivors has led to increased awareness of the importance of improving quality of life by creating an array of supportive services that address spiritual, psychosocial, vocational, and rehabilitative needs, among others. Through these services, cancer survivors can enjoy active, productive lives, and be able to achieve and maintain the highest possible level of function. Since cancer affects the survivor's family members as well, many other people are also affected by the cancer survivor's quality of life. Pain management is also recognized as an element central to the Quality of Life discussion and is included in the Palliative Care chapter, which follows.

Some of the factors in improving survivors' quality of life include follow-up and psychosocial services, services for teenagers and children, and awareness on the part of consumers and providers of the need for the services and their availability. In addition, survivors and their families must be empowered to act as self-advocates, fully engaged and participating in their treatment plans, whenever possible, and based on their needs and preferences. Health care providers must be encouraged to engage survivors as self-advocates in all phases of treatment. This chapter outlines strategies to address these issues.

GOAL 1: MANAGEMENT AND SURVEILLANCE

By 2010, 80% of survivors should receive care according to appropriate clinical treatment guidelines throughout their cancer experience (diagnosis to end of life).

STRATEGIES

- Collect, assess and distribute appropriate surveillance protocols to primary care and specialist groups.
- Educate survivors on prevention of secondary cancers and other sequelae.

- Encourage research into cancer survivors' knowledge of recommended protocols; the barriers encountered when trying to comply with recommendations, and reasons for non-compliance with follow-up recommendations. Consider relevant attitudes, beliefs and behaviors as well as age-appropriate protocols and cultural and linguistic appropriateness.
- Encourage survivors to be self-advocates and active participants in their courses of treatment.
- Describe appropriate roles of primary care providers versus specialists in ongoing care of cancer survivors.
- Actively seek survivors' input into treatment decisions and enable survivors to self-advocate for treatment based upon their needs and preferences.
- Encourage individualized case management plans that take into account survivor's age, stage of disease, resources available, and other factors.
- Identify local, 24-hour support systems, where families can obtain answers to questions as they arise, and receive help in emergencies.

GOAL 2: PSYCHOSOCIAL SUPPORT

By 2010, increase the availability of psychosocial support services for cancer survivors, their families, and friends through all phases of the cancer experience.

STRATEGIES

- Make available relevant materials and coordinate activities related to cancer survivorship and quality of life issues.
- Collect information on the number and type of support groups available to NYS residents (consider those available to patients with specific diagnosis and their families, focused on specific ethnic/cultural groups, etc.).
- Identify psychosocial support activities not based on the medical model of care, but integrated whenever possible with medical care.
- Gather information on the efficacy of various types of psychosocial support services.
- Use cancer survivor and caregiver supportive programs that cross cancer "site-specific" boundaries.
- Communicate with patients, their families, friends, and health care workers about the availability of such services through use of individually and generally targeted written and electronic materials.
- Raise awareness of the importance of psychosocial support in conjunction with appropriate medical care.
- Assist providers in communication with survivors, family members and friends relating to psychosocial and other support issues.
- Identify ethnically and culturally sensitive psychosocial interventions for those most severely underserved.
- Provide additional opportunities for cancer survivors to share their expertise with newly diagnosed individuals and their families and friends.
- Identify reimbursement models that promote comprehensive support throughout cancer treatment and post-treatment.
- Identify and remediate barriers to utilization of support and educational programs by survivors and their families and friends.
- Assist children who have a parent and/or caregiver undergoing treatment for cancer or addressing end-of-life issues.
- Assist parents and caregivers undergoing treatment for cancer to communicate with their children regarding the treatments, survivorship, and, as necessary, addressing end-of-life issues.

GOAL 3: REDUCE EMPLOYMENT/ INSURANCE BARRIERS

By 2010, cancer survivors can be informed about their rights concerning employment and insurance issues from a centralized source.

STRATEGIES

- Collect qualitative and quantitative data on barriers to employment and insurance coverage and other relevant issues.
- Identify offices that help cancer survivors with employment and insurance-related issues.
- Make available information on disability income support and legal issues such as permanency planning for cancer survivors.
- Develop collaborative relationships with employers, HMOs, insurers and other payors to reduce negative experiences on the part of cancer survivors related to employment and insurance.

GOAL 4: CHILDREN AND TEENS

By 2010, the needs of children and teens undergoing treatment or surviving cancer are met with services that are age appropriate and consider life stage differences.

STRATEGIES

- Collect information on young cancer survivors to better understand the unique challenges faced by children and teens with cancer.
- Provide navigation assistance to families of children with cancer to address the unique needs of this population.

The increased number of cancer survivors has lead to increased awareness of the importance of improving quality of life by creating an array of supportive services that address spiritual, psychosocial, vocational, and rehabilitative needs.

- Empower young cancer survivors to talk about their experiences with their peers, with treatment providers and with support services providers to enable those individuals to better understand the issues faced by young cancer survivors.
- Enable teachers and students to understand and support the special needs of children with cancer in schools.
- Encourage availability of support groups and websites, online chat rooms, and other venues for children and teens that include information on non-cancer related topics.
- Make available age-appropriate information to hospitals, oncologists' offices, and others regarding available services for children and teens.
- Make available to the public and providers enhanced levels of information related to the long-term implications of the effects of cancer treatment in children and teens.

GOAL 5: SPECIAL POPULATIONS

By 2010, address disparities affecting cancer survivors and their quality of life.

STRATEGIES

- Increase the enrollment of minority and underserved populations in clinical trials.
- Make cancer-related materials available in languages other than English and assess materials for their relevance in other cultures.
- Provide opportunities for minority cancer survivors and their families to act as role models for others in the community.
- Increase outreach to all survivors regarding quality of life issues and where to find support, with input by survivors and their caregivers.
- Enhance research on the adequacy of follow-up and support services provided to minority cancer patients, their families and friends, and reasons for disparities in services.
- Use community navigators for the healthcare system and involve them in programs for cancer survivors, their families, and friends.
- Increase access to existing support services for minority and underserved populations.
- Encourage research on prediction of recurrence of cancer in survivors.

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V. Palliative Care

Palliative care is an interdisciplinary, therapeutic model for cancer patients of all ages, focused on maintaining culturally sensitive and competent care. Palliative care includes pain management, symptom control, and also addresses psychosocial, spiritual, family and bereavement needs. Palliative care should complement cancer treatments along the continuum of illness and intensify with advanced, progressive disease.

A number of steps must be taken if we are to provide quality palliative care to all of the people who need it. For example, more service delivery models are needed which integrate palliative care with treatment services, and barriers to receiving quality palliative care must be researched and addressed. Consumer education will make more people aware of the benefits of palliative care, the variety of services, coverage, and physician involvement. Although palliative care is being increasingly introduced into the curricula of the health professions schools, more continuing education programs are needed for practicing professionals. Also, research targeting palliative care issues must be continued.

The foundation of any and all goals related to palliative care is to promote understanding that palliative care includes explicit management of cancer-related symptoms, such as pain and shortness of breath. As it relates to this Plan, palliative care is a specific strategy that is considered from diagnosis forward. Hospice care is that component of palliative care focused at the end of life.

GOAL 1: PAIN MANAGEMENT

By 2010, ensure access to appropriate pain management for all patients throughout all stages of the disease.

STRATEGIES

- Identify the availability of cancer centers with pain management services, and develop strategies for providers to offer such services.
- Balance the control of medications and their appropriate use. Examine the extent to which state law and regulations permit the use of pain medication. Identify impediments to such use and facilitate the availability of medication for all appropriate indications.
- Dispel myths among the public and professionals regarding controlled medications. Inform the public, cancer patients and their families that pain can be controlled and pain measures should be offered as part of their care.
- Identify quality assurance programs for pain management, and encourage health care systems to adopt and institutionalize quality standards.
- Teach pain management courses in medical, nursing and pharmacy schools in the state, and identify sources of continuing education for practicing professionals.
- Research the role of complementary medicine as an option in pain management services and make findings available to providers and survivors.

GOAL 2: INTEGRATION OF PALLIATIVE CARE

By 2010, palliative care will be an integral part of oncology practices throughout New York State.

STRATEGIES

- Encourage oncology and inpatient programs to incorporate components of palliative care.
- Include evidence-based, effective palliative and end-of-life curricula in schools of medicine and nursing and other relevant health professional schools and programs.
- Identify best practice models for quality palliative and hospice care in all relevant settings.
- Identify standards for optimizing transfer between all relevant palliative and hospice care settings in particular as it relates to the special needs of children and teens.
- Identify and work toward eliminating barriers to quality palliative and hospice care.
- Collaborate with professional associations to identify and/or develop competency standards for national certification.
- Identify quality indicators to monitor implementation of palliative care.
- Identify reimbursement models that promote expanded palliative care access (including care "upstream" of hospice).
- Identify and promote the use of culturally and linguistically appropriate information.
- Incorporate the concept of palliation into support groups for cancer survivors, their families and friends.
- Encourage inclusion of practitioners of evidence-based complementary therapies in integrated palliative care programs.

GOAL 3: ACCESS TO PALLIATIVE CARE SERVICES

By 2010, improve access to a specialist-level palliative care team for all cancer patients in need. (A specialist level implies certification, where certification is available, within each professional discipline).

STRATEGIES

- Encourage the availability of palliative care in inpatient and outpatient settings in NCI-designated cancer centers, tertiary hospitals, children's hospitals and community cancer centers in New York State.
- Identify best practices models for interdisciplinary collaboration in palliative care, including age-appropriateness and cultural/ linguistically appropriate care.
- Identify relevant parameters for "specialist level" providers for palliative care.
- Improve assessment of pain and other symptom distress in cancer patients.
- Identify barriers to access to hospice care for all ages.
- Utilize hospice providers as palliative care consultants.
- Reduce the time between diagnosis and referral to hospice for support, considering the survivors preferences.
- Identify best practices models for palliative care in long term care settings.
- Encourage partnerships between hospice providers, cancer centers, hospitals, long-term care and other providers.
- Assess reimbursement systems for changes needed to increase access to palliative care.
- Develop best practices quality improvement palliative care programs.
- Support patients and their family and friends in making end-of-life decisions (e.g. death with dignity).

GOAL 4: PUBLIC AWARENESS OF PALLIATIVE CARE

By 2010, increase awareness that palliative care is available and an integral part of cancer care at any stage of diagnosis, treatment and survival. Also, encourage earlier referral to hospice care as a means of providing palliative care in the last months of life.

STRATEGIES

- Increase awareness of palliative care services as an option for care, and make available materials for providers and institutions for distribution to people undergoing treatment for cancer.
- Encourage health care providers, institutions, voluntary organizations, government agencies, and others to provide education and information on palliative care and hospice care, including scope of services, locations, access to care, and reimbursement.
- Identify culturally relevant health care proxies and advance directives for use by cancer patients.
- Include language in Internal Review Board consent forms for clinical trials that incorporates palliative care.
- Make available bereavement services to cancer patients and their friends and families.
- Implement existing National Comprehensive Cancer Network practice guidelines in the domains of palliative care, including pain management, symptom control and psychosocial assessment.
- Increase cancer survivor's awareness that the consequences of cancer and its treatment-related side effects can be managed.
- Utilize technology, such as the Internet, as educational tools and provide links to appropriate organizations.

GOAL 5: PALLIATIVE CARE RESEARCH

By 2010, increase cancer research in the area of palliative care.

STRATEGIES

- Increase awareness among funders of research in New York of the need for funding palliative care research, including health service research outcomes, research fellowships, demonstration projects, and performance improvement.
- Identify a core set of palliative care quality measures in accordance with the National Cancer Data Base (NCDB) Report.
- Encourage research and demonstration studies for children's hospice and palliative care services.

> The foundation and all goals related to palliative care is to promote understanding that palliative care includes explicit management of cancer-related symptoms, including but not limited to pain and shortness of breath.

VI. Health Personnel

An adequate supply of trained and qualified personnel is vital in order to provide cancer-related prevention, detection, treatment, and palliative care services. New York State will need more professionals providing cancer-related care simply because the population of persons surviving cancer will grow over the next ten years due to key demographic factors. The general population will increase, perhaps as much as 8%-9%; the over 65 population will grow by as much as 25%; and, the period of survival will continue to lengthen. As the need for more personnel increases, the state is faced with an aging workforce seeking retirement. To meet these increased patient and family needs, staff recruitment and retention strategies must be employed.

Fortunately, many of the successful strategies for recruitment and retention—job satisfaction, adequate pay, career ladders, scholarships—are known. Alternative means also support the workforce, including more efficient workflow and greater use of technology. However, determining the extent and degree to which these strategies should be pursued is difficult. Data addressing shortages or surpluses by profession type, by geographic region, or by underrepresented minority groups can be used to design and implement personnel policies over the next several years which, in turn, will define a workforce that is adequate and appropriate in size.

This chapter also advocates continuing education for health professionals. In order to control cancer, properly prepared professionals who are also current in their knowledge and skills about cancer-related prevention, detection, treatment, palliative care, and quality of life for cancer survivors and their families are needed. Data is also needed to address the gaps in continuing education programs, design effective classes, facilitate greater participation, and train people on using emerging technologies.

GOAL 1: CANCER CARE WORKFORCE SYSTEM

By 2010, identify gaps and needs, and explore collection, monitoring, analysis, and dissemination of quantitative and qualitative data that will improve decision-making regarding the cancer health workforce in NYS.

STRATEGIES

- Identify the data of interest, such as numbers of providers, types of providers, regional distribution, racial/ethnic diversity, primary care/specialist mix, years of experience, number recertified in specific areas, patient/provider ratios, salaries of new/experienced workers, and workforce needs of cancer care providers.
- Review existing health workforce data such as "Report on Supply and Demand of Registered Nurses," exit interviews of medical residents trained in NYS.
- Build cancer workforce data elements into existing data collection systems relating to the health care workforce.
- Encourage tracking of the cancer care health workforce supply, demand and need.
- Identify data needed to profile the current workforce providing cancer-related services.
- Inform the provider community, the health professions education and training community, public policy makers and the public on the data needed and the number and types of workers needed to provide high quality care to individuals with cancer.

- Project the specific health professional groups expected to be in short supply in the future.
- Assess the views of survivors, family members and health workers on accessibility, quality and adequacy of the workforce, including staffing levels, skill sets and training.
- Supplement regular data collection systems by facilitating special studies of the cancer care workforce, exploring factors likely to influence satisfaction and retention.

GOAL 2: ADEQUATELY PREPARED PROVIDERS

By 2010, health care providers will have access to continuing educational opportunities that enhance and update their knowledge, skills and competencies in the area of cancer care.

STRATEGIES

- Encourage development of model curricula for medical schools, nursing programs, and other health professions schools.
- Meet the priority continuing education needs of existing providers based on the information gathered from focus groups, surveys and other sources.
- Assess adequacy of cancer-related material in curricula of various professions' continuing education programs, particularly related to communicating and partnering with patients and families, survivorship issues, palliative care, and end-of-life care.
- Research the feasibility of providing incentives to facilitate providers' (at all levels) access to continuing education opportunities.
- Facilitate distance learning and web-based education strategies for cancer care practitioners throughout the state.
- Distribute information about conferences, grand rounds, and other educational opportunities available to NYS practitioners.
- Assess adequacy of education in "new" areas such as emerging technologies, palliative care guidelines, and cancer genetics.
- Identify educational tools such as CD-ROMs and "virtual libraries" for isolated providers, such as home health care workers and other providers who cannot leave their patients.
- Include in educational opportunities help for providers to deal with end-of-life issues and encompass a broader, more enlightened approach to living with cancer.
- Consider educational modules that will be useful across health professional groups.
- Offer health care providers continuing education courses on the role of genetics in cancer and counseling, testing and management options for people at higher risk.
- Strengthen health training in areas of language (bilingual) and cultural sensitivity.

Data is needed to address the gaps in continuing education programs, design effective classes, facilitate greater participation, and train people on using emerging technologies.

GOAL 3: ADEQUATE SUPPLY

By 2010, increase retention of experienced workers providing cancer care services.

By 2010, supply cancer care providers, including providers from under-represented minority groups, to underserved areas.

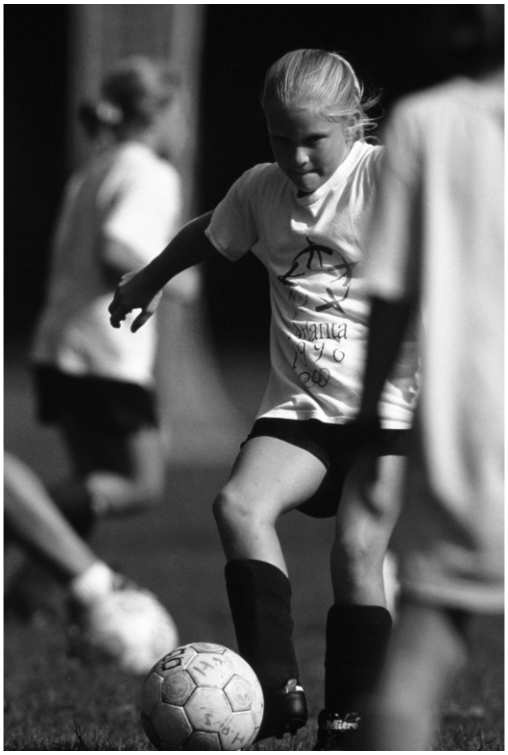
By 2010, increase the supply of cancer care providers in professions where shortages have been demonstrated.

STRATEGIES

- Respond to the needs of the existing cancer care workforce based on information gathered under Goal #1.
- Consider criteria utilized in designating magnet hospitals and, if judged likely to affect retention, attempt to increase number of NYS hospitals meeting magnet criteria from 3 to 12.
- Encourage employers to increase options and flexibility for staff, such as job sharing, benefits for part-time workers, and other options.
- Convene groups of cancer care practitioners to address issues such as improving collaboration, reducing burnout and interacting with patients and families.
- Identify financial models aligned with workforce development goals and research strategies such as "sign-on" bonuses and loan repayment programs to increase the number of cancer care providers in rural and other underserved areas of the state.
- Research the feasibility of providing scholarships and other incentives to increase the number of students in the cancer care arena.
- Make available to guidance and career counselors in underserved areas, career kits and other useful recruitment tools.
- Recruit and retain researchers, including graduate students, through the New York State Office of Science, Technology and Academic Research (NYSTAR).
- Collaborate with Area Health Education Centers (AHECs) on training and recruitment projects in rural and underserved areas.
- Assist family members, cancer survivors and caregivers in becoming caregivers in the future.
- Analyze the need for new or additional training programs or voluntary certification for specific professions.
- Use team delivery models that combine medical, psychosocial, child development and spiritual aspects into a unified approach to outpatient and inpatient care.
- Test alternate delivery systems and job redesign strategies to increase worker satisfaction, improve productivity, increase patient and family satisfaction, or improve outcomes.

VII. Research

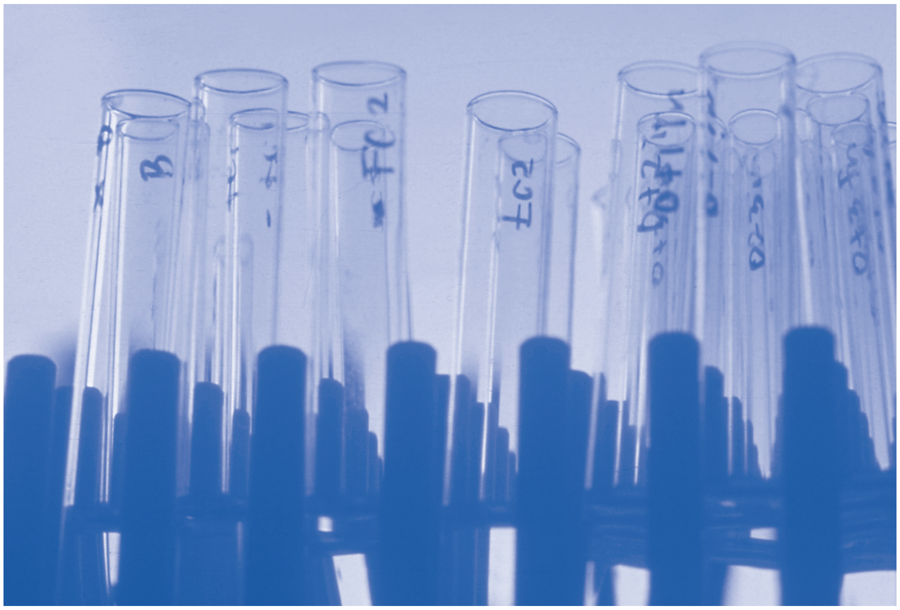
Research on cancer is moving forward at a dizzying pace. It is dramatically changing our understanding of cancer. Cancers previously thought to be the same are actually multiple, molecularly distinct diseases. At the heart of cancer research is an entire paradigm shift away from microscopic characterizations of a cancer with adjuvant chemical or radiological treatments to the creation of complete tumor gene indices that will allow for targeted treatments. Such research can lead to molecularly targeted therapies which are highly selective in effectively treating cancer with minimal side effects.[1] Molecular information of a cancer cell and its components, including proteins, is being revealed. Central to research at this level (molecular biology and system biology) is an increasing appreciation for the microenvironment in which a cancer cell exists. Much as an individual's interaction with his or her environment can influence the development of specific cancers, a cancer cell's interaction within its own microenvironment can encourage and even enable growth. Simply put, just as we humans conspire with our world, the cancer cell has conspirators too.



There are many notable discoveries. For one, scientists are trying to fathom how communication among cancer cells, surrounding cells, and immune cells can either control or promote tumor growth. Through identification of molecular signatures, for instance, it may be possible to devise treatments that selectively target only implicated cells, i.e. the cancer cell and its conspirators. Such progress might improve the side effects of cancer treatments. At the same time, scientists are trying to finds ways to halt the growth of cancer cells, or even revert a cancer cell to a normal cell. To this end, intriguing findings have been published. Professor Robert Newbold from Brunel University in Uxbridge, Great Britain has found the switch that flicks back on and allows cancer cells to transform into what he describes as a "Peter Pan mode" where they never grow old and can live forever. The molecule involved, telomerase, normally shuts down after birth, but appears to be reactivated by cancer cells allowing their aggressive growth to go forward.[2]

Rigorous research must continue so that its benefits can be conferred on the clinical setting for better public health. Bioinformatics can assist in this process by translating pioneering research into better medicine. In many respects, research is the key to a future of living better with cancer and perhaps someday living without it. Recent advances in the fields of genetics and molecular biology are expected to have a significant impact on prevention, diagnosis and treatment of various kinds of cancer by the year 2010. New York State must ensure that it assumes a role of leadership as we take the next step forward in cancer research.

New York State historically leads the nation in different fields of health-related research, and cancer has been no exception. Our state has many premier research facilities designated by the National Cancer Institute such as those at Memorial Sloan-Kettering Cancer Center, Roswell Park Cancer Institute, Cold Spring Harbor Laboratory, the Cancer Research Center at Albert Einstein College of Medicine, Herbert Irving Comprehensive Cancer Center, Kaplan Cancer Center, and American Health Foundation. New York State has also taken significant steps in the past few years to support the development of new biomedical facilities. All of these resources, in the aggregate, offer a large number of dedicated staff that conduct research on cancer, and we can build upon their future efforts.



New York State has made significant contributions to cancer research. More recently, however, funding from the National Institutes of Health (NIH) has declined. In the 15-year period from 1984-1998, the national research budget of NIH tripled from $3.25 billion to almost $10 billion while New York State's share declined by almost 27%. NYS fell to third place in research funding levels, behind California and Massachusetts; New York lost an estimated $130 million in additional income from NCI by not maintaining its 1984 share of funding.[3] In order to keep up with the demands of research, facilities must develop the infrastructure necessary to more successfully apply for grants, including the development of links between academic institutions and organizations conducting work in non-academic settings.

This chapter advocates an unparalleled effort over the next few years for the purpose of elevating New York State to its role as a world-class leader in cancer research. To realize this goal, the NYS strategy is one of collaboration among all research facilities to identify priority projects, obtain funding for them, conduct research, share resources, recruit and retain researchers, and increase the number and diversity of people participating in clinical trials.

GOAL 1: INFRASTRUCTURE

By 2010, New York State will seek to increase its cancer research funding from federal and other sources by 50%.

STRATEGIES

- Promote a statewide cancer research alliance to allow researchers the opportunity to interact and network with peers and obtain input from community members.
- Work toward increased collaboration through means such as a collaborative database to provide researchers with access to information on research projects, available skills, equipment and laboratory space, and new funding sources.
- Share information on current cancer research areas, identify the most important research projects that should be pursued in New York State and recommend areas for collaboration among researchers, incorporating input from community members.
- Enable out-of-state companies and pharmaceutical corporations to support research efforts in New York State through a research fund or other means.
- Encourage existing and potential start-up companies to develop cancer-related business plans and grant applications.
- Develop, recruit and retain researchers, including graduate students and members of minority and underrepresented groups.
- Review regulations, statutes and policies that impede research activities and the acquisition of research funds, and make recommendations to revise or eliminiate them, as feasible.

GOAL 2: CLINICAL TRIAL PARTICIPATION

By 2010, New York State will have a clinical trial population that increasingly represents the age, gender, race, and ethnic distribution of the population.

STRATEGIES

- Promote participation in clinical trials by individuals.
- Increase referrals to cancer prevention trials by primary care and other health care providers.
- Increase the number of clinical trials focusing on cancer prevention and control in high-risk populations.

- Identify barriers to minority individuals' participation in clinical trials.
- Foster and support collaboration on Phase I and Phase II clinical trials.
- Disseminate research findings among relevant populations.
- Increase outreach designed to decrease fear of participating in clinical trials.
- Educate the public regarding the importance and relevance of clinical trials.
- Identify mechanisms to use as "brokers" for research and collaboration that will also market clinical trials to hospitals across the state.
- Increase the integration and collaboration among private academic institutions, medical researchers and State University of New York/City University of New York.
- Utilize and promote existing clinical trial information sources to providers, survivors and their families.

GOAL 3: CANCER BURDEN STUDIES

By 2010, disseminate information on the cancer burden and impact of cancer on populations most affected by cancer.

STRATEGIES

- Identify research funding across the continuum of cancer, including cancer prevention and population-based behavior change.
- Identify research and studies on the role of prevention, nutrition, and physical activity on cancer burden.
- Identify studies related to cancer treatment and its impact on quality of life.
- Encourage people to engage in prevention activities by sharing with them the data on their cancer risk.
- Disseminate research and population-based studies.
- Promote health services delivery research on quality, quantity and outcomes of care.
- Research guidelines for the integration of research initiatives.

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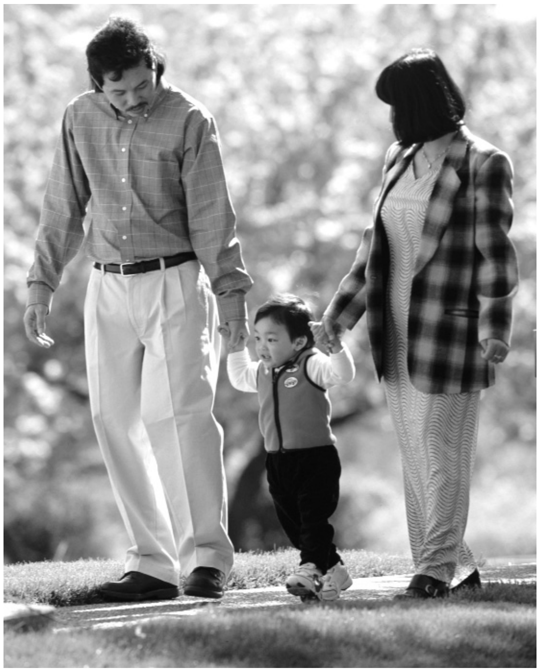
1. National Institutes of Health. *Plans and priorities for cancer research: The Nation's investment in cancer research for fiscal year 2004*. Bethesda, MD: National Institutes of Health, National Cancer Institute; 2002.

2. Szutorisz H, Lingner J, Cuthbert AP, Trott DA, Newbold RF, Nabholz M. A chromosome 3-encoded repressor of the human telomerase reverse transcriptase (hTERT) gene controls the state of hTERT chromatin. *Cancer Research*; 2003(63)3: 689-695.

3. Sturman LS, Sorin MD, Hannum RJ, Opportunities lost: NIH research funding to New York's medical schools. *Journal of Urban Health*; 2000(77)1: 86-95.

VIII. Data and Surveillance

All aspects of the New York State Comprehensive Cancer Control Plan—from defining the burden of cancer and guiding planning activities, to monitoring changes and evaluating intervention efforts—rely upon the availability of both strong and relevant data and surveillance activities. Currently these vital functions are supported through a variety of data sources in New York State. These sources include: (1) NYS and NYC vital statistics, particularly death registration systems, (2) the NYS Cancer Registry, (3) hospital discharge data (Statewide Planning and Research Cooperative System—SPARCS), (4) Behavioral Risk Factor Surveillance System (BRFSS), (5) Youth Risk Behavior Surveillance System (YRBSS) as well as population statistics provided by the U.S. Bureau of the Census and NYS Data Center partners.



Ready access to relevant data is key in promoting comprehensive public health interventions and to support training programs that ensure the proper and appropriate collection and use of data. The proposed surveillance goals and activities described below are intended to strengthen the existing surveillance system, to support greater collaboration between clinical, public health, and research professionals, and to disseminate data relevant to cancer control.

The CDC's National Program of Cancer Registries and the National Cancer Institute's Surveillance, Epidemiology and End Results Program (SEER) both underwrite and support accurate reporting of cancer incidence. They are perceived to be complementary to one another; however, collaboration is underway to enhance their cooperative efforts. A report sponsored by both agencies was published in Fall, 2002 that comprised nearly 78% of all cancers diagnosed in the United States in 1999. This included statistics for all states regarded as having high quality data. New York was among those states.[1]

GOAL 1: DATA AVAILABILITY

Through 2010, collect complete, accurate, and timely data related to cancer in New York.

STRATEGIES

- Use the New York State Cancer Registry:
    - Continue to emphasize complete reporting of cancer by non-hospital reporting sources (e.g., pathology laboratories, radiation treatment centers, ambulatory surgery centers, etc.).
    - Accurately record cancer data specific to minority and immigrant populations. Work with reporting facilities to improve the collection of race, Hispanic origin, and birthplace information to SEER standard level.
    - Decrease the percentage of unknown data values including "unknown stage" and "unknown first course of treatment" to SEER program standards.
    - Identify "at-risk" facilities in need of further training, such as those not supplying data or not meeting quality or timeliness standards.
    - Provide pre-certification training programs to enable reporting facilities to comply with the mandate to employ certified tumor registrars for purposes of cancer reporting.
    - Improve the collection of follow-up information on cancer patients through linkage with administrative databases, for the purpose of generating survival data.

  - Link the Cancer Registry web page to other related web sites.
- Utilize BRFSS data:
  - Collect complete, accurate, and timely data on knowledge and behaviors that affect the risk of the development or detection of cancer (cancer-related behaviors).
  - Generate regional and/or county-level prevalence estimates. Coordinate efforts with New York City.
  - Collect data on cancer-related behaviors critical to the evaluation of the primary prevention and early detection goals.
- Collect data on the impact of cancer on the health care system and health system capacity for cancer detection, prevention and treatment.
- Research the feasibility of capturing outpatient service utilization data and data on "quality of life" for cancer patients and their caregivers.
- Monitor developing technologies and trends in cancer diagnosis and treatment and reflect in data collection relevant procedures.

GOAL 2: DATA ANALYSIS

By 2010, continue to analyze data on cancer and cancer-related behaviors in New York.

STRATEGIES

- Enhance partnerships with organizations such as the American Cancer Society and academic institutions.
- Compare levels of screening and stage distribution of New York cancer patients belonging to different population groups and analyze survival.
- Analyze cancer at the county level, utilizing incidence (including stage), mortality, screening and risk factor data.

GOAL 3: DATA/INFORMATION DISSEMINATION

By 2010, make New York cancer surveillance data available, accessible, and useful.

STRATEGIES

- Identify data sources relevant to cancer prevention and control. Make data sources available on the New York State Department of Health web site.
- Describe, for current datasets, the data collection method used, all available variables, limitations of data and potentials for use, level of data available (i.e., record level, county, state, etc.), and procedures for user access.
- Propose modifications to current datasets if data elements are inconsistent, lack specificity, or are not used. Make recommendations on data that need to be added to increase or create capacity for important analyses.
- Ensure that data confidentiality is maintained by masking small numbers in all public use datasets.
- Make available annual incidence, mortality and risk factor analyses through copy dissemination of Cancer Registry and BRFSS publications and through the continued production of the ACS-NYSDOH publication, *New York State Cancer Facts and Figures*.
- Analyze cancer incidence, stage, mortality and risk factor data by age, gender, race, ethnicity and geographic area.
- Make available data to support cancer profiles for use by local planners, legislators, health departments, and citizen groups.
- Create public use datasets including incidence and mortality data.
- Disseminate data to the diverse populations of New York State.
- Utilize partnerships with organizations and universities to educate communities on the proper use and interpretation of cancer-related statistics. Make available web-based teaching tools on epidemiology and statistical methods.

GOAL 4: EVALUATION OF DATA STRATEGIES

By 2010, evaluate cancer surveillance activities.

STRATEGIES

- Assess the use of cancer surveillance data in risk reduction programs.
- Evaluate the use of disseminated cancer surveillance data by provider, community and health organizations.
- Assess the readability and use of available cancer statistics as well as user satisfaction with the means of information dissemination. Revise the format of data products and methods of dissemination as necessary.

Reference

1. U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999 Incidence*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Institutes of Health, National Cancer Institute; 2002.

IX. Public Policy

Progress with any disease, notably one as complicated and complex as cancer, must also be evident beyond the research laboratories, the halls of academe, the hospitals and physicians' offices right into the world of public health policy. Public policy is an integral part of all cancer prevention and control efforts. As such, the following principles represent public health guidelines when considering Comprehensive Cancer Control Planning for New York State:

1. All public health policy and practice will be consistent with and promote primary prevention based on the most current scientific evidence and recognize the importance of community and individual behavior;
2. All written and electronic information should be easily available, understandable and accessible to improve health literacy on cancer issues among NYS's population;
3. All NYS citizens should have access to high quality preventive, diagnostic, treatment, palliative and supportive cancer services and clinical cancer trials regardless of insurance type;
4. All public policy and practice should seek to address health disparities in cancer incidence, prevalence, treatment outcomes and survivorship; and,
5. All public policy and practice should seek consumer input and facilitate advocacy to assure diverse public input and participation in policy development and program implementation.

Because cancer affects so many individuals, its impact has repercussions far beyond the scope of any individual person. Families are affected, so too are employers, support networks both formal and informal communities and even entire governments. For this reason, policies that are engaged at all these levels that seek a balance between investments in prevention and responses to acute care needs, must be developed.

GOAL 1: PRIMARY PREVENTION POLICY

By 2010, policies promoting primary prevention of chronic diseases, including cancer, will be in place.

STRATEGIES

- Continue to implement policies to change community and individual behaviors toward healthy lifestyles and health promotion, including emphasis on tobacco prevention and cessation, diet and nutrition, and physical activity.
- Encourage partnering between organizations working on similar issues.
- Offer consistent health promotion messages across agencies and across private, not-for-profit health organizations.
- Encourage policies that address the supply of primary care practitioners across geographic areas of the State.
- Identify reimbursement policies that support health counseling by primary caregivers.
- Make accessible accurate, scientific information about healthy lifestyles to providers and consumers.
- Encourage specific policies in schools that address cancer prevention and support of children and families affected by cancer.

GOAL 2: HEALTH COMMUNICATION AND LITERACY

By 2010, encourage development of policies to promote health literacy on cancer issues.

STRATEGIES

- Evaluate health literacy policies and programs.
- Track measures of health literacy.
- Increase the reach of interventions to those individuals with low health literacy.
- Make available accurate information on issues related to cancer prevention, cancer treatment and cancer support services to consumers.
- Educate practitioners about health literacy and improve communication with patients with low health literacy.
- Encourage partnerships between organizations to improve health literacy in New York State so citizens can access appropriate health information, understand options and treatments, manage their disease and improve their overall health.
- Increase awareness among policy makers, including corporations and government officials, about cancer issues.

GOAL 3: DIAGNOSIS AND TREATMENT

By 2010, provide standard-of-care diagnosis and treatment of cancer for all affected New Yorkers.

STRATEGIES

- Encourage coverage for diagnosis of cancer and treatment for cancer in insurance programs and reimbursement for the provision of the caliber and quality of services described in this plan.
- Research the feasibility of publicly subsidized insurance supplements to achieve adequate cancer coverage, including buy-in by diagnosed cancer patients without private coverage whose incomes exceed current public program eligibility.
- Encourage development of partnerships between health care providers to ensure better care navigation systems for the uninsured and under insured.
- Eligibility for public programs should allow for the buy-in of diagnosed cancer patients without private coverage but whose income exceeds current public program eligibility.
- Provide accessible cancer screening to all New Yorkers regardless of insurance status or geographic location.
- Provide New Yorkers with access to quality, IRB-approved clinical trials.
- Provide cancer patients with prompt access to appropriate cancer treatment and supportive services through appropriate public reimbursement and insurance and access services such as case management or navigation success.
- Work with managed care organizations to remove barriers to timely referral to out-of-network providers for medically appropriate care when necessary.

GOAL 4: DISPARITY REDUCTION

By 2010, address health disparities in access to cancer screening and treatments.

STRATEGIES

- Require screening and treatment programs to demonstrate how they will reach racial, ethnic, gender, and geographic populations.
- Include specific geographic, ethnic, gender and racial information in cancer research.
- Identify research to further understand and reduce disparities.
- Identify and promote the use of culturally, linguistically and developmentally appropriate information regarding screening and treatments.
- Increase minority and underserved enrollment in clinical trials.
- Promote diverse populations in medical and other health professions.

> Public policy is an integral part of all cancer prevention, control and quality of life efforts.

Looking to the Future: Plan Implementation

No one organization can hope to undertake all of the goals and strategies developed within this Plan. Collaboration is needed with agencies that are undertaking work in its various components. By engaging these partners, it will be possible to utilize this document as it was intended to be: a road map designed to lead the State toward a future of reduced cancer burden for all New Yorkers.

Implementation will be the responsibility of all the partners—including health care providers, community based organizations, state and local government and others. They will use this Plan while moving forward in individual and collaborative activities related to cancer control and prevention.

Linkages between and among the groups are necessary to best coordinate work and to make progress on the Plan based on its intended directions. Developing effective and efficient communications between these groups is an important step in successful Plan implementation. Sustaining these partnerships and communication systems will be a vital part of implementing this Plan and ensuring its success over time.

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Appendix B: Community Forums

An important process for developing the New York State Comprehensive Cancer Control Plan has been developing and enhancing partnerships with community-based groups, programs, organizations, agencies and those directly impacted by cancer.

A primary vehicle for ensuring a community voice in the development of the New York State Comprehensive Cancer Control Plan was a Community Forum process to support broad based input and recommendations. Over 1,000 organizations and individuals were provided an overview of the goals and strategies of the Plan and invited to share their perspectives, define the approach and become active participants in developing the solutions. In January 2003, ten Forums, staffed by members of the Core Work Group, were hosted across the state. Over 350 stakeholders attended at a forum in their community and many more offered comments either before or after the events.

Forums were held across the state and were structured to maximize the communities' participation, expertise and experience in cancer control. Stakeholders included providers, community organizations and groups, businesses, insurers and those touched by cancer as survivors and caregivers, who provided input on:

- Content areas related to overall statewide goals.
- Prioritization of the goals.
- Identification of their commitment to accomplish the goals.

Core content areas and goals provided to the participants of the Community Forums were supplemented through the Forum process by the development of strategic initiatives. In addition, common themes emerged from the discussion and input process. The following highlights the key areas related to the focus of the Plan and/or suggestions for enhancements that emerged from the Community Forum process.

Community Forums
Input from Across the State

Common Themes:

- A comprehensive approach is the most effective strategy for achieving goals.
- Health Promotion and Disease Prevention was identified as the highest priority content area across the state, followed by Early Detection.
- Incentives should be structured to support access to testing and treatment as well as preventive strategies.
- Treatment systems from early detection through palliative care need to:
    - Treat the whole person (medical and psychosocial care and support for the individual AND their immediate "community"/family);
    - Recognize the nature of cancer as a chronic disease;
    - Ensure equal access to all regardless of race/ethnicity, income or geography.

There is a need to enhance efforts related to quality of life and palliative care. Each is linked to health promotion activities and life-long behaviors and is vital in treatment program considerations. Supplemental content recommendations for the Plan include:

- Support of practices that promote quality of life;
- Promotion of strategies that cross all relevant professions;
- Assurance that every individual with cancer is able to achieve the highest level of function possible throughout the course of illness;
- Support structures to ensure that every individual with untreatable or incurable cancer is offered optimal comfort care until the end of life.

All New York State residents (regardless of income, race/ethnicity and geography) and all professionals should have access to:

- Comprehensive information on cancer prevention, treatment strategies and research findings;
- State-of-the-art treatment and palliative care;
- Early detection testing;
- Systems such as transportation to assist access.

Research activities should be expanded to include:

- Improved methods for dissemination of information;
- Need for more and better information on population-based burden;
- Increasing studies on the interrelationship of factors contributing to cancer;
- Additional need for information on genetics and environmental issues;
- Enhancements to promotional activities, information and access to clinical trials.

The involvement of communities across New York State through the Community Forums has been a vital part of the revision of the Plan that was presented for further review at the Leadership Summit.

Stakeholders include providers, community organizations and groups, businesses, insurers and those touched by cancer — survivors and caregivers...

Appendix C: Leadership Summit

Purpose

The Leadership Summit was the final step in shaping the New York State Comprehensive Cancer Control Plan. At the Summit, reputational leaders, including cancer advocates, survivors, policy makers, representatives of business and industry and individuals working in state and local government met to review and convey a final set of comments on the draft plan's goals and strategies. They recommended revisions and identified the means by which their organizations could help implement the Plan.

Structure

The first day of the summit was devoted to plenary sessions in which attendees were given an overview of national and state issues regarding cancer control and prevention. Two speakers, Jon Kerner, PhD, Assistant Deputy Director for Cancer Control and Population Sciences, National Cancer Institute, and Nancy Lee, MD, Director for Cancer Prevention and Control, Centers for Disease Control and Prevention, gave an overview of national progress and recommended actions and perspectives to consider in completing and implementing the Plan. Also, an overview was provided on the New York State Comprehensive Cancer Control Planning process. A panel discussion was conducted on five areas of the Plan—Quality of Life, Early Detection, Palliative Care, Research and Treatment. After each session, attendees had the opportunity to ask questions of the speakers and panelists. A dinner was hosted in the evening in which a cancer survivor provided moving testimony on her struggle and triumph over cancer.

The second day, using the background context provided in the plenary sessions, the participants met to discuss and provide comments on the goals and strategies in the plan. At the closing session, a panel discussed the importance of utilizing evidence-based cancer control methods and the challenges and opportunities in controlling and preventing cancer. The Summit concluded with attendees identifying ways their respective organizations would commit resources to implementation of the plan.

Objectives

One of the Summit's objectives was to ensure the Plan represented the range of perspectives and experiences of the diverse cancer community in New York State. Another objective was to ensure that expert review occurred for all nine areas of the Plan. These objectives were fully addressed by the attendees of the conference. The scope of representation included NCI-designated cancer centers, clinics, hospices, professional medical societies, local health departments, advocacy organizations, people with cancer and research organizations, among others. All geographic regions of the State were represented, providing a statewide perspective and diverse feedback on the Plan's contents.

Plan Review

The Summit participants provided over 200 comments on the goals and objectives of the Plan, which have been considered and addressed in this final release of the Plan. Some of the comments helped clarify the goals in the plan and have made the strategies for implementation more concrete and effective. Many comments recommended additional strategies, which have improved the comprehensiveness of the plan, while others suggested ways in which strategies could be integrated, making them more effective and less costly. Participants also identified the strategies in which they are currently participating, as well as those they are committed to in the future.

NOTES