

# **New Jersey Comprehensive Cancer Control:**

## ***2006 Status Report to the Governor and Legislature***

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

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**Prepared under the auspices of the Task Force  
Evaluation Committee**

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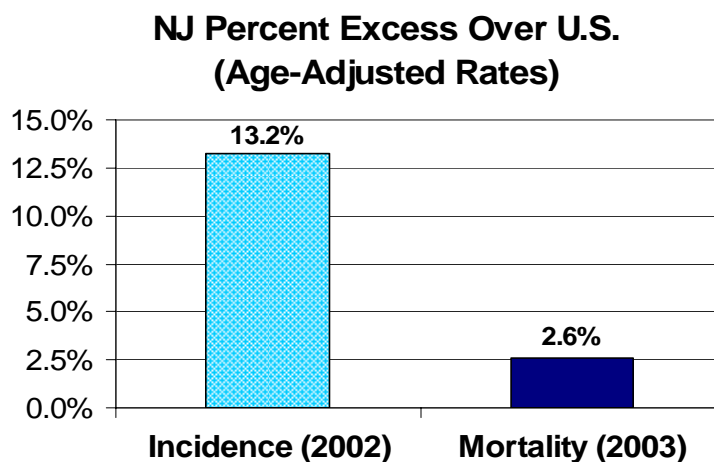
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## Executive Summary

The Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force) was institutionalized by the New Jersey legislature in January 2006 (P.L.2005, c.280). The Task Force oversees New Jersey's efforts in comprehensive cancer control, a process which aims to develop "an integrated and coordinated approach to reduce the incidence, morbidity, and mortality of cancer through prevention, early detection, treatment, rehabilitation, and palliation."<sup>a</sup> This is the Task Force's second biennial status report, and it reviews recent accomplishments, activities, and recommendations.

There is a need for the New Jersey Legislature and Governor to allocate additional resources to increase cancer funding for existing and new programs.<sup>b</sup> These should include an expanded focus on prevention activities and on research concerning cancer risk factors and public health interventions.

**The Need:** In New Jersey, incidence of all types of invasive cancers combined remains high, while cancer mortality is close to the national average. For the years 1999–2002, New Jersey consistently ranked among the three states with the highest rates of new cancer cases, well above the rates for the country as a whole. In contrast, in recent years, New Jersey has ranked near the national average in cancer mortality rates. This suggests that excellent treatment exists for New Jersey's residents and that prognosis has been improving. The continuing high incidence rate indicates that an increased emphasis on prevention is needed.



Continued efforts are needed to close the gaps in health disparities. Incidence and mortality rates remain high for some minority groups. For example, in New Jersey and in the U.S. overall, prostate cancer mortality is more than twice as high among African American men as among white men. Cervical cancer incidence is almost two-thirds higher among Hispanic women than all women combined.<sup>c</sup>

Some segments of the population are also underrepresented in clinical trials, leading to limitations in the applicability of both prevention and treatment findings to those groups. In addition to the widely recognized gender and ethnic/racial issues, there is a paucity of clinical data on optimal treatment for the elderly, who constitute the majority of cancer patients. The "New Jersey Cancer and Aging Task Force" of the New Jersey Commission on Cancer Research

<sup>a</sup> Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, *Guidance for Comprehensive Cancer Control Planning, Volume 1: Guidelines*. Published 03/25/2002. p. 2

<sup>b</sup> Including, but not limited to, the Office of Cancer Control and Prevention and the New Jersey Commission on Cancer Research of the New Jersey Department of Health and Senior Services.

<sup>c</sup> The magnitude of the difference is understated by the comparison with the entire population. Separate data on non-Hispanics are not available for direct comparison.

issued a call to action in 2002, including recommendations concerning basic science research related to the participation of the elderly in clinical trials. This mission overlaps with the need for comprehensive cancer control to include a focus on the elderly. There remain unmet needs, such as encouraging the inclusion of the elderly in clinical trials by expanding enrollment eligibility criteria to facilitate their inclusion and their participation, and by designing clinical trials explicitly tailored to the elderly when appropriate.

**The Accomplishments:** Comprehensive cancer control was implemented only recently in New Jersey, but the improved health outcomes which are its ultimate goals take years to observe and are thus inherently not yet detectable. However, there are already some laudable accomplishments resulting from New Jersey's efforts, including:

- ◆ **Strategies to implement the New Jersey Comprehensive Cancer Control Plan** (henceforth, **the Plan**) **have seen substantial progress** since the last report in 2004. The majority of all strategies (82%) are either completed or ongoing. The remaining strategies (18%) have encountered barriers, primarily insufficient funding or a shortage of volunteers to spearhead the strategy.
- ◆ With the hiring of additional staff made possible by CDC funding, **the Office of Cancer Control and Prevention (OCCP) has been able to substantially enhance its support for and leadership of both workgroups and county cancer coalitions.** For example, in the 2004 Report, it was reported that there was no information on the status of 22% of the strategies in the Plan, while there are now no strategies whose status is unknown.
- ◆ One of the greatest successes of New Jersey's program so far is **the establishment of a cancer coalition in each county.** Many coalitions have been extremely successful in establishing themselves within their communities and in bringing together various stakeholders, including those from competing organizations, to implement cancer control and prevention activities.
- ◆ Results of the statewide initiative of County Cancer Capacity and Needs Assessments have been **disseminated to the public and are continually utilized by county cancer coalitions and other groups to prioritize local cancer initiatives.** The development of the comprehensive county-based assessments was an innovative approach. Its success has led other venues to turn to New Jersey to learn and emulate.
- ◆ In 2004, the New Jersey Office of Cancer Control and Prevention (OCCP) was selected to join the National Comprehensive Cancer Control Program of the Centers for Disease Control and Prevention (CDC) through a Cooperative Agreement award. **The CDC has praised the nature and extent of evaluative efforts in New Jersey.** Some assessments in this report are responses to specific recommendations and requirements of the CDC. Prominent among these was an assessment of stakeholders conducted in 2006, which led to the following observations:
  - There is overall satisfaction among the Task Force and its workgroups and standing committees with respect to membership, climate, communication, implementation, process, and collaboration.
  - There was overwhelming enthusiasm for the leadership demonstrated by the Office of Cancer Control and Prevention and its Executive Director.
  - Stakeholders involved in New Jersey's program represent the key types of organizations suggested by the CDC and are representative of the three major geographic regions of the state.

**The Future:** The continuing high cancer incidence relative to other states indicates a need for more vigorous prevention efforts. When early detection of pre-cancerous lesions and their removal is possible, cancer can be prevented and incidence decreased.<sup>d</sup> The implementation in April 2006 of the New Jersey Smoke-Free Air Act (P.L. 2005, c. 383), which bans indoor tobacco use, is likely to be an important step in prevention of tobacco-associated cancers. In addition, a frequent consequence of screening is the systematic detection of cancer at earlier stages of disease.

For New Jersey to apply the findings from research advances to reduce the cancer burden, and to develop and explore new avenues of epidemiologic research into the causes of cancer, increased resources for comprehensive cancer control are urgently needed. It is nevertheless critical that ongoing screening efforts be continued and expanded. Thus, existing funding for the OCCP and related efforts cannot be reallocated. To sustain the momentum of efforts already undertaken and widen their impact, new funding is necessary for New Jersey to take advantage of evolving opportunities such as the following.

- ◆ A key goal for comprehensive cancer control is to increase screening efforts in each county. Data from the New Jersey Behavioral Risk Factor Survey could potentially be useful to evaluate their efforts, but the number of surveys conducted in each county would need to be increased to adequately examine trends.
- ◆ The next plan should include added emphasis on prevention, reflecting new and developing opportunities.<sup>e</sup> This increased focus on prevention is warranted at this time for several reasons. First, new epidemiologic data have identified additional modifiable risk factors.<sup>f</sup> Second, clinical trial data provide new opportunities for pharmacologic intervention to prevent cancer. This also highlights the importance of prevention trials, not just treatment trials. Third, diagnostic advances are providing new opportunities to diagnose precancerous and *in situ*<sup>g</sup> lesions, holding the promise of possible prevention of invasive cancer, not merely detection at earlier stages. New Jersey needs to take advantage of these advances, and should also participate in creating new advances.
- ◆ Epidemiologic research that focuses on etiology may provide new opportunities for intervention. Research that may be particularly relevant to the needs of New Jersey should be vigorously encouraged, both nationally and within the state. For example, Cancer Epidemiology Services at NJDHSS has been conducting such research for nearly thirty years with over one hundred publications on cancer in New Jersey.

The National Comprehensive Cancer Control Program of the Centers for Disease Control and Prevention has acknowledged great successes in New Jersey, and therefore the Governor and State Legislature can be proud of the achievements in the state. Indeed, New Jersey's programs are now being promulgated nationally and in Canada as a model. Investment by New Jersey in cancer control has been productive, but needs to increase if the continuing, large cancer burden faced by New Jersey's residents is to be reduced.

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<sup>d</sup> These types of successful prevention interventions occur, for example, with some colorectal and cervical lesions. Trends need to be interpreted with care. For example, institution of new or expanded screening programs can cause a paradoxical transient increase in incidence rates as a result of detection earlier than usual. Whether or not morbidity and mortality improve in these instances are complex issues that are dealt with by epidemiologists and biostatisticians.

<sup>e</sup> The initial cancer plan mostly emphasized screening and changing alterable behaviors such as smoking.

<sup>f</sup> For example, breast cancer incidence may be reduced by avoiding the use of post-menopausal hormonal therapy.

<sup>g</sup> *In situ* lesions are those that are only in their original location and have not yet invaded surrounding tissue.

## Section 1 – Introduction and Overview of the Evaluation Plan

### A. Background and Purpose of the Report

The Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force), established by Executive Order No. 114 on May 9, 2000, was institutionalized by the New Jersey legislature on January 6, 2006 with the enactment of P.L.2005, c.280.<sup>h,i</sup> Continuing the requirements of the earlier Executive Order, this law specifies that “The task force shall report to the Governor, the Commissioner of Health and Senior Services and the Legislature on its findings, recommendations and activities at least biennially.”<sup>j</sup> The present report is the second biennial status report (and the first to be submitted under this legislation).

The *New Jersey Comprehensive Cancer Control Plan* (henceforth, the Plan)<sup>1</sup> is the framework for comprehensive cancer control in New Jersey for the first five-year implementation period, 2003-2007. (Please refer to the first biennial status report<sup>2</sup> for additional details on the structure of the Task Force and the Plan.<sup>k</sup>) In the Evaluation chapter (Chapter 15) of the Plan (strategy EV-1.1.3, p. 270), the Task Force specified that a New Jersey academic institution was to develop and implement an Evaluation Plan in partnership with the Task Force. The University of Medicine and Dentistry of New Jersey–New Jersey Medical School (UMDNJ-NJMS) was selected, and leadership of the Task Force’s standing Evaluation Committee<sup>l</sup> remains housed in UMDNJ-NJMS’s Department of Preventive Medicine and Community Health.

#### Comprehensive Cancer Control... what is it and why evaluate?

The purpose of comprehensive cancer control is to develop “an integrated and coordinated approach to reduce the incidence, morbidity, and mortality of cancer through prevention, early detection, treatment, rehabilitation, and palliation.”<sup>3</sup>

“The availability of adequate evaluative information is crucial, not only for effective implementation of the [Comprehensive Cancer Control] Plan, but also for development of future plans.”<sup>1</sup>

“Comprehensive cancer control is a highly complex and dynamic initiative.... Attempting to measure health outcomes prematurely (such as decreases in morbidity and mortality or reductions in disparities) can lead to disappointing results. While the health outcomes remain always in view as the ultimate outcome desired, they will not be achieved until some years hence. Task Force efforts are currently concentrated on building an implementation infrastructure able to put into action the statewide cancer plan that New Jersey cancer experts believe will lead to the desired health outcomes.”<sup>1</sup>

New Jersey was selected to join the National Comprehensive Cancer Control Program<sup>4</sup> of the Centers for Disease Control and Prevention (CDC) through a Cooperative Agreement award to the Office of Cancer Control and Prevention (OCCP) in 2004. Some assessments included in this report are in response to specific recommendations and requirements of the CDC. As

<sup>h</sup> Footnotes that further explain the text of this report are designated with *letters* and appear *on the same page* as the relevant text. References to the literature are designated with *numbers* and appear *at the end of the whole report*.

<sup>i</sup> Incorporated into New Jersey Statutes as Title 26, Chapter 2, sections 26:2-182 through 26:2-184.

<sup>j</sup> See NJ Statutes 26:2-183, 2.b.(1)

<sup>k</sup> In January 2003, the Commissioner of Health and Senior Services issued Executive Order 197 establishing a Task Force on Cancer Clusters in New Jersey with a charge including the evaluation of cancer cluster investigation policies, procedures, guidelines and best practices. That task force issued a comprehensive report dated April 2004, so these issues are not further addressed in the present report, since there is no reason for duplication of effort.

<sup>l</sup> Chaired by Professor Stanley H. Weiss, MD.

described in the Plan's Evaluation chapter, based on recommendations of the CDC and the Battelle Centers for Public Health Research and Evaluation (CPHRE), it is recognized that

Comprehensive cancer control is a highly complex and dynamic initiative .... Attempting to measure health outcomes prematurely (such as decreases in morbidity and mortality or reductions in disparities) can lead to disappointing results. While the health outcomes remain always in view as the ultimate outcome desired, they will not be achieved until some years hence. Task Force efforts are currently concentrated on building an implementation infrastructure able to put into action the statewide cancer plan that New Jersey cancer experts believe will lead to the desired health outcomes. It is documenting success in this aspect of the endeavor that should be the initial evaluation focus, while systems are established to eventually measure long-term health outcomes.

Thus, the present report focuses primarily on evaluation of the process of implementation of the Plan. Given that the effects of comprehensive cancer control interventions take years to become manifest and that the Plan is still in its early years, evidence of effects on outcomes remains intrinsically scarce and can be only a secondary component of evaluation at this stage. The first (2004) biennial status report details systems that were established to provide long-term evaluation structures. These, in conjunction with data from other ongoing collection efforts, will be useful in future, longer-term evaluations.

## ***B. Current Status of Cancer in New Jersey***

The rate of occurrence of new cases of invasive cancer (incidence) in New Jersey in 2002 was 523.4 per 100,000, the highest rate in the United States,<sup>5</sup> and the number of New Jersey cases was 47,584. The rate of death from cancer (mortality) in New Jersey in 2003 was 195.1 per 100,000, near the national average, with a total of 17,957 deaths. In the U.S. as well as in New Jersey, both incidence and mortality rates have declined in recent years. More "Detailed Information on Incidence and Mortality" appears at the end of Section 1.

In this report, we note the continuation of the previously observed pattern of relatively high cancer incidence in New Jersey. We examine this issue in greater detail below, and also consider it in the context of New Jersey's neighboring states. Critical issues related to racial, ethnic and socioeconomic disparities are reviewed in the Plan and in the 2004 Status Report. While reiterating their importance in the present report, we also highlight age-related issues that deserve increased attention.

Disparities continue to cause concern. Incidence and mortality rates are elevated for some minority groups, requiring special attention.<sup>6</sup> Thus, because substantial minority populations reside in New Jersey, the elevated incidence rates in minorities contribute to the state's substantially overall high rates. Many of these rates are, however, intrinsically high across population subgroups.

Historically, cancer prevention has generally concentrated on reduction in modifiable risk factors, such as tobacco smoke exposure, or detection and removal of precancerous lesions, such as *in situ* or dysplastic lesions (e.g. of the uterine cervix) or polyps (e.g. of the colon and rectum). In these instances, reduction of incidence is expected to translate into reduction in mortality rates.



Mitigation of cancer mortality may also occur when screening, leading to detection earlier in the course of disease, confers a net survival advantage.<sup>m</sup> It is very likely that increased screening efforts lead to the detection of more cancers, resulting in a higher observed incidence rate. However, cancer screening rates as assessed in national surveys are similar in New Jersey to those in many other regions in the United States, and in New Jersey there are no recent dramatic shifts towards an earlier stage at diagnosis. Thus, screening does not appear to be a viable explanation of either the significant discrepancy in New Jersey's relative ranking between incidence and mortality or of New Jersey's historically comparatively high cancer incidence rate.

Early detection and treatment of cancer is generally believed to be more cost-effective than treatment and palliative care for cancer detected in later stages.<sup>n</sup> Thus, provision of adequate funds for screening the uninsured and underinsured benefits the public in the long-term, as detailed in the Plan.

Given the relatively high cancer incidence, the proportionately lower mortality rate suggests that New Jerseyans receive excellent treatment with improved prognosis (as compared to treatment elsewhere in the United States) and/or improved detection (leading to diagnosis of earlier stage disease that is more amenable to treatment). Alternatively, it is possible that New Jerseyans have a disproportionately high rate of cancers that are relatively treatable compared to the rest of the U.S.

The increasing incidence trends for some cancers, such as lobular carcinoma of the breast, hepatocellular carcinoma, and thyroid cancer, may mitigate future improvement in the overall cancer incidence rate. Thus, continued attention to issues related to specific cancers, including appropriate sub-groups thereof, remains important.

Despite the relative attenuation of mortality, the continuing high incidence compared to other states indicates a need for more vigorous prevention efforts. Although the impact on incidence is not expected to be observable for many years, the implementation in 2006 of the New Jersey Smoke-Free Air Act (P.L. 2005, c. 383<sup>o</sup>), which bans indoor tobacco use, is likely to be an important step in prevention of tobacco-associated cancers.

An increased focus on prevention is warranted at this time for several reasons. First, new epidemiologic data suggest additional modifiable risk factors, such as use of post-menopausal hormonal therapy. Second, clinical trial data provide opportunities for pharmacologic intervention to prevent cancer. These also highlight the importance of prevention trials, not just treatment trials. Third, diagnostic advances are providing new opportunities to diagnose precancerous and *in situ* lesions, holding the promise for prevention of invasive cancer, not merely detection at earlier stages. Fourth, more sophisticated interpretations of existing diagnostic tests, such as the measurement of "velocity" in sequential PSA tests to assess both the presence and the aggressiveness of prostate cancer<sup>7,8</sup> and of tumor marker and genetic

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<sup>m</sup> Earlier diagnosis does not necessarily convey a survival advantage, due to phenomena such as "stage shift bias" Unless the earlier diagnosis leads to detection during a critical period, involving either an improved (net) natural history or permitting more effective therapy, apparent benefits of earlier diagnosis may be merely illusory. Other important sources of bias were discussed in detail in the 2004 Report. For an excellent technical discussion, see Sackett DL, Haynes RB, Tugwell P, *Clinical Epidemiology: A Basic Science for Clinical Medicine*, 2<sup>nd</sup> Ed. (Boston: Little, Brown), 1991. Alternatively, a lay explanation may be found in Welch HG, *Should I Be Tested for Cancer? Maybe Not and Here's Why* (Berkeley: University of California Press), 2004; it should be noted that other aspects of this book are controversial.

<sup>n</sup> Life prolongation, continued workforce productivity, and quality of life factors may be included in more complete cost-benefit models.

<sup>o</sup> Incorporated into New Jersey Statutes as Title 26, Chapter 3D, sections 26:3D-55 to 26:3D-64

data, are also expected to improve both detection and decisions about appropriate treatment. New Jersey needs to take advantage of these advances, and should also participate in creating new advances.

The Task Force workgroups are actively assessing these issues in developing the next five-year comprehensive cancer control plan. The initial cancer plan had an emphasis upon screening and alterable behaviors such as smoking.

- ❖ We recommend that the next plan include added emphasis on prevention, reflecting new and developing opportunities.

Additional epidemiologic research focused on etiology may provide new opportunities for intervention. Data from relevant studies conducted elsewhere may provide important guidance for New Jersey, so that these developments should be continually monitored. Furthermore, research that may be particularly relevant to the needs of New Jersey should be more vigorously encouraged, for example, the work by Cancer Epidemiology Services.

Participation in clinical trials is poor in the United States overall. The New Jersey Consensus Agreement of 1999, in which the state's nine largest health insurers voluntarily cover the routine health care costs of their members enrolled in Phase I–III approved cancer clinical trials, was an important step.<sup>9</sup> The organization of data and promotion of cancer trials by the Cancer Institute of New Jersey, supported by the New Jersey Commission on Cancer Research, may help. Furthermore, institutions such as UMDNJ have set community education about clinical trials and the protection of human subjects as priorities.

**Table 1.1 – Median Age at Diagnosis, New Jersey 1999–2003, by Primary Cancer Site, Race and Gender<sup>10</sup>**

Site	All Races		White		Black	
	Male	Female	Male	Female	Male	Female
All Sites	69	67	69	68	65	63
Oral Cavity and Pharynx	61	67	62	69	57	57
Colon and Rectum	71	75	72	75	66	68
Lung and Bronchus	70	71	71	71	66	66
Melanoma of the Skin	64	59	64	59	59	70
Breast	67	61	69	62	62	58
Cervix Uteri	-	49	-	49	-	51
Prostate	69	-	69	-	66	-

A dash (“-”) indicates that the cancer site is not applicable to that gender.

However, there are critical disparities in participation in clinical trials. This affects both racial and ethnic minorities and, perhaps even more strongly, the elderly. The importance of issues affecting the elderly has been recognized by the New Jersey Commission on Cancer Research (NJCCR),<sup>p</sup> which held a conference on cancer and the aging in 2002, at which the underrepresentation of the elderly in clinical trials was acknowledged as critical.<sup>11</sup> These issues are now under the purview of the New Jersey Cancer & Aging Task Force, which was established within the NJCCR as a major initiative following the 2002 conference; current

<sup>p</sup> The NJCCR is a separate body from the Task Force within the NJDHSS. Further information is available on its web site, [www.nj.gov/health/ccr/](http://www.nj.gov/health/ccr/).

membership of the Cancer & Aging Task Force is listed in the most recent NJCCR annual report.<sup>12</sup> That the elderly are a particularly significant population in issues of cancer is indicated by the fact that for the period 1999-2003, the median age of diagnosis among New Jerseyans for all cancers was 68, and a similar picture prevails for most individual cancers (see Table 1.1). Yet there remains a crucial absence of clinical data on the elderly. For example, a recent editorial<sup>13</sup> opens thus:

Women 65 years or older (hereafter referred to as older women) constitute half of the new breast cancer patients each year, and the absolute number of patients will double by 2030 with the “graying of America.” Despite their large numbers, over the past several decades, when older women develop breast cancer, they fail to receive care consistent with prevailing guidelines.<sup>14,15</sup> Reasons for the divergence of care from professional recommendations may be partially explained by the lack of clinical trial data for this age group, uncertainty about the balance of treatment toxicity and benefits, differential access, the potential for therapy to amplify pre-existing medical conditions, and the effects of competing non-cancer causes of mortality. There is also minimal data on older women’s preferences for treatment and its outcomes.

This is but one example of the deficiencies of clinical data on how to optimally treat the elderly with cancer. Since most clinical trials place eligibility restrictions based on age, the paucity of data is not surprising.<sup>9</sup> Similar deficiencies have been described for women, for racial and ethnic minorities, and for persons with disabilities.

- ❖ We recommend enhanced collaboration with the New Jersey Commission on Cancer Research to increase inclusion of women, underrepresented minorities, the elderly and the disabled in clinical trials, especially an increase (a) in trials focused on these populations in order to provide data for the future care of all New Jersey residents with cancer, and (b) in trials focused on the prevention of cancer.
- ❖ In summary, we recommend that issues of disparities should remain a priority in the formulation of the next five-year comprehensive cancer control plan, which will cover the period 2008-2012.

Quality of life and palliation issues also continue to need attention. The Task Force’s Palliation Workgroup remains actively dedicated to addressing these, and its authorship of a section in the next (2008-2012) five-year comprehensive cancer control plan will be important in helping to guide overall cancer efforts.

New funds are required for implementation of these opportunities. However, ongoing screening efforts also need to be expanded and, as documented in Section 2 (below), individuals working to implement the present plan have expressed a clear need for an increase in funding levels. Thus existing funding for the OCCP, for the New Jersey Cancer Education and Early Detection (NJCEED) program, and for related efforts cannot be reallocated to these new endeavors. In summary, there is an acute need to significantly increase resources for cancer control, in order

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<sup>9</sup> Altered metabolism, liver and kidney function, and the relatively high prevalence of co-morbidities in the elderly can contribute to substantial differences in outcomes, including the rate of adverse sequelae. Thus, modifications in the trial design and/or dosage may be needed for the elderly. Many clinical trials have as a primary goal the establishment of efficacy and demonstrating a relatively safe profile, to aid in garnering initial drug approval from the Food and Drug Administration. Thus, complexities that might impede approval are undesirable – further contributing to why the elderly tend to be systematically excluded from trials. However, these very same issues are the reasons why specific data are needed by clinicians in order to properly treat the elderly.

to take advantage of the research advances and translate these to a reduction in incidence, and to develop and explore new avenues of epidemiologic research.

- ❖ We recommend that the New Jersey Governor and Legislature significantly expand cancer funding for existing and new programs at both the New Jersey Department of Health and Senior Services (NJDHSS) and at relevant external entities, with an expanded focus on prevention activities and public health interventions.

### ***C. Evaluation Plan and Logic Model***

Program evaluation is an ongoing process with a dual goal of showing that a program works and improving the program.<sup>16</sup> Understanding how the program functions, examining the internal and external factors that influence the program, and assessing the impact of the program on participants, organizations, and the community provide stakeholders with necessary information to improve the program. The evaluation plan approved in June 2006 for the first five-year implementation period of the New Jersey Comprehensive Cancer Control Plan uses a three-tiered evaluation design outlined below, and was developed using the W.K. Kellogg Foundation Logic Model Development Guide.<sup>17</sup> Integration of these three different aspects of evaluation is critical to understanding how and why a program is working, monitoring the program, and developing recommendations for improvement as needed.

**Context evaluation** describes how the program functions within its environment, and can help identify strengths and weaknesses of the program and the effect of unanticipated and/or external influences on the program.

**Implementation evaluation** seeks to assess how well the program tasks are being performed relative to their specifications in the Plan.

**Outcome evaluation** addresses progress toward the desired change in individuals, organizations, communities, and/or systems as a result of the program. The effectiveness of the program's activities is assessed.

Reducing the cancer burden is a long-term process. Changes in outcomes generally take years or decades to observe. This evaluation structure lends itself to early assessments that are more heavily focused on process, rather than outcomes. Thus, this approach is particularly appropriate for New Jersey, which is in the first years of comprehensive cancer control planning.

### ***D. Detailed Information on Incidence and Mortality***

**Age-adjustment:** All the incidence and mortality data cited in this report are annual rates, age-adjusted to the 2000 U.S. standard population. Age adjustment is a statistical correction for differences in age of populations. Most forms of cancer become much more common as people age. Thus, it would be misleading to compare cancer incidence rates among a young population (which would generally be low) with rates among an elderly population (which would generally be high). Age adjustment is a way of compensating for the differences in age makeup of different populations to fairly compare incidence rates.<sup>18</sup>

**Incidence Data:** New Jersey's ranking highest in incidence in 2002 is not a transient aberration. It has tended to consistently rank amongst the highest states in recent decades.

For example, New Jersey ranked second highest among the states in incidence in 2001, 535.4 per 100,000.

In 2002, the incidence rate among men was 631.7 per 100,000 (highest in the U.S.) and among women 446.2 per 100,000 (3<sup>rd</sup> highest in the U.S.).<sup>r</sup>

For the data years 1995 through 2003, the New Jersey State Cancer Registry, a part of Cancer Epidemiology Services, New Jersey Department of Health and Senior Services, has received the highest (Gold) recognition certificate by the registry certification program of the North American Association of Central Cancer Registries, which annually reviews the member registries for their ability to produce complete, accurate, and timely incidence data. There were 19 registries awarded the Gold standard for the data year 1995, and 47 registries for the data year 2003.<sup>20</sup> It is possible that cancer incidence data collection in New Jersey by the NJSCR is more complete than in many other states, which could contribute to an artificially high incidence ranking.

**Disparities in Incidence:** Numerically, there is a great disparity between blacks and whites, both in New Jersey and nationally. (See Table 1.2, below.) State-level five-year age-adjusted incidence rates for white men, white women, black men, and black women for 1998–2002 demonstrate some important differences. For this five-year period based on reporting from 37 states, New Jersey is second only to Rhode Island in white male rates and New Jersey is first in white female rates.<sup>21</sup> For black males, New Jersey ranks 7<sup>th</sup> out of 37 states, and for black females 11<sup>th</sup> out of 35 states. Note that among males, both state and national incidence rates are higher for blacks than for whites; however, when the races are considered separately, it is New Jersey's white males who suffer from notably higher rates than their counterparts nationally.<sup>s</sup>

**Mortality Data:** For the four-year interval 2000–2003, the age-adjusted cancer mortality rate for New Jersey was 199.8 (standard error 0.75), with a rank of 23<sup>rd</sup> in the U.S., compared to 194.5 (standard error 0.13) for the U.S.;<sup>t</sup> New Jersey's rate remains statistically significantly higher than the U.S.'s rate.<sup>22</sup> However, there has been relative improvement in cancer mortality ranking as compared to two years ago, when it was 203.0 per 100,000 in New Jersey, the 18<sup>th</sup> highest in the U.S.

The modest continuing reductions in mortality rates may underestimate the health impact of new interventions, since survival and quality of life may improve without necessarily having a significant effect on the ultimate mortality risk. For example, whereas for breast cancer five-year survival was once a common measure, now ten-year or even longer survival endpoints are frequently used. The methodologies to estimate survival remain under development and are

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<sup>r</sup> Rankings exclude 6 states for which no incidence data were provided because the data did not meet USCS data quality standards for one or more years during the rate period of data collection. While 93% of the U.S. population resided in geographic areas with population-based cancer registries meeting the registry eligibility criteria for 2002, 7% of the U.S. population was not yet represented in the [United States Cancer Statistics](http://www.cdc.gov/cancer/npcr/uscs/) ([www.cdc.gov/cancer/npcr/uscs/](http://www.cdc.gov/cancer/npcr/uscs/)). American Cancer Society's *Facts & Figures* ([www.cancer.org/docroot/stt/stt\\_0.asp](http://www.cancer.org/docroot/stt/stt_0.asp)) provides estimates of numbers of new cancer cases and deaths.

<sup>s</sup> In contrast to men, overall cancer incidence in black women is lower than among white women. However, mortality is greater among black women than among white women.

<sup>t</sup> Source of mortality data in State Cancer Profiles: death data provided by the [National Vital Statistics System](http://www.cdc.gov/nchs/nvss/) public use data file. Death rates calculated by the National Cancer Institute using [SEER\\*Stat](http://www.cdc.gov/nchs/seer/). Death rates are age-adjusted to the [2000 U.S. standard population](http://www.cdc.gov/nchs/seer/) by 5-year age groups. (Although the goals in *Healthy People 2010* goals are based on rates adjusted using different methods, the differences should be minimal.) Population counts for denominators are based on Census populations as [modified](http://www.cdc.gov/nchs/seer/) by NCI. All states are included in the mortality data.

highly sensitive to the assumptions, as well as the data estimates, used in the underlying mathematical models. Thus, it is critical for analyses of survival to explicitly and thoroughly detail these issues and to critically assess the sensitivity of the estimates provided to departures from these assumptions. Evolving data suggest improvements in survival for many cancers over recent decades. Independent of survival, quality of life is another important parameter; most studies are subject to severe selection bias related to participation rates well below typical benchmarks of 80%. Since the full spectrum of patients is not generally represented, the results are rarely generalizable. Incorporation of quality-of-life measures in clinical trials is of value, so they should be included as priority components of such trials, which will help to reduce selection biases. There have been clear improvements in palliation of multiple components of cancer-related symptoms. The improvements in mortality, survival and quality of life all combine to paint a continually improving picture for those who have been diagnosed with cancer.

**Comparative Incidence and Mortality for Total and Selected Cancers:** In the chart below, listing a few selected cancers, cancers for which the NJ age-adjusted rate is more than 10% higher than the corresponding U.S. rate are shaded in light green. Cancers for which the age-adjusted rate among blacks in NJ is more than 10% higher than the corresponding rate among whites in NJ are shaded in darker turquoise.

Whereas incidence rates for many specific cancers are higher in blacks, the rate is significantly lower for breast cancer in females. However, this does not translate to improved mortality; the mortality rate from breast cancer is much higher in black women. The magnitude of the true total disparity is probably even greater. Given the chronicity of many breast cancers, some women die with, not from, their cancer. These competing causes of death likely have a differential impact on blacks, reflecting and related to other known health disparities, and thus may partially obscure the true difference. Detailed assessments of the epidemiology of cancer trends document many other important disparities. These will require data-driven focusing of resources for progress to be made in reducing them.<sup>u</sup>

The ratios of black to white incidence and black to white mortality in New Jersey generally show a similar pattern to the corresponding ratios for the U.S. However, in several instances, these disparities in New Jersey are less pronounced than the corresponding disparities between blacks and whites in the U.S. overall. For instance, the ratios of black to white colorectal cancer mortality for both men and women in New Jersey are both 1.18, while the ratios of black to white colorectal cancer mortality for men and women in the whole U.S. are 1.40 and 1.43 respectively.

Since it is well known that despite efforts at reduction, disparities remain in cancer care delivery and treatment,<sup>u</sup> as well as in incidence, these do not need to be detailed at length herein. These disparities are of great importance with respect to all health care, not just cancer. Therefore, continuation of the efforts of the NJDHSS to address these issues therefore remains crucial.

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<sup>u</sup> A special issue of the *Journal of Clinical Oncology* was recently published addressing some important and topical concerns.

**Table 1.2**  
**Incidence and Mortality, All Races, 1998-2002**

	Incidence			Mortality		
	NJ Rate	US Rate	Ratio	NJ Rate	US Rate	Ratio
<b>Males</b>						
All Sites	629.0	561.4	1.12	249.9	247.5	1.01
Colorectal	75.5	65.9	1.15	27.4	24.8	1.10
Lung	87.6	90.1	0.97	71.0	76.3	0.93
Prostate	201.2	163.8	1.23	29.9	30.3	0.99
<b>Females</b>						
All Sites	450.2	418.2	1.08	176.9	165.5	1.07
Colorectal	53.7	47.9	1.12	19.4	17.4	1.11
Lung	55.4	54.6	1.01	40.8	40.9	1.00
Breast (invasive)	136.1	131.0	1.04	29.5	26.4	1.12

All rates are average annual rates per 100,000, age-adjusted to the 2000 U.S. population standard.

**Incidence, by Race, 1998-2002**

	White			Black			NJ Ratio Black-to-White	US Ratio Black-to-White
	NJ	US	NJ-to-US Ratio	NJ	US	NJ-to-US Ratio		
<b>Males</b>								
All Sites	642.6	553.7	1.16	702.6	641.5	1.10	1.09	1.16
Colorectal	75.6	65.5	1.15	78.3	70.2	1.12	1.04	1.07
Lung	86.6	89.3	0.97	109.7	112.2	0.98	1.27	1.26
Prostate	192.0	155.0	1.24	283.2	242.6	1.17	1.48	1.57
<b>Females</b>								
All Sites	461.8	423.3	1.09	408.8	384.5	1.06	0.89	0.91
Colorectal	53.5	47.2	1.13	57.3	53.8	1.07	1.07	1.14
Lung	57.3	55.9	1.03	51.9	51.2	1.01	0.91	0.92
Breast (invasive)	140.7	133.5	1.05	115.2	111.8	1.03	0.82	0.84

All rates are average annual rates per 100,000, age-adjusted to the 2000 U.S. population standard.

**Mortality, by Race, 1998-2002**

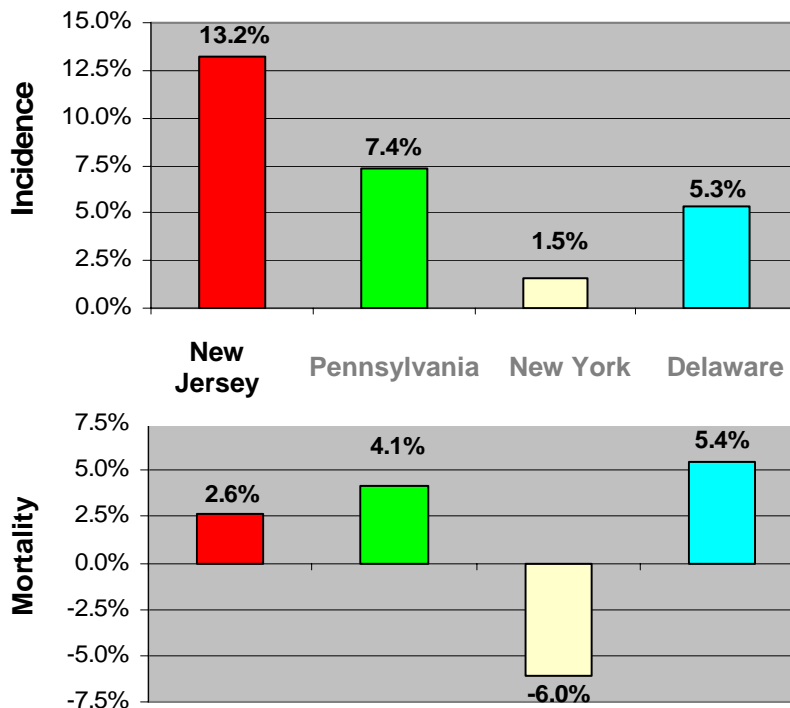
	White			Black			NJ Ratio Black-to-White	US Ratio Black-to-White
	NJ	US	NJ-to-US Ratio	NJ	US	NJ-to-US Ratio		
<b>Males</b>								
All Sites	245.9	242.5	1.01	331.3	339.4	0.98	1.35	1.40
Colorectal	27.3	24.3	1.12	32.2	34.0	0.95	1.18	1.40
Lung	70.2	75.2	0.93	93.6	101.3	0.92	1.33	1.35
Prostate	27.3	27.7	0.99	66.3	68.1	0.97	2.43	2.46
<b>Females</b>								
All Sites	177.8	164.5	1.08	195.9	194.3	1.01	1.10	1.18
Colorectal	19.3	16.8	1.15	22.8	24.1	0.95	1.18	1.43
Lung	41.9	41.8	1.00	40.9	39.9	1.03	0.98	0.95
Breast (invasive)	29.5	25.9	1.14	34.3	34.7	0.99	1.16	1.34

All rates are average annual rates per 100,000, age-adjusted to the 2000 U.S. population standard.

Light (green) shading indicates that the rate in NJ is more than 10% than the U.S. rate. Darker (turquoise) shading indicates that the rate among blacks in NJ is more than 10% higher than the corresponding rate among whites in NJ

**Comparing States:** The total cancer incidence and mortality rates in New Jersey, as well as the three states on our borders, are compared to the U.S. rates in Figure 1.1. The percentage difference of each state from the U.S. is displayed. New Jersey leads the group in cancer incidence. In contrast, New Jersey fares quite well in comparison to two of its neighboring states, Pennsylvania and Delaware, with respect to mortality, especially considering that New Jersey has a much higher incidence rate than these two states. The fact that New York has a lower mortality rate than New Jersey is not unexpected since New York has a much lower incidence than its neighboring states. This parallels the comparison of New Jersey to the country as a whole, in which, as noted earlier, New Jersey has had a history of relatively high incidence rates but in recent years has had mortality rates near to national averages.

**Figure 1.1 – Percent Excesses in Cancer Incidence and Mortality Rates in New Jersey and Neighboring States over National Rates**



**Discussion:** New Jersey has similar lung cancer incidence compared to the U.S. The legislature's recent passage of the Smoke-Free Air Act should improve New Jersey's standing relative to the rest of the country, since similar legislation is not yet the national norm. The apparent increased risk of lung adenocarcinoma nationally — as discussed in detail on p. 23 of the 2004 Status Report — warrants specific continued attention, as this may mitigate future improvement.

The comparisons of New Jersey to U.S. incidence and mortality by race indicate that for several cancers, such as colorectal, breast, and prostate, differences in rates between New Jersey and the whole country are particularly pronounced in whites. While, in any consideration of cancer disparities, the overall disparities between blacks and whites remain paramount, it is also incumbent on New Jersey not to disregard cancer's effect on every sector of the population.



## Section 2 – Context Evaluation

The assessment of the environment in which New Jersey's program in comprehensive cancer control functions focuses on two key areas:

- An assessment of the stakeholders involved in the program;
- Evidence of collaboration that creates a healthy environment.

One goal of a context evaluation is to help identify strengths and weaknesses of the program and the effect of various internal and external influences on the program.

New Jersey's program is comprised of five key groups of partners: the Task Force, its workgroups, its standing committees, county cancer coalitions, and the Office of Cancer Control and Prevention (OCCP) in collaboration with the NJCES and NJCCR within the New Jersey Department of Health and Senior Services (NJDHSS). These groups are described fully in the 2004 Status Report. While each group plays a distinct role in the program, it is the interaction and partnerships between these groups that creates breadth and depth in the overall program. This web of interconnections and the synergies it creates is fundamental to the underlying conceptual framework of the Centers for Disease Control and Prevention for optimal comprehensive cancer control. This section therefore focuses on the membership and collaborations of the whole program.

### **A. Stakeholder Assessment**

An outcome of the 2005 Comprehensive Cancer Control Leadership Institute (CCCLI, an annual meeting of key state-level leaders hosted by the CDC and a number of other organizations<sup>v</sup>) was a recommendation that a more detailed stakeholder assessment of New Jersey's comprehensive cancer control program should be conducted. This led the OCCP to conduct a partnership self-assessment survey. Findings from that survey and from a separate assessment of the stakeholders represented in New Jersey's program are described below.

#### **PARTNERSHIP SELF-ASSESSMENT SURVEY**

In May 2006, OCCP conducted an anonymous web-based survey to assess the level of satisfaction among individuals currently involved in the comprehensive cancer control program in New Jersey. All active Task Force, workgroup, and standing committee members were asked to complete the survey. The survey focused on seven key areas of the overall program: membership, climate, communication, leadership, implementation, process, and collaboration. Within each of these topics, more specific issues were listed and members were asked to comment on their level of satisfaction for each issue. In addition, members were able to add unlimited comments on each topic.

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<sup>v</sup> The Comprehensive Cancer Control Leadership Institutes (CCCLI) are a collaborative effort convened by the American Cancer Society, the American College of Surgeons, the Association of State and Territorial Health Officers, C-Change, the Centers for Disease Control and Prevention, the Chronic Disease Directors, the Intercultural Cancer Council, the National Cancer Institute, and the North American Association of Central Cancer Registries. See [www.cdc.gov/cancer/ncccp/institutes.htm](http://www.cdc.gov/cancer/ncccp/institutes.htm).

A profile of those who responded, an overall summary of the results, and detailed results for each topic are provided below. Comments from respondents highlighting areas that were favorably assessed and recommendations for improvement are also described under the appropriate topic.

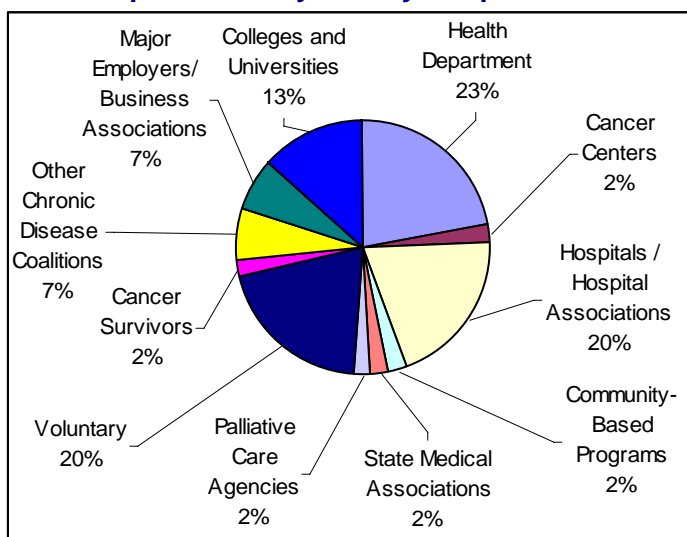
### **Profile of Survey Respondents**

The survey was sent by the OCCP to 237 individuals and generated 103 responses (a 43% response rate),<sup>w</sup> of which 92 were complete (89% of the returned responses, or 39% of the surveys sent out).<sup>x</sup> The 103 responses were analyzed for the types of organizations the respondents represented, the workgroups, standing committees, and county coalitions they were members of, and the length and level of involvement in the comprehensive cancer control program in New Jersey. The Evaluation Team also randomly selected several data items and verified their values using Epi Info™ 3.3.2. In all cases there was perfect agreement. These results are summarized below.

**Types of Organizations Represented by Survey Respondents:** Because this question was marked “optional,” 45 (fewer than half) of the respondents identified the organization they represent. The responses were categorized in Figure 2.1, based on the CDC’s list of 16 types of organizations that would be useful partners in a comprehensive cancer control program. Among these, health departments, hospitals or hospital associations, and voluntary organizations were the groups with the greatest representation.

**Workgroups and Committees Represented by Survey Respondents:** The Task Force and the 13 statewide workgroups and standing committees were broadly represented, with 72% of respondents (74 of 103) affiliated with a single workgroup or committee, 14% with two workgroups or committees, and 9% with three or more. Only six respondents did not indicate which workgroup or committee they belong to.

**Figure 2.1: Types of Organizations Represented by Survey Respondents**

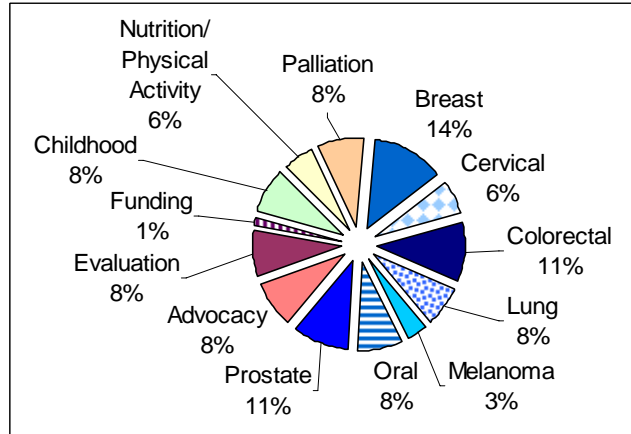


<sup>w</sup> Response rates to surveys in excess of 80% are optimal for high validity and accuracy. With respect to individual items, similar response rates are desirable among returned surveys. As there are reasons why favorable and unfavorable responses might be selectively under- or over-represented by non-responses, the data should be examined as returned to avoid introducing additional bias. In any truly anonymous survey, it is not possible to re-contact non-respondents to increase the response rate.

<sup>x</sup> The OCCP compiled the data from the survey and conducted a preliminary analysis. The OCCP provided the Evaluation Team with both the raw data and tabulated summaries.

Figure 2.2 shows the distribution of representation of workgroups and committees. The Breast Cancer (19), Colorectal Cancer (15), and Prostate Cancer (15) Workgroups had the most representation among survey respondents.

**Figure 2.2: Workgroups and Committees Represented by Survey Respondents**

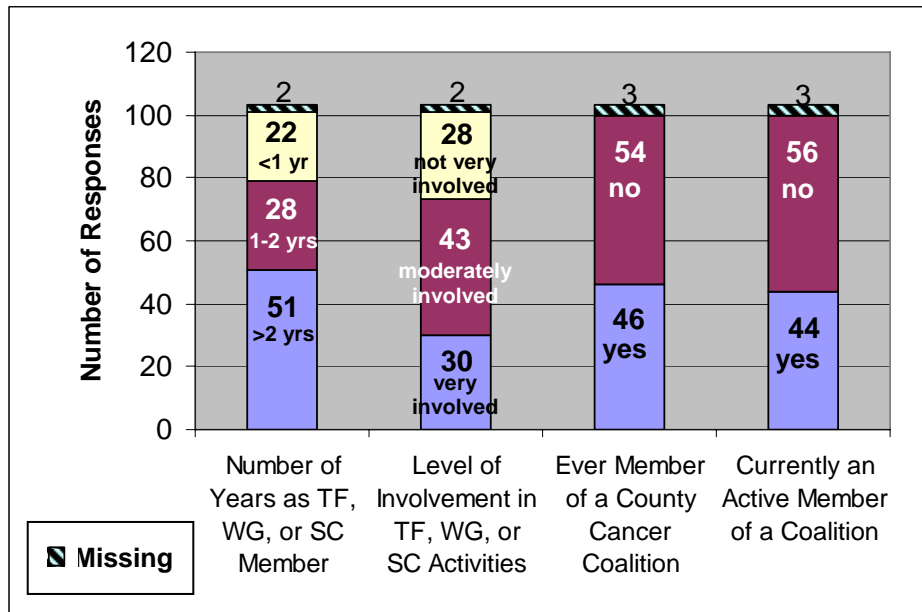


**Level of Involvement of Survey Respondents:**

Among the respondents, 50% (51 of 101) reported having been a member of the Task Force, a workgroup, or a standing committee for more than two years, 28% for one to two years, and 22% for less than one year. These results demonstrate a balance between both continuity and new membership. Half of the respondents have been involved for over two years, reflecting continuity in leadership among Task Force, workgroup, and standing committee members. At the same time, almost one-quarter of respondents have been involved for less than one year, representing those who have been successfully recruited in New Jersey's efforts more recently. Thus, these data indicate that the recommendation from the CDC's Comprehensive Cancer Control Leadership Institute to actively recruit new members has been implemented.

- ❖ We recommend that the OCCP augment the rosters with a record of the dates when new members join, as well as when members leave, to enable systematic monitoring over time.

**Figure 2.3: Level of Involvement of Survey Respondents**



Note: Figure 2.3 displays actual counts within each response category. See text for percentages.

When asked how involved they have been in Task Force (TF), workgroup (WG), and/or standing committee (SC) activities, 30% of respondents (30 of 101) reported being “very involved”, 43% “moderately involved”, and 28% “not very involved”. Local involvement was slightly less common, with 46% (46 of 100) reporting ever having been a member of a county cancer coalition, and 44% currently active members of a county cancer coalition. Fifteen of the 21 counties were represented by those responding to this survey.

### **Survey Results**

**Summary:** Respondents showed high levels of satisfaction with all seven key topics listed above. For the first six topics, respondents were asked to indicate their level of satisfaction for several issues within each topic. Level of satisfaction was assessed using a 5-point scale, from “very dissatisfied,” “somewhat dissatisfied,” “neither satisfied nor dissatisfied,” “somewhat satisfied,” to “very satisfied,” with an option to indicate “don’t know.”

The summary table below shows the number of issues within each topic and the range of satisfied responses, which include responses of “somewhat satisfied” and “very satisfied.” Percentages of results of this survey given in Table 2.1, as well as in all discussions below, exclude responses of “don’t know.” The proportion of “don’t know” responses ranged from 2% to 14%; details are shown in Figures 2.4–2.9 below.

**Table 2.1: Summary of Satisfied Responses**

<b>Topic</b>	<b>Number of specific issues within this topic</b>	<b>Satisfied Responses*</b>
Overall Membership	6	73% to 86%
Overall Climate	3	84% to 95%
Overall Communication	4	82% to 92%
Overall Leadership	3	77% to 84%
Overall Plan Implementation		
Non-financial	6	66% to 78%
Financial	1	35%
Overall process	6	65% to 88%

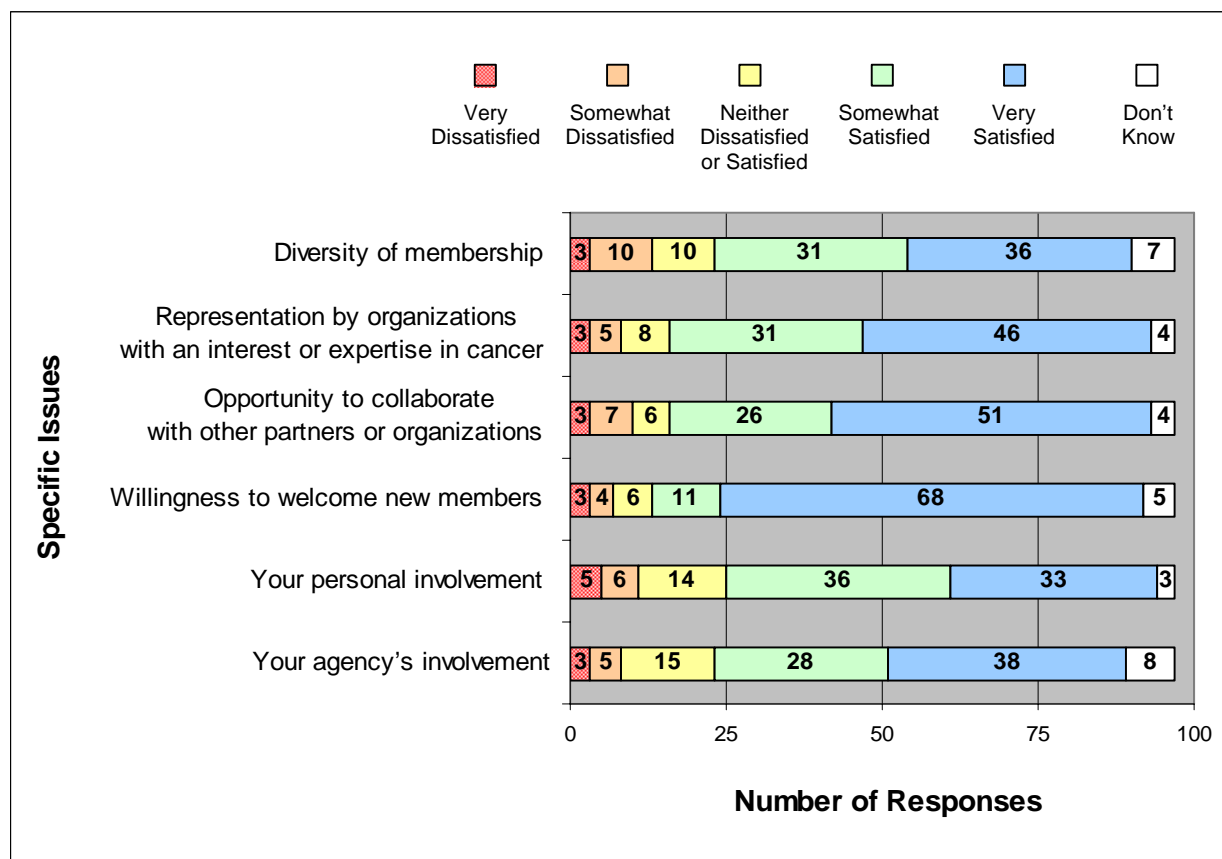
\* Responses of “somewhat satisfied” or “very satisfied” are considered satisfied responses for the purposes of this evaluation.

Excluding responses of “don’t know,” at least 65% of respondents indicated they were “somewhat satisfied” or “very satisfied” to all issues but one. The one exception was in response to satisfaction with the adequacy of financial resources generated to support implementation (see discussion below of specific results in the Implementation section). Thus, every area received overwhelming praise from the participants, with especially high marks for overall climate and overall communication. Of the “very dissatisfied” responses to these 29 questions, three of the 103 respondents accounted for 68% of them, and two more for an additional 11%, indicating that only a small minority of respondents felt strong overall dissatisfaction.

For simplicity of presentation, the text below summarizes data in terms of response percentages, whereas the figures display the actual number of responses (counts). The size of the horizontal bars reflects the relative proportion of responses.

**Membership:** More specifically, 74% were satisfied with diversity of membership, 83% with representation by organizations with an interest or expertise in cancer, 83% with the opportunity to collaborate with other partners or organizations, and 86% with the willingness to welcome new members. Responses to the last question was particularly favorable, 74% very satisfied with the willingness to welcome new members. Figure 2.4 shows the responses on each issue within membership.

**Figure 2.4: Overall Membership Issues\***



\* In this, as well as in Figures 2.5, 2.6, 2.7, 2.8, 2.9 and 2.10, the numbers in the bars are counts, not percentages. The lengths of the bars are proportional to the counts.

One recurring theme raised in the comments is a desire for broader participation. Respondents from different workgroups and county cancer coalitions suggested that more diversity in membership is needed. For example, specific comments include needing “diversity in members from State and Federal agencies and private organizations who support the area,” “participation of other organizations who are currently not part of the workgroup,” “more active involvement of other members, organizations, government, foundations and industries, specially the pharmaceutical and chemical,” “local political and insurance payer representation,” “representation from business, education and local government,” and that “Not enough of the ‘right’ agencies at the table (ACS, CINJ),”. In addition, one respondent stated, “involving more (MPH, pharm, nutrition, PE etc.) students may be useful in obtaining an on-going group of interested partners.”

Several respondents also expressed a need for greater involvement among those who medical expertise. For example:

- “More health care organizations, physicians and practitioners need to be actively involved at both the Coalition and workgroup levels.”
- “I have believed that a good, academically-inclined [specialist] should be on the Work Group.”
- “At times, it seems as if people with limited medical knowledge in the workgroups are making or planning change for which they do not have the medical expertise.”

Another recurring comment was a need for greater support from other government representatives, and for continued or increased advocacy to garner such support. Many respondents implicitly remarked on this by commenting on the need for greater funding. One respondent commented that increased visibility of New Jersey politicians’ involvement could benefit comprehensive cancer control efforts. Review of documents from county cancer coalitions indicate that many have developed or are developing relationships with local government officials. Because state laws limit the type of direct involvement that state health officials may have with legislators, contact at the state level has been largely initiated by the Task Force’s Advocacy *Ad Hoc* Committee. That committee should examine whether an increased role by legislators can be fostered.

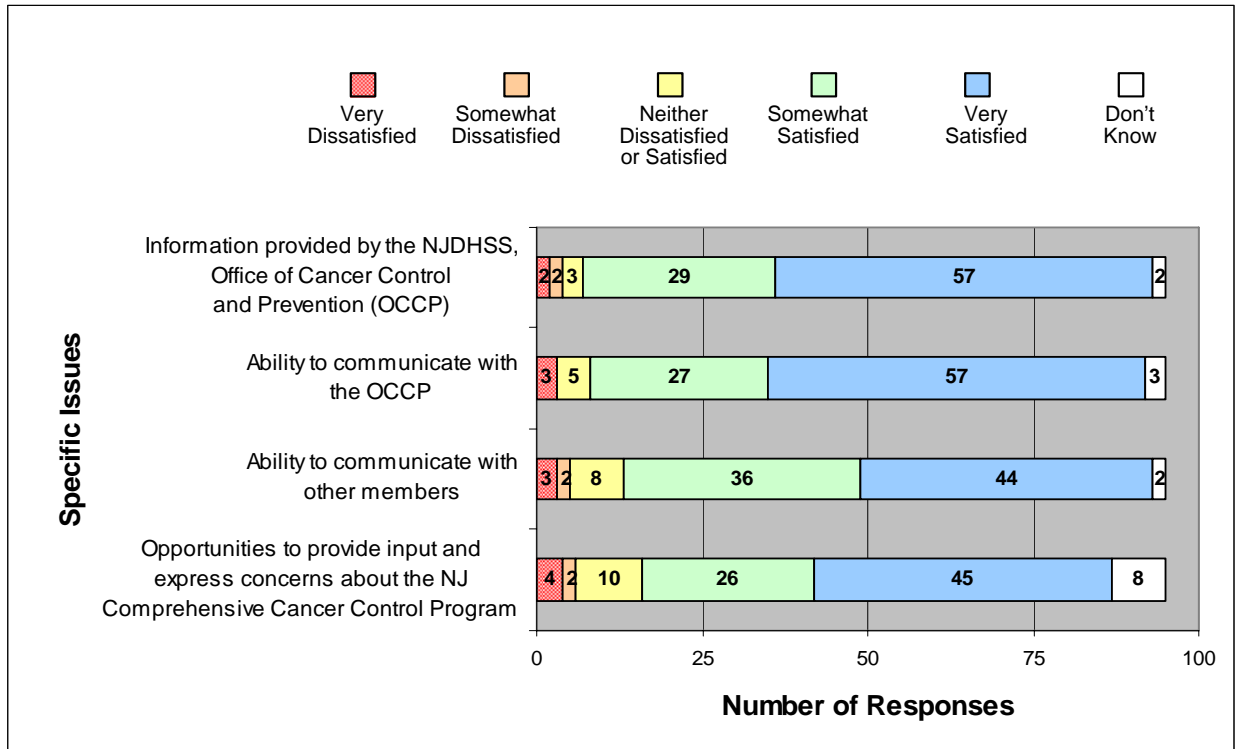
**Climate:** The overall climate of the cancer control program in New Jersey is also well regarded, with 95% satisfied with the leadership’s friendliness, pleasantry, and helpfulness, 87% satisfied with cooperation from others, and 84% satisfied with acceptance of others’ opinions (Figure 2.5).

**Figure 2.5: Overall Climate**



**Communication:** Similarly, overwhelming satisfaction with communication was reported, with 92% satisfied with information provided by the OCCP, 91% satisfied with their ability to communicate with the OCCP, 86% satisfied with their ability to communicate with other members, and 82% satisfied with opportunities to provide input and express concerns about the Plan (Figure 2.6).

**Figure 2.6: Overall Communication**

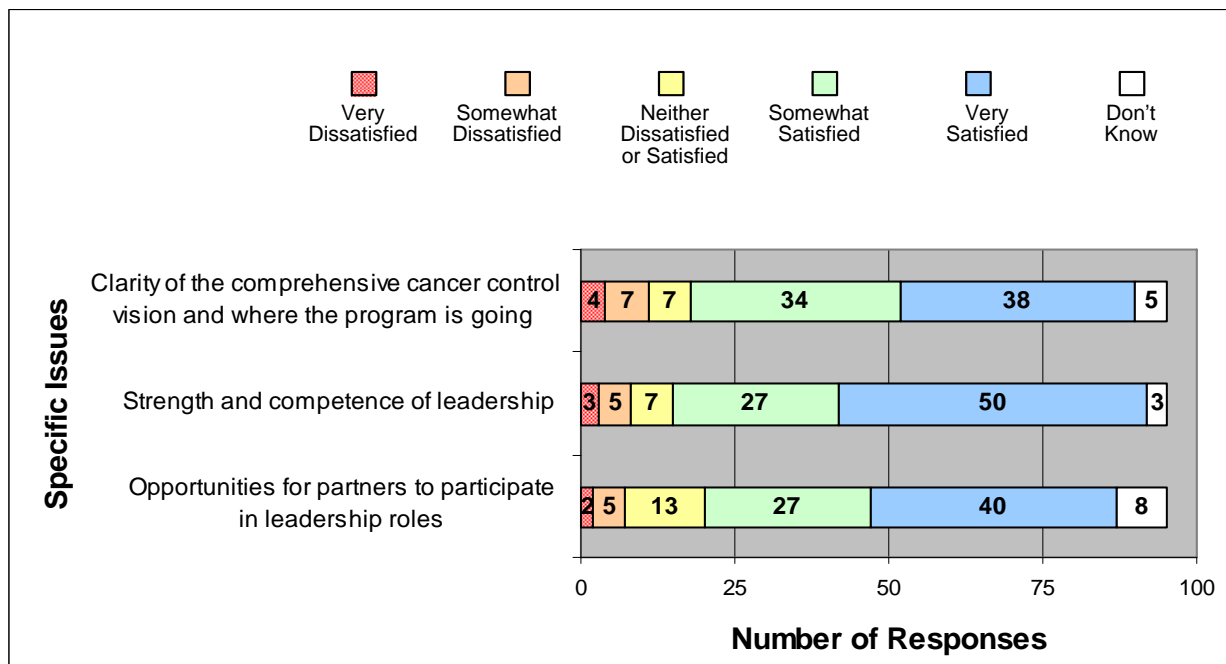


Several respondents suggested there was a need for increased communication about what progress has been made with respect to the overall Plan, so that members can hear about accomplishments of other workgroups and coalitions and appreciate the bigger picture of cancer control efforts. One suggestion for improvement in this area is to provide access to a shared website where prior accomplishments and future activities can be posted.<sup>y</sup>

<sup>y</sup> Examples from respondents: (1) a local issue: “A challenge to implementation is a direct line of communication indicating the exact chain of command. Most of the field people answer to those who hired them and do not understand the bigger picture.” (2) a statewide issue: a county coalition coordinator suggested “a website for Coalition members where we post activities that are coming up long range and other coalitions can look at them and see how they may also benefit by getting involved in that project.” It should be noted that the OCCP has asked each county cancer coalition to develop its own website; this comment suggests the need to evaluate whether additional types of websites may be useful to share information. Discussions within librarians in New Jersey should be continued, to provide input on this issue.

**Leadership:** Assessment of leadership was also highly favorable, with 80% satisfied with the clarity of the comprehensive cancer control vision and the direction of the program, 84% satisfied with the strength and competence of leadership, and 77% satisfied with opportunities for partners to participate in leadership roles (Figure 2.7).

**Figure 2.7: Overall Leadership**



Most striking among the comments, across all categories, is the praise for the existing statewide cancer control leadership. A Task Force member writes that “[the Task Force Chair]<sup>z</sup> has been setting an excellent example for meeting chairing, non-judgmental and welcoming management of discussions. And he does his homework.” There were repeated accolades for the Executive Director of OCCP,<sup>aa</sup> for being “very helpful and enthusiastic” and easy to communicate with, and for leadership of meetings that is “effective, concise and skilled.” The same Task Force member writes that “[the Executive Director of OCCP] and her staff are of the highest caliber – efficient, pleasant, capable, faultless.” A member of the Advocacy Committee, who participates on county cancer coalitions, states, “The original staff were superb and handled a new task very well. The team has now been complemented by adding excellent staffing choices.” Even those who complained about other aspects of the program (for instance, one person stated meetings were prone to focusing on one project or one person’s accomplishments, overshadowing others’ efforts) singled out OCCP’s or the OCCP’s Executive Director’s conduct of meetings for praise.

In the section in which respondents were asked to name something working extremely well that should not be changed, 42% (15 out of 36) mentioned the leadership, the Task Force, the OCCP, or the OCCP’s Executive Director by name. Among the remaining 21 responses, no other single topic was mentioned remotely as many times. Furthermore, leadership was never mentioned as a barrier or challenge to implementation.

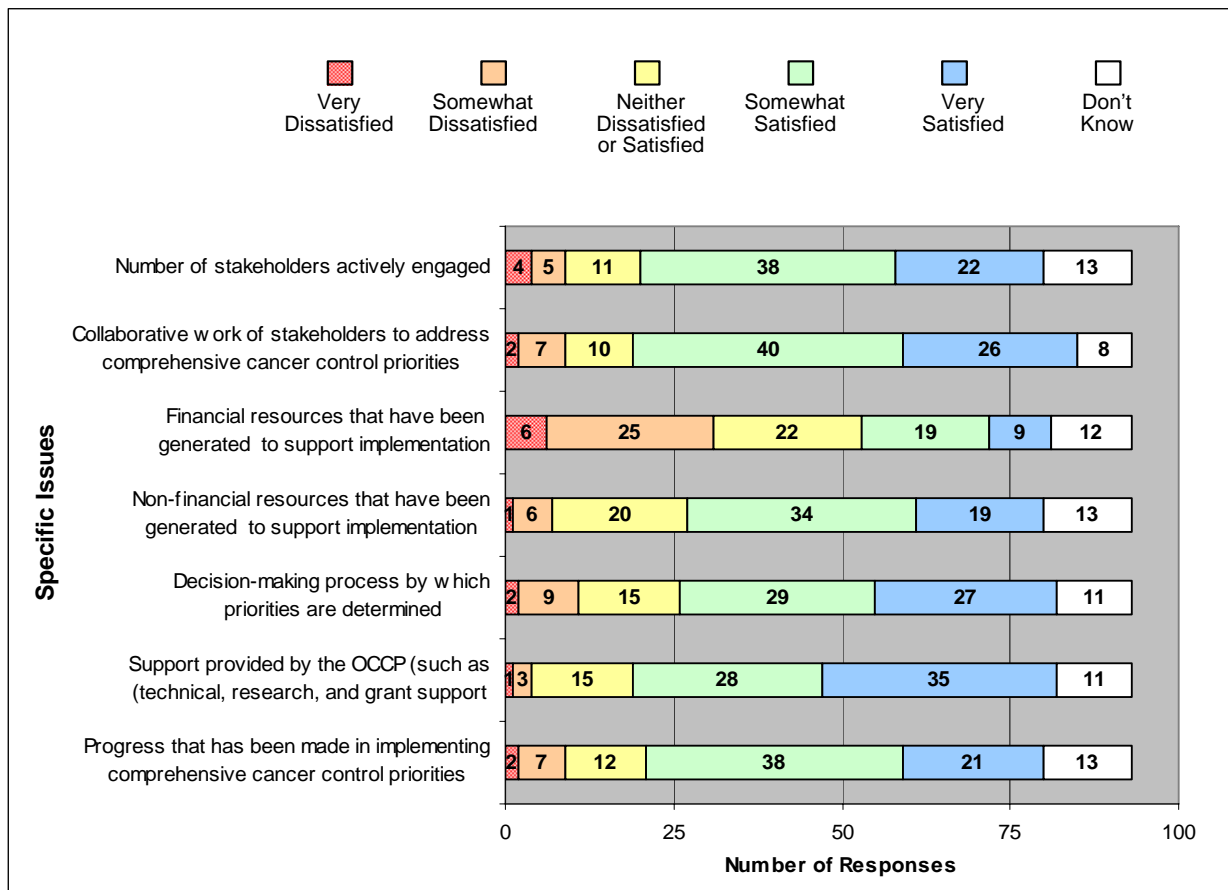
<sup>z</sup> The Chair of the Task Force is Arnold H. Baskies, MD.

<sup>aa</sup> The Executive Director of the Office of Cancer Control and Prevention is Margaret L. Knight, RN, MEd.



**Plan Implementation:** The one area for which survey respondents showed less than 65% satisfaction was financial resources generated to support implementation. Only 35% of respondents (28 of 81) were somewhat or very satisfied, while 38% (31 of 81 respondents) were somewhat or very dissatisfied. Responses to all other issues of implementation showed overall satisfaction, ranging from 66% satisfied with non-financial resources to support implementation to 78% satisfied with collaborative work of stakeholders to address comprehensive cancer control priorities. Within this topic, a higher proportion of respondents (9–14%) responded “don’t know” than in other topics. Figure 2.8 shows the number of responses in each category for each question on implementation.

**Figure 2.8: Overall Plan Implementation**



There were a number of comments related to Plan implementation. Several respondents expressed concern that some workgroups and coalitions seemed to lack vision, and that their activities were not specifically focused on the Plan itself or were distracted by interests of particular individuals and/or organizations. Other respondents suggested that the leadership of certain workgroups may need to be changed.

- ❖ We recommend that the OCCP review those comments related to specific workgroups and discuss these issues with the Chair of the Task Force, as deemed appropriate.

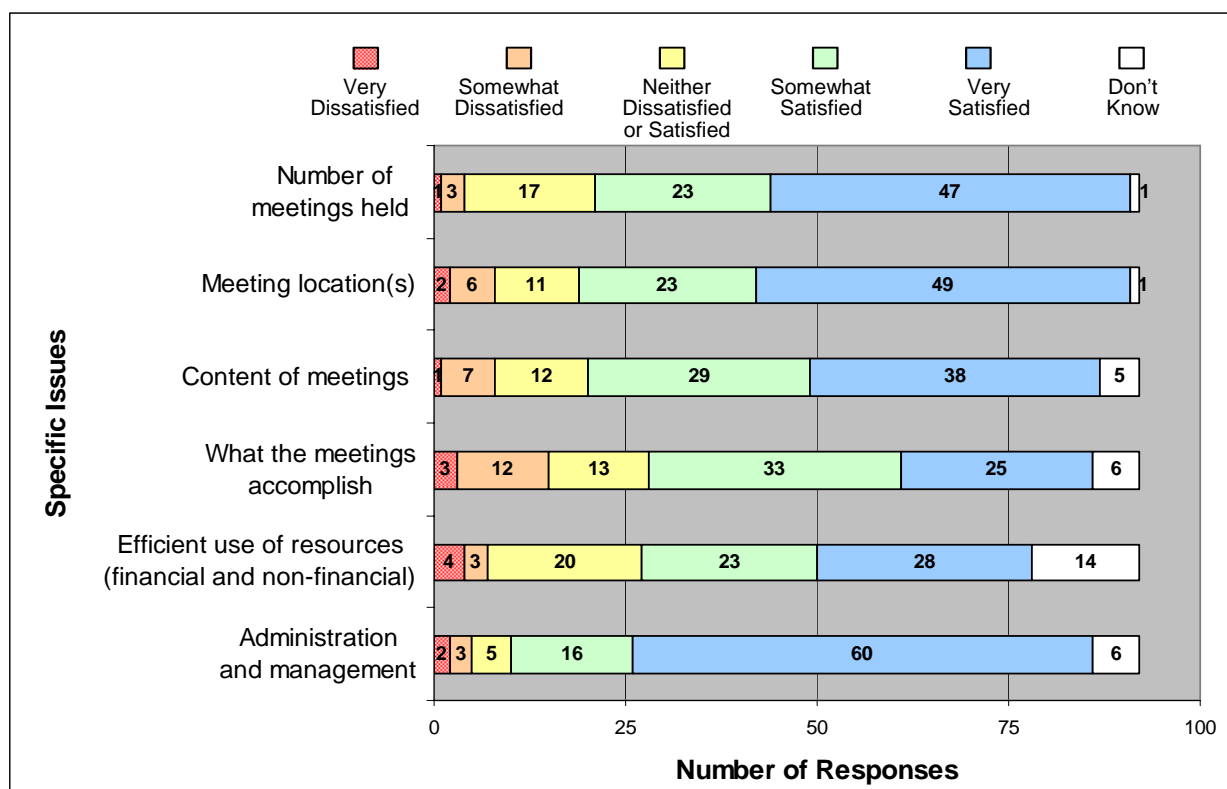
Several members commented on the critical role of assessment, expressing a need for increased efforts to ascertain the effectiveness of workgroup activities. For example, a workgroup member said that “we need to consider looking at the outcomes of what the

committee does to see if effective and if not, redesign them, “and then called for “doing a group internal and external needs assessment and setting of goals and priorities in line with those of the NJ Cancer priorities.” Several others echoed this sentiment by pointing out the need for more information on how to conduct program evaluation and for updated statistical information on a regular basis for evaluation purposes.<sup>bb</sup>

According to several respondents, one change that would most improve the effectiveness of this collaborative effort was a “large increase in OCCP budget even despite the state’s fiscal situation.” Other respondents commented that advocacy efforts need to be focused on raising awareness of comprehensive cancer control efforts and increasing recognition of its importance among politicians and other influential leaders.

**Process:** Overall, respondents were satisfied with administration and management as well as content, location, and number of meetings (range between 77% and 88%). Only about two-thirds (65%) of respondents were satisfied with meeting accomplishments and use of resources (financial and non-financial). About 1 in 4 respondents (26%) were neither satisfied nor dissatisfied with use of resources, while a high proportion (15%) responded “Don’t Know” to this item.

**Figure 2.9: Overall Process**



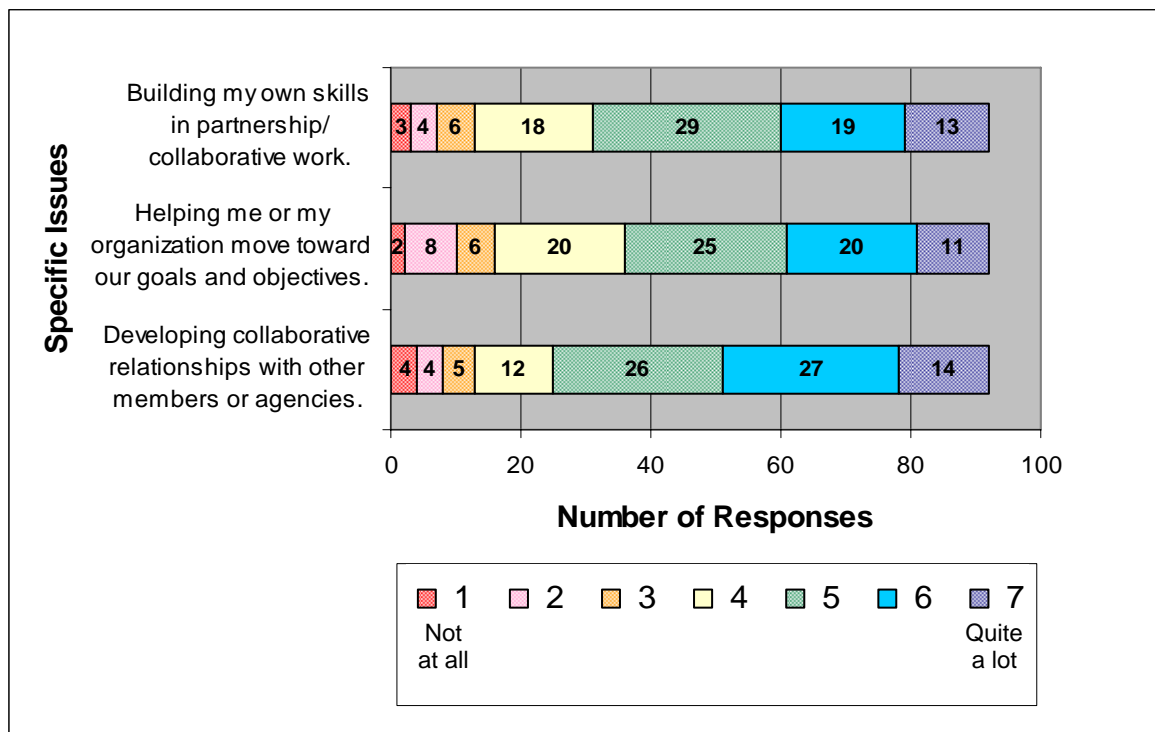
A number of respondents commented that they would like to see some of the in-person meetings replaced by telephone conferences, to make it easier to fit meetings into their

<sup>bb</sup> Some examples: (1) “...updated statistical info [should be provided] on a regular basis.” (2) “Not enough information on how to evaluate a program both quantitatively and qualitatively. This is imperative and not only an academic exercise but will help validate programs that then can be used in more coalitions.” (3) A need “for focused objectives with measurable outcomes.”

schedules. A few respondents indicated that their own conflicting commitments were a barrier to increased participation, with one member suggesting evening meetings as a remedy. Meeting location was a barrier for one respondent, who felt all meetings were held in the central or southern part of the state. Thus, the ability to attend meetings via telephone could be a potential remedy for barriers of limited time and meeting location, and could also facilitate efforts to include a broader group of participants (such as medical experts) in the workgroups and committees. It is recognized that the option to phone in to a meeting is best used sparingly, as many meetings are run most effectively face-to-face.

**Benefits of Participation:** Overall, involvement in the implementation of the Plan has been beneficial to participants. Respondents were asked three items on how their involvement has benefited themselves and/or their organizations, using a scale from a low of 1 (representing “not at all”) to a high of 7 (representing “quite a lot”). Combining responses of 5, 6, and 7 to denote that members perceived benefit, 73% of respondents (67 out of 92) reported that their involvement has helped them develop collaborative relationships with other members or agencies (Median: 5, Mode: 6). Over 60% of respondents (56 out of 92) indicated their involvement has helped them or their organization move toward their goals and objectives (Median: 5, Mode: 5), and 66% reported that their participation resulted in an enhancement of their skills in partnership/collaborative work (Median: 5, Mode 6).

**Figure 2.10: Benefits of Participation**



In conclusion, findings from the partnership self-assessment, fully completed by 92 members of the Task Force, workgroups, and standing committees, demonstrate overall satisfaction with the program’s membership, climate, communication, implementation, process, and collaboration. There was overwhelming enthusiasm for the leadership demonstrated by the Office of Cancer Control and Prevention and its Executive Director. As noted previously, the only improvement

that respondents widely called for was an increase in financial resources. Other specific suggestions of respondents concerning are discussed in context above.

## **PARTNERSHIP REPRESENTATION**

The following section describes representation of the New Jersey comprehensive cancer control program based on the Task Force, workgroups, and standing committees. Although an integral part of the New Jersey program, the county cancer coalitions were not included in this part of this assessment at this time.

Since the inception of the Governor's Task Force, nine of the original sixteen appointed Task Force members remain. These nine members provide continuity in leadership, which provides stability for progress. The Task Force is well represented by different types of organizations, including cancer centers, hospitals, hospital associations, community-based organizations, voluntary organizations, cancer survivors, major employers, and medical/dental schools.

Among the broader statewide cancer control partnership, 318 volunteers are listed on the most current workgroup and standing committee rosters. Of these, 37 of the 256 individuals (14%) are listed on two workgroups and/or committees, and 25 are listed on three or more (10%).

Note that county cancer coalition rosters were not systematically analyzed for this report. It may be useful to analyze coalition membership rosters in the future. The county cancer coalitions include significant representation in many counties from many diverse groups, including the faith-based organizations, county and local government, major employers, hospitals, etc.

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### **Representation by Primary Organizational Type**

The CDC recommends engaging a mix of different partners in state-level comprehensive cancer control planning and implementation. The organization that each individual represented, based upon the most current workgroup and committee rosters, was grouped into one of 16 categories on the CDC's list of suggested partners.

Below is a breakdown of types of organizations represented in New Jersey. Each individual's organization was given a primary designation and is therefore represented only once. An individual may represent more than one type of organization (e.g., hospital and faith-based organization), but **only** the organization listed on the roster is represented in Table 2.2, below. In instances where one individual serves on multiple workgroups and/or committees, each individual is counted only once.

**Table 2.2: Types of Organizations (Specified as Primary Affiliations) Represented by Workgroup and Committee Members\***

<b>Organizational Type</b>	<b>Number of Individuals</b>	<b>Percent</b>
Health Department (State and Local)	36	14%
Cancer Centers	19	7%
Hospitals and Hospital Associations	47	18%
Community-Based Programs	5	2%
Cancer Patient Support Programs	4	2%
State Medical or Other Health Care Provider Associations	5	2%
Palliative Care Agencies	8	3%
Voluntary Organizations	29	11%
Cancer Survivors*	2	1%
Other Chronic Disease Coalitions	9	4%
NCI Regional Cancer Information Service	2	1%
Major Employers and Business Associations	20	8%
Managed Care or Other Health Insurance-Related Organizations	7	3%
Colleges and Universities	41	16%
Unknown	22	9%
<b>Total</b>	<b>256</b>	<b>100%</b>

\* Three types of organizations, faith-based organizations, cancer survivors, and state legislators and Governors, are included in the CDC's list of suggested partners, but since only the primary affiliation for each individual is listed on the roster, ascertainment of these types are particularly incomplete. See discussion below.

There are many individuals who have additional affiliations, such as membership or leadership in faith-based organizations, that are not captured here. The CDC-recommended category "State Legislators and Governors" does not specifically include local government officials, such as County Executives, several of whom are involved in comprehensive cancer control at the county level. It should be noted that the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey was established by Executive Order in 2000 and enacted into law in 2006. Thus, it is clear that support from the Governor and State Legislature exists in New Jersey. Although representatives of the Governor, namely the gubernatorially

appointed Task Force, are integrally involved, this is not reflected above. As a result, Table 2.2 under-represents the diversity of members.

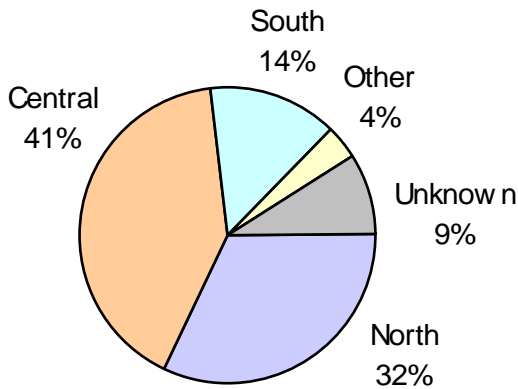
- ❖ We recommend that OCCP ascertain additional affiliations of members, not just primary affiliation, for a more complete understanding of representation in future assessments. Similarly, since the county cancer coalitions provide an important complement of partners to those participating in the workgroups, coalition memberships should also be included in future assessments.

In summary, based on the information available in the most current workgroup and standing committee rosters, New Jersey has engaged the broad types of organizations suggested by the CDC, with 14 of the 16 types documented in Table 2.2, above.

**Geographic Representation by New Jersey Region**

Similarly, the pie chart below describes the geographic representation of individuals involved in New Jersey’s comprehensive cancer control efforts, based upon the address listed on the most current workgroup and committee rosters. All members were grouped into one of three regions of New Jersey and other. The counties included within each region are listed in Figure 2.11, below, along with the proportion of New Jersey’s overall population residing in each region in parentheses.

**Figure 2.11: Representation of Workgroup and Standing Committee Members**



**Region (with Percent of State’s Total Population) and Counties within each Region**

<b>North</b> (48%)	Bergen Essex Hudson Morris Passaic Sussex Union Warren	<b>South</b> (21%)	Atlantic Burlington Camden Cape May Cumberland Gloucester Salem
<b>Central</b> (31%)	Hunterdon Mercer Middlesex Monmouth Ocean Somerset	<b>Other</b>	includes partners in CT, FL, OH, PA, VA, WA

Based on the information available in the most current rosters, all geographic regions are well represented by members, with the northern and southern regions somewhat under-represented, compared to their relative proportions of the general population. Excluding those of other and unknown regions, 37% of workgroup and standing committee members are from the northern region, 47% from the central region, and 16% from the southern region.

## **B. Collaboration among Workgroups and Coalitions**

Of the Task Force, workgroup, and standing committee members who responded to the partnership self-assessment survey, 44% (44 of 100) indicated that they were currently active members of a county cancer coalition. This robust overlap of representation encourages collaboration. Furthermore, OCCP attends all workgroup, standing committee, and county cancer coalition meetings. OCCP fully embraces its responsibility to facilitate communication between these different entities, and provides quarterly updates to all coalitions about activities of the workgroups and standing committees. Coalitions are encouraged to assist, collaborate with, or become members of statewide workgroups and standing committees.

In addition to relying upon OCCP to give the coalitions updates, workgroups and standing committees are encouraged to present their group's activities to the coalitions directly, either by attending the quarterly statewide meetings of the coalition coordinators or by attending individual county coalition meetings. Statewide county cancer coalition coordinators meetings took place monthly between March 2005 and June 2005 (4 meetings) and then quarterly between July 2005 and June 2006 (5 meetings). Between January 2005 and July 2006, almost half (six) of the workgroups and committees have presented at a statewide coordinators' meeting:

- Oral Cancer Workgroup Member, "A Role for Health Care Professionals in the Fight Against Oral Cancer" (March 2, 2005)
- Prostate Cancer Workgroup Member, "The Barbershop Initiative" (April 6, 2005)
- Melanoma Workgroup Member (May 11, 2005 and April 5, 2006)
- Lung Cancer Workgroup Chair and Oral Cancer Workgroup Member, Discussion of the Quit to Win Campaign (September 7, 2005)
- Colorectal Cancer Workgroup Chair, "Dialogues for Action" (January 11, 2006)
- Advocacy *Ad Hoc* Committee Chair, "Advocacy Issues and Legislative Efforts" (July 19, 2006)
- Advocacy *Ad Hoc* Committee Member, "Helping Patients Make Decisions about Complementary and Alternative Approaches" (July 19, 2006)

County cancer coalitions are also important to help implement workgroup priorities. Several county coalitions are currently collaborating with the Prostate Cancer Workgroup in its implementation efforts to improve patient education about prostate cancer screening, risk factors, symptoms, follow-up, and treatment (Goal PR-2 of the Plan). The workgroup has collaborated with The Prostate Net in its Barbershop Initiative, a national program that enlists barbershops in primarily black communities to serve as centers for education and screening referrals for prostate cancer.

The county-level cancer capacity and needs assessment highlighted the burden of prostate cancer, in several counties in particular. As a result, several counties identified a need for education to increase awareness of prostate cancer in their communities. As of June 2006, six county cancer coalitions (Burlington, Camden, Essex, Gloucester, Somerset, and Union) in New Jersey are involved in local implementation of the Barbershop Initiative. Additional county cancer coalitions, including those in Mercer and Union counties, are committed to becoming involved in the near term. The coalitions host or help organize events to promote the initiative in the community to assist with recruitment of medical centers and barbershops.

Through the overarching structure of the comprehensive cancer control program in New Jersey, coalitions have become involved in a broader, community-based effort, and have developed partnerships that may not have otherwise occurred.

Similarly, workgroup members are encouraged to become involved in county coalitions. One workgroup, in particular, has taken this task to heart. In 2006, the Oral Cancer Workgroup formed its own subcommittee, the Committee on Oral Cancer Awareness, to increase oral cancer awareness. The two main strategies it will use include forming a panel of speakers available to speak at county cancer coalition meetings and regional New Jersey Dental Association meetings, and increasing representation by a dental health professional on each county cancer coalition.

Collaborations also extend across counties, as exemplified by the Tri-County Workgroup of Burlington, Camden and Gloucester counties (further discussed below), or by participation in multiple coalitions by the coalition coordinators, such as in Hudson, Union, and Essex counties, and in Morris and Passaic counties.

Among respondents to the partnership self-assessment survey who indicated that they are currently active members of a county cancer coalition, an overwhelming proportion (93%, 38 out of 41 respondents) reported having collaborated with others in the implementation of the Plan. It appears that workgroup members actively involved in county cancer coalitions, although smaller than the general pool of respondents, were more satisfied with various aspects of collaboration than those members who currently are not actively involved in a county cancer coalition. This observation may represent individual members' interests, which may be beneficial to cross-fertilization and mutual understanding of local and statewide issues. Encouragement of active participation in both workgroups and county cancer coalitions may be worthwhile. It may be important to understand what can be done to increase the activity level of those less satisfied and active.

To more accurately assess the perspective of coalition members, further assessment may be needed.



## Section 3 – Implementation Evaluation

Four key aspects of implementation of the New Jersey Comprehensive Cancer Control Plan will be discussed in this section:

- (A) Baseline information and programs, including the capacity and needs assessment process;
- (B) Biennial status reports mandated by Executive Order;
- (C) Strategies of the Plan; and
- (D) Local implementation through county cancer coalitions.

### **A. Baseline Information and Programs**

The key tools deemed necessary for implementation and evaluation of the Plan include: (1) a baseline assessment of the capacity and needs, (2) a standardized database of health care resources (Cancer Resource Database of New Jersey), (3) mechanisms to systematically collect data to monitor the extent of progress and achievement (strategy tracking database), and (4) utilization of standardized methods and time periods for cancer data in order to establish common baselines and enable valid comparisons. All of these tools were developed and utilized during the first implementation period of New Jersey's Plan. The development and utilization of these tools are described in detail in the Task Force's 2004 Status Report to the Governor, and thus will not be discussed in this report.

For continued utility of these tools, the centralized monitoring of workgroups, committees, and coalitions, which has proven to be a successful method of assessing progress, needs to be maintained. With the assistance of UMDNJ-New Jersey Medical School and the Battelle Centers for Public Health Research and Evaluation (CPHRE), the OCCP has centralized the process to systematically monitor progress of the Plan's strategies, and has hired staff with CDC funding to accommodate this additional function. The centralized method for updating the database has proven to be a successful and efficient way to monitor progress in a timely fashion.<sup>cc</sup>

- ❖ The OCCP maintains centralized monitoring of the Plan's strategies, and reports its results to the workgroups and to the Evaluation Committee periodically, which is necessary for ongoing implementation and evaluation. We recommend that funding be obtained for the continued maintenance of this open system of monitoring and reporting.

The above current system for monitoring progress entails only itemization of activities and their status. It would be useful to include objective critical assessment of strategies and activities; however, this task is beyond the scope of the present mandate of the Evaluation Committee and of the current Report, in part related to availability of data as well as funding limitations.

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<sup>cc</sup> While the decentralized structure to track progress of strategies that was initially developed by UMDNJ–NJMS, the OCCP, and Battelle CPHRE would have empowered workgroups by providing direct involvement, it proved more technically challenging for the workgroups to handle this directly than initially envisioned. Its continued direct use by workgroups would have required resources to provide the ongoing technical support necessary for volunteers to gain sufficient expertise to effectively utilize its capabilities. Only minor modifications were necessary to implement the strategy tracking system in its present centralized form.

## CAPACITY AND NEEDS ASSESSMENT (C/NA)

The results of each county's Cancer Capacity and Needs Assessment (C/NA) were summarized into two key documents: a Report Summary and Fact Sheet. Following a scientific and technical review, and approval by the Office of Cancer Control and Prevention and the Department of Health and Senior Services, all Report Summaries and Fact Sheets were released in September 2005. The processes were discussed in detail in the 2004 Status Report.

A mechanism for disseminating these results is built into New Jersey's infrastructure for cancer control efforts: county cancer coalitions. Seven county cancer coalitions have incorporated into their mission statements the use of findings from the C/NA in the planning and implementation activities to reduce the countywide cancer burden (discussed further in Section D). These reports are also available to the public through the OCCP web site, [www.njcancer.gov](http://www.njcancer.gov). In addition, OCCP created an e-newsletter, distributed quarterly to a mailing list of over 1,200 individuals. The first issue was released in October 2005, and the first article in the newsletter described the results of the C/NA.

The successful completion of county-level C/NAs demonstrates that delegating to the local level a capacity and needs assessment for widespread and common diseases that show local variability, such as cancer, is a useful method for developing policy. All counties described a baseline assessment of the cancer burden in each county, and used a standardized approach, enabling comparisons across counties as well as future comparisons. While it is acknowledged that this method requires a substantial commitment of resources, it is highly unlikely that any other method could have resulted in a database of cancer resources as thorough as the Cancer Resource Database of New Jersey, which contains information on over 2,700 facilities that provide cancer-related services in the state. Furthermore, by explicitly taking into account local variation in demographics and cancer epidemiology, these C/NAs permitted the development of locally relevant cancer priorities which would have been difficult to formulate had only a statewide assessment been done.

While the use of county evaluators was essential to completion of the C/NAs, an extensive amount of time and effort was needed to provide training in demographic and epidemiologic techniques.

- ❖ We recommend that if collection and assessment of demographic and epidemiologic data, such as was undertaken in the 2003-2004 capacity and needs assessment, is feasible in the future, it be handled by a centralized group with demonstrated expertise. That group could then disseminate and interpret such data to appropriate staff who are based locally and who would continue to be responsible for collecting information on local resources. Similarly, to use state resources more efficiently, we recommend that requests for local data should be discouraged except as part of a centrally organized effort.

Each county developed both local and statewide recommendations in its C/NA. Statewide recommendations were subsequently systematically categorized by topic and compiled into a summary document for OCCP by the Evaluation Team at UMDNJ-New Jersey Medical School. This summary included only recommendations that were plausibly supported by a reasonable level of evidence, and reflect statements from the C/NA Report Summaries.<sup>dd</sup> The summary

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<sup>dd</sup> However, they do not reflect any opinion of the Task Force, the Evaluation Committee, the OCCP or any other division of NJDHSS on whether the recommendation should or should not be implemented. The level of evidence

document included a list of counties from which the recommendation was drawn and suggested lists of parties that may be appropriate for further review of the recommendation. The OCCP plans to distribute this summary to the county cancer coalitions.

Insofar as health policy should respond to changing trends in the incidence and mortality of disease to remain relevant, it would be valuable if the C/NAs could be periodically updated, along with supporting documents such as the summary document of statewide recommendations. This would serve two purposes: state and local policies can reflect changes in the cancer burden and available resources; and the effects of comprehensive cancer control can be monitored. Since this would require a substantial level of funding and commitment, significant advance planning would be necessary.

## ***B. Biennial Status Reports to the Governor from the Task Force***

The Executive Order establishing the Governor's Task Force also mandated updated reports every two years. In 2005, the Task Force's mandate was extended to include reporting to the legislature, as well as the Governor. The 2004 Status Report to the Governor was the first report submitted to the Task Force by the Evaluation Committee. It summarized progress during the first two years of implementation (2003–2004). Following approval by the Task Force and then the New Jersey Department of Health and Senior Services, the Task Force's first Status Report to the Governor on comprehensive cancer control efforts in New Jersey was released in September 2005. This report is also available to the public through both the OCCP and the Evaluation Committee web sites ([www.njcancer.gov](http://www.njcancer.gov) and [www.umdj.edu/evalcweb](http://www.umdj.edu/evalcweb), respectively), and its release was promoted through the October 2005 issue of OCCP's e-newsletter.

The OCCP reviewed and organized the recommendations contained in the 2004 Status Report, including the recommended detailed, systematic analysis of incidence and mortality issues. The OCCP has also taken appropriate steps toward implementation, including forwarding recommendations to the appropriate workgroups and/or committees in 2005 for further consideration, and incorporation into the next five-year cancer plan as appropriate. A subcommittee of the Evaluation Committee examined the recommendations, identified data that would be needed to initially assess some of these recommendations, and the full Evaluation Committee has submitted these to OCCP for consideration. The OCCP has reviewed these data request recommendations and is now working with appropriate partners to obtain and disseminate these data and to utilize expert consultants as appropriate in the analysis of these data.

Many of the issues raised in the 2004 Status Report remain relevant to the development of the second comprehensive cancer control plan. It is anticipated that the Task Force or relevant workgroups will be addressing these issues.

- ❖ We recommend that the Task Force, its Workgroups, and the OCCP continue to build upon their own expertise by regularly involving other professionals, as appropriate, for

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varies based on the type of data source, without further comment on its accuracy and reliability. Recommendations derived from key informant interviews were included. Key informant interviews, while they may represent a biased sample, are often a good indicator of views held by well-informed parties and can raise legitimate issues for consideration. A sample of topics that the recommendations focused on include issues related to health care coverage, including Medicaid eligibility for cancer treatment and lack of insurance; access to cancer services and screening; cancer screening and other services through the NJCEED Program; tobacco-related issues; transportation.

the tasks of integrating this information into the writing and implementation of the next five-year cancer plan.

- ❖ We recommend that the OCCP continue to periodically review the recommendations from all Status Reports, and take appropriate steps toward implementation, including incorporation into the five-year cancer plans.

### **C. Implementation of the Plan's Strategies**

This section describes a summary of progress for the strategies contained in the Plan. The development and structure of the database developed to track strategies of the Plan have been described in detail in the 2004 Status Report.

A total of 56 goals, 104 objectives, and 319 strategies are contained within the Plan.<sup>ee</sup> Once every six months, each workgroup and standing committee is asked to provide updates to OCCP on all aspects of its respective goals, objectives, and strategies, including the target year for commencement and completion of each strategy. One or more target years for completion are designated to each strategy for this five-year implementation period. "Ongoing" is another possible target year designation, used for strategies that are intrinsically continual and not intended to be contained within a five-year interval.

As part of its review, each workgroup and standing committee updates the status of each strategy, using six possible designations: (1) Complete (all tasks are completed to date to satisfy the requirements of the strategy); (2) In Progress<sup>ff</sup> (strategies that have a well defined ending date and are currently ongoing); (3) Ongoing–Continuing (at least one task is ongoing); (4) Ongoing–Recommend Dropping (progress has been started, but due to new or updated information, the workgroup no longer deems completion of the strategy feasible or relevant); (5) No Progress–Obstacles (an obstacle, such as lack of funding or lack of a primary change agent, has impeded progress, but the workgroup deems completion of the strategy feasible or relevant); and (6) No Progress–Recommend Dropping (an obstacle has impeded progress, and the workgroup does *not* deem completion of the strategy feasible or relevant). For the purposes of this report, strategies with a status of either "In Progress" or "Ongoing–Continuing" are combined and considered "Ongoing."

In 2006, 16% of all strategies, including those with a final target year in the future, are reported as completed, and progress is being made on 66% (3% in progress, 63% ongoing-continuing). Workgroups and standing committees indicated that no progress has been made on 13% of all strategies due to various obstacles and that 5% of all strategies should be dropped (no progress made).

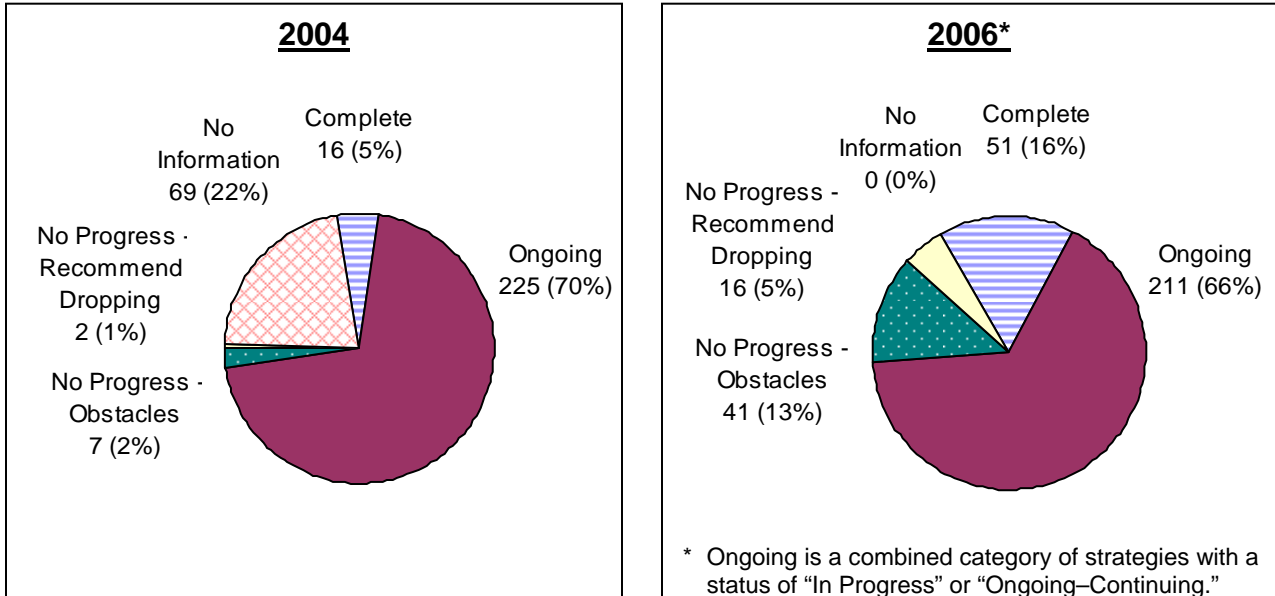
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<sup>ee</sup> As described previously, strategies related to Chapter 13, Emerging Trends, were not intended to be tracked during the 2003–2007 implementation period and are thus excluded from this evaluation. Cf. the 2004 Report ; abridged versions are posted at [www.njcancer.gov](http://www.njcancer.gov) and [www.umdnj.edu/evalcweb/](http://www.umdnj.edu/evalcweb/).

<sup>ff</sup> "In Progress" is a new category, added by OCCP in 2006. This status is used only for strategies with updated status information. In particular, OCCP has **not** retroactively reviewed all strategies with statuses of Ongoing–Continuing to determine whether to reclassify them as In Progress.

Progress has been made on many of the Plan's strategies since the last report in 2004. The percent of all strategies completed increased from 5% in 2004 to 16% in 2006. The majority of all strategies were reported in 2004 as ongoing (70%), and a similar proportion (66%) was observed in 2006.

**Figure 3.1: Distribution of Strategy Statuses**



The proportion of strategies for which no progress has been made, due either to various obstacles or to an assessment that the strategy should be dropped, increased substantially from 3% in 2004 to 18% in 2006. This suggests that a more rigorous and frequent review of the strategies may be occurring. Further evidence for this is given by the elimination of the number of strategies for which no information was available. In 2004, no information was available on 22% of the strategies; there are none in 2006.

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Table 3.1 below summarizes the status of all the Plan's strategies, with a subtotal for strategies with a final target year of 2005 and earlier, based on the most recent information available.

**Table 3.1  
Status of the Plan's Strategies by Final Target Year\***

Final Target Year**	Initial Target Year	Total Number of Strategies (100%)	Percent of Strategies			
			Complete	In Progress or Ongoing – Continuing	No Progress Due to Obstacles	No Progress and Recommend Dropping
2003	2003	44	43%	36%	14%	7%
2004	2004	36	28%	42%	25%	6%
2005	2005	27	11%	59%	19%	11%
<b>Subtotal – through 2005</b>		<b>107</b>	<b>30%</b>	<b>44%</b>	<b>19%</b>	<b>7%</b>
2007	2003	3	0%	67%	33%	0%
	2007	129	9%	78%	10%	4%
Ongoing	2003	70	11%	76%	9%	4%
	2004	3	0%	100%	0%	0%
	2005	6	0%	100%	0%	0%
	2007	1	0%	0%	100%	0%
<b>Total for All Strategies</b>		<b>319</b>	<b>16%</b>	<b>66%</b>	<b>13%</b>	<b>5%</b>

\* Last updated July 2006.

\*\* Only those combinations that occur are shown (not all possible combinations of initial and final target year exist). For example, all strategies with a final target year of 2007 have an initial target year of either 2003 or 2007, and no strategies have an initial or final target year of 2006.

Given the timing of this report, progress only through the end of calendar year 2005 can be included in this report. Of the 319 total strategies, 107 strategies (34%) have a final target year designation for completion of 2003, 2004, or 2005; 132 strategies (41%) have a 2007 final target year, and 80 strategies (25%) are designated Ongoing as the final target year.

Of the 107 strategies with 2003, 2004, and/or 2005 as the target year for completion, 30% are complete, 44% are ongoing-continuing, 19% are reported to have no progress due to obstacles, and an additional 7% are reported to have no progress due to obstacles and should be dropped. This demonstrates a higher proportion of strategies completed on time than in the last assessment in 2004, when 13% of the strategies with 2003 and/or 2004 as the target year for completion were complete. Furthermore, as shown in Table 3.1, greater proportions of strategies with earlier final target years are complete (43% for 2003, 28% for 2004, 11% for 2005, 8% for 2007, and 10% for Ongoing), while greater proportions of strategies with later final target years are continuing (36% for 2003, 42% for 2004, 59% for 2005, 77% for 2007, and 78% for Ongoing).

As described above, progress has been made since the 2004 Status Report. Even though workgroups have clearly made great advances in moving a majority of their strategies forward, it has become clear that there is only limited success in completing strategies by their originally

scheduled target years. The Task Force structure assumes that each workgroup is the best source of expertise on its area within the overall comprehensive cancer control structure. Workgroups have always been empowered to show this expertise by informally assigning their own internal priorities to strategies and acting accordingly. As indicated by the general satisfaction level of participants in the partnership survey and the overall progress, this has generally worked well as a means of assigning priorities to strategies, even though the strategies have not been addressed in the order in which they were originally assigned when the Plan was first developed. Thus, the addition of explicit priorities would help both in implementation and in evaluation. For these reasons, the Task Force and the OCCP should reconsider the use of only fixed strategy target years in the design of the next five-year plan, and should also consider the advisability of adding explicit priorities to the strategies.

In Table 3.2 below, strategies with final target years of 2003, 2004, and/or 2005 are tabulated by chapter of the Plan. A list of strategies for all final target years is in Table 3.3.

**Table 3.2  
Status of the Plan's Strategies by Chapter,  
Final Target Year of 2003, 2004, and/or 2005**

Chapter (Chapter Label)	Total Number of Strategies	Complete	In Progress or Ongoing-Continuing	No Progress-Obstacles	No Progress-Recommend Dropping
<b>Section I. Overarching Issues</b>					
Access and Resources (AC)	9	22%	67%	11%	0%
Advocacy (AD)	1	100%	0%	0%	0%
Palliation (PA)	7	0%	100%	0%	0%
Nutrition and Physical Activity (NP)	5	20%	80%	0%	0%
Childhood Cancer (CC)	25	40%	28%	32%	0%
<b>Section II. Site-Specific Cancers</b>					
Breast Cancer (BR)	4	0%	75%	25%	0%
Cervical Cancer (CE)	6	0%	50%	33%	17%
Colorectal Cancer (CO)	5	40%	40%	0%	20%
Lung Cancer (LU)	2	50%	50%	0%	0%
Melanoma (ME)	7	14%	14%	14%	57%
Oral and Oropharyngeal Cancer (OR)	15	27%	40%	33%	0%
Prostate Cancer (PR)	14	29%	43%	14%	14%
<b>Section III. The Future of Cancer Control and Prevention in New Jersey</b>					
Evaluation (EV)	2	100%	0%	0%	0%
Implementation (IM)	5	80%	20%	0%	0%
<b>Total</b>	<b>107</b>	<b>30%</b>	<b>44%</b>	<b>19%</b>	<b>7%</b>

**Table 3.3 – Status of the Plan’s Strategies by Chapter and Target Year**

Chapter (Chapter Label)	Final Target Year	Total Number of Strategies	Complete	In Progress	Ongoing-Continuing	No Progress-Obstacles	No Progress-Recommend Dropping
Access and Resources (AC)	2003	5	2	0	2	1	0
	2004	4	0	0	4	0	0
	2007-Ongoing	29	3	1	19	6	0
Advocacy (AD)	2003	1	1	0	0	0	0
	2007-Ongoing	15	2	3	10	0	0
Palliation (PA)	2003	2	0	0	2	0	0
	2004	2	0	1	1	0	0
	2005	3	0	0	3	0	0
	Ongoing	1	0	0	1	0	0
Nutrition and Physical Activity (NP)	2004	3	1	0	2	0	0
	2005	2	0	0	2	0	0
	2007-Ongoing	17	0	1	11	4	1
Childhood Cancer (CC)	2003	5	4	0	0	1	0
	2004	11	5	0	3	3	0
	2005	9	1	0	4	4	0
Breast Cancer (BR)	2003	4	0	0	3	1	0
	2007	38	1	0	32	5	0
Cervical Cancer (CE)	2003	5	0	0	3	1	1
	2005	1	0	0	0	1	0
	2007-Ongoing	24	6	0	14	0	4
Colorectal Cancer (CO)	2003	2	2	0	0	0	0
	2004	1	0	0	1	0	0
	2005	2	0	0	1	0	1
	2007-Ongoing	7	0	0	6	0	1
Lung Cancer (LU)	2003	2	1	0	1	0	0
	2007-Ongoing	15	4	0	11	0	0
Melanoma (ME)	2003	2	0	0	0	0	2
	2004	3	0	0	1	1	1
	2005	2	1	0	0	0	1
	2007-Ongoing	20	0	5	11	4	0
Oral and Oropharyngeal Cancer (OR)	2003	3	2	0	1	0	0
	2004	8	2	0	1	5	0
	2005	4	0	0	4	0	0
	2007-Ongoing	15	0	0	14	1	0
Prostate Cancer (PR)	2003	7	2	0	3	2	0
	2004	3	1	0	1	0	1
	2005	4	1	0	2	0	1
	2007-Ongoing	22	1	0	18	1	2
Evaluation (EV)	2003	1	1	0	0	0	0
	2004	1	1	0	0	0	0
	2007	1	1	0	0	0	0
Implementation (IM)	2003	5	4	0	1	0	0
	2007-Ongoing	8	1	0	7	0	0
<b>All Chapters</b>	2003	44	19	0	16	6	3
	2004	36	10	1	14	9	2
	2005	27	3	0	16	5	3
	2007-Ongoing	212	19	10	154	21	8
<b>Total</b>		<b>319</b>	<b>51</b>	<b>11</b>	<b>200</b>	<b>41</b>	<b>16</b>



An assessment of progress for each chapter shows varying levels of completion, with 100% of strategies in the Advocacy and Evaluation chapters completed. All strategies within Nutrition and Physical Activity, Palliation, Lung Cancer, and Implementation chapters are either complete or in progress/ongoing. The Childhood Cancer, Cervical Cancer, Melanoma, and Oral/Oropharyngeal Cancer Workgroups have indicated they have encountered obstacles to implementation of at least one-third of their respective strategies.

- ❖ We recommend that the OCCP continue to monitor and review these strategies with these workgroups.

Through the ongoing assessment of New Jersey's experiences, it has become apparent that even the best comprehensive cancer control planning cannot predict all the exigencies that may arise in the course of implementation, such as new scientific information,<sup>99</sup> new data on cancer epidemiology, and unforeseen promoters of or obstacles to progress. This is illustrated in the present plan, for example, by the approval in 2006 of a human papillomavirus (HPV) vaccine to prevent cervical cancer that was discussed in detail in the Emerging Trends chapter of the current plan. Even though there is no explicit strategy related to the HPV vaccine in the Plan, the Cervical Cancer Workgroup assumed ownership of the issue and initiated active steps, which was quite appropriate given its importance and considerations of timeliness. Another indicator of the need for flexibility is the completion of some strategies before their planned target years and the need for continued progress on others beyond their target years.

Incorporating the necessity for such flexibility in the Plan is problematic, since the Plan undergoes extensive review during its approval process and it is not expected to be revised and resubmitted for approval during the period while it is in force. The Task Force decided during the course of the first Plan, on September 8, 2003, that the Plan would not be changed after it was adopted.

Given the continuing rapid pace of advancement, it is essential that subsequent five-year plans be structured to internally incorporate the flexibility needed to place priority on strategies that may not have been explicitly propounded and foreseen. In particular, there is a need to take into account new scientific information and unforeseen exigencies that may arise.

- ❖ We recommend that the next five-year cancer plan should allow for such flexibility within established workgroups by (a) constructing each chapter, including its strategies, with sufficient breadth to allow implementation to be driven by the most current data and research findings, (b) allowing workgroups to take on issues raised in a chapter concerning emerging trends, such as was included in the first Plan, (c) continual analysis of relevant data and scientific reports, (d) inclusion of generic strategies throughout the plan, and (e) periodic review of and appropriate dynamic change in the priorities of strategies, based upon evolving events, data and funding.

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<sup>99</sup> Given the high volume of pertinent research in oncology, numerous examples can be cited of active areas of research that can be expected to result in new or altered recommendations for clinical practice in both diagnosis and treatment within the new Plan's five-year lifetime. Among these are such developments as (1) low-dose spiral CT scanning for earlier lung cancer detection, although increased morbidity related to false positives may limit its utility, and (2) the possibility that emphasis on PSA velocity rather than PSA level alone will sufficiently improve prostate cancer detection and influence treatment to lead to its adoption for routine screening.

## ***D. Local Implementation***

In September 2004, county cancer coalitions were formed with support from the Office of Cancer Control and Prevention (OCCP). Currently, there are 21 county cancer coalitions, each dedicated to addressing the unique cancer-related issues in New Jersey's 21 counties. This section describes the coalition itself (its mission, structure, and membership), the coalition's activities, and evaluation of the coalitions.

### **COALITIONS**

**Mission:** All coalitions formulated mission statements, stating their purpose. Common themes include:

- Raising awareness of cancer prevention, early detection, treatment, and survivorship
- Use and dissemination of findings from the C/NA in the planning and implementation activities to reduce the countywide cancer burden
- Involvement of a diverse group of stakeholders

The majority of coalitions have a documented annual review of their mission statement to allow for opportunity for revisions, to reflect any changes in the coalition's priorities. Several coalitions did not report an annual review of their mission statement, but have scheduled a review in the second half of 2006, as recommended by the OCCP.

Pertinent issues, obstacles and potential solutions to implementation, and tools to implement evaluation strategies are described in the coalition's **action plan**. Nineteen out of 21 county cancer coalitions have a documented action plan. The two counties without an action plan are those that had initial difficulty recruiting and hiring a coalition coordinator. Those coalitions have been advised by the OCCP to develop an action plan.

**Structure:** Coalitions are led by a full-time coordinator who is responsible for prioritizing cancer needs in the county and implementing strategies for reducing the cancer burden. Funding from the OCCP enables each coalition to hire a dedicated coordinator. In addition, many coalitions reported receiving in-kind support, mainly from the grantee agency, for meeting space, refreshments, printing costs for coalition activities, and IT support. The CDC, the OCCP, and the Evaluation Committee have mutually agreed that documentation of in-kind support is of great value. The CDC has developed a prototype form to document such contributions, which the OCCP provided to the coalition coordinators in July 2006. The OCCP encouraged all coalitions to document all future in-kind contributions of their coalition members.

- ❖ We recommend that this type of systematic data collection to document in-kind contributions should be done analogously for the members of the workgroups and standing committees.

To support some of their coalition activities, some coalitions have applied for grants in partnership with OCCP from public and private foundations, federal agencies, hospitals, and corporations, including pharmaceutical companies. Coalitions also use innovative approaches to raise support. For example, the Hudson and Union County Cancer Coalitions have enrolled in the Commerce Bank Affinity Program. Organizations participating in this program enroll customers of the bank to pledge support to their organization. At the end of each calendar year, the bank donates 0.5% of the combined balances of all enrolled customers to the designated cause. Other coalitions are exploring the feasibility of participating in this program.

Many coalitions have formed committees and/or workgroups to address specific issues related to cancer control and prevention, to accomplish goal-oriented tasks, and to allow stakeholders to invest their efforts and expertise where they can be best utilized. These committees and workgroups often meet separately, between quarterly meetings of the entire coalition. Some committees and workgroups are focused on a cancer site (e.g. lung, breast), a target population (e.g., undocumented individuals), or a specific function (e.g., advocacy, outreach). For example, the Atlantic County Healthy Living Coalition formed committees on Professional/Community Education, Healthy Lifestyle Events, Advocacy, and Palliative Care. The Essex County Cancer Coalition formed a Leadership Council to guide the overall direction of the coalition and committees on Advocacy, Development (funds, grants), and Education/Outreach. Burlington, Camden, and Gloucester counties share a Tri-County Workgroup to facilitate tri-county initiatives. Independently, the Burlington County Cancer Coalition has workgroups on By-Laws and Health Education; the Camden County Cancer Coalition has workgroups on Eliminating Health Disparities and Lung Cancer & Smoking Cessation Issues; and the Gloucester County Cancer Coalition has workgroups on Healthy Lifestyles, Minority Issues, and Youth.

**Membership:** County coalition members represent diverse organizations and include representatives from:

- Healthcare providers
- Community-based programs
- State, county, and local health departments
- Faith-based organizations
- Voluntary organizations
- Health or chronic disease coalitions
- Academia
- Palliative care agencies
- Cancer patient support programs
- Businesses and corporations
- Managed care organizations
- Cancer survivors
- Legislators and other elected officials

County coalitions have recently been mandated by the OCCP to perform an **annual self needs assessment**, which includes an assessment of its stakeholders to identify and fill any gaps in membership (organizational, geographic, etc.). Needs assessments may be qualitative, quantitative, or a combination of both, and assess: (1) types of organizations represented, (2) attendance at coalition meetings, (3) involvement in coalition workgroups and/or committees, (4) satisfaction with coalition meetings, (5) satisfaction with progress in achieving coalition goals, (6) coalition strengths, and (7) areas for improvement.

To facilitate performing the needs assessment, the OCCP provided coalition coordinators with several different stakeholder assessment tools, including sample questionnaires and tools from the National Comprehensive Cancer Control Program and *Communities of Excellence in Tobacco Control: Community Planning Guide*, in April 2006. These tools facilitate the assessment of various components of membership breadth and diversity such as the number of people served, geographic location served (specific municipalities versus county-wide), focus (i.e., advocacy, education), and role/discipline (nursing, physician, data, education, faith-based, etc), as well as strengths and perspectives that members bring to and receive from the coalition. These assessments are critical in guiding ongoing recruitment of new stakeholders and

ensuring that all voices, which can further county cancer control efforts, are heard and represented through the coalition.

In 2006, 14 coalitions performed a stakeholder assessment and reported the results in their respective Quarterly Progress Reports. Of the seven counties that have not performed a self needs assessment, two had not been in existence for one year by June 2006. Future assessments would benefit from mandating all coalition to use a systematic format to measure strengths and gaps in membership diversity and to facilitate the overall evaluation of these stakeholder assessments. Additional guidance from OCCP in conducting a stakeholder assessment would also be beneficial to county cancer coalitions.

Some coalitions face barriers to membership recruitment, such as 'turf' issues among competing organizations. Coalitions with success in overcoming some of these barriers should share their strategies with other coalitions facing similar obstacles. For example, the Atlantic County Healthy Living Coalition has been effective in bringing competing hospital systems to the table and working toward a common goal. Similarly, in the Tri-County area (Burlington, Camden and Gloucester), the three major competing health systems (Virtua Health System, Cooper Health System, and Our Lady of Lourdes) all joined forces to hold the Tri-County event, "The Big C" on April 27, 2006. This was so successful that they are planning to repeat it and undertake other collaborations. In Passaic County, attitudes toward and support for the coalition are improving despite hospitals' need to compete for limited resources.

In order to maximize resources and avoid duplication of efforts, the OCCP has mandated the county cancer coalitions liaise with local health departments through the Partnership Coordinator responsible for Practice Standards and with other state-funded organizations in the county that share common or related missions, such as NJCEED, Community Partnership Coalition (formerly Communities Against Tobacco (CAT) Coalition), and the New Jersey Local Information Network and Communications System (NJ-LINCS).

- ❖ We recommend that the NJDHSS add reciprocal clauses to the scopes of work for each of these organizations to ensure that they cooperate reciprocally with the county cancer coalitions.

Similar to county cancer coalitions, there is at least one NJCEED and/or Community Partnership coalition serving each county. Many county cancer coalitions work closely with their respective NJCEED lead agencies, and address issues related to early detection and screening for breast, cervical, prostate, and colorectal cancers. County cancer coalitions also work with the Community Partnership Coalitions to address smoking prevention and cessation. In many counties, establishment of such collaborations have been convenient and successful. For example, the Somerset County Cancer Coalition works very closely with NJCEED and has collaborated with the Community Partnership Coalition on many successful activities, such as World No Tobacco Day. The coalition has created a Tobacco Workgroup, which is chaired by the Director of the county's Quit Center. In fact, the Somerset County Communities Against Tobacco Coalition will be disbanding and will be absorbed by the Somerset County Cancer Coalition.

In many counties, such as Essex, the NJCEED coalition served as the foundation for expansion into the broader Essex County Cancer Coalition. The coalition's leadership includes, among others, the local NJCEED Program Coordinators and the county health officer. The Essex County Cancer Coalition and the two NJCEED programs in the county have held joint meetings for over two years.

Several county cancer coalitions are closely collaborating with the American Cancer Society's Urban Initiatives, as they share common goals and have overlap in membership. In New Jersey, the ACS has established Urban Initiatives for the cities of Asbury Park, Camden, Jersey City, Morristown, Newark, Paterson and Trenton.

## COALITION ACTIVITIES

### 2006 Cancer-Related Project

All county cancer coalitions were required to complete at least one cancer-related activity for the grant period from July 2005 through June 2006. Nineteen coalitions successfully planned and implemented at least one community event or activity related to cancer control and prevention during this time period. Many projects focused on raising awareness about cancer and promoting early detection through the NJCEED program. Other projects focused on promoting lifestyle changes through adoption of healthy diets, physical activity, smoking cessation, and preventive health screenings (for both cancer and other chronic conditions). Activities were both long- and short-term and included educational presentations, health fairs, cancer screenings, public service announcements, and development of cancer education materials [e.g. bilingual NJCEED informational cards (Monmouth County) and a cancer resource guide for adults (Ocean County)]. Two coalitions did not complete a cancer project by June 2006. Funding-related difficulties prevented one coalition from successfully completing a project, while another coalition is implementing its project in fiscal 2007.

- ❖ We recommend that coalition projects be grounded upon substantial bodies of evidence which support, as one of their primary benefits, specific cancer-related improvements that are consistent with the Plan.

A sample of the 2006 coalition projects across the northern, central, and southern regions of New Jersey, including one tri-county event, are described below.

Northern New Jersey: **Hudson County Cancer Coalition** – “2006: A New Year, A New You” Campaign: The Hudson County Cancer Coalition (HCCC) launched an initiative to increase cervical cancer screening, with the support of Hoboken Family Planning, one of the NJCEED/OCCP grantees in Hudson County. Hudson County's cervical cancer incidence and mortality rates were, respectively, 23% and 35% higher than New Jersey's corresponding rates during the five-year period from 1996 through 2000.<sup>hh</sup> The campaign was conducted in January, which is National Cervical Health Awareness Month and capitalized on other health promotion efforts targeting cervical cancer. Partnerships were established between the HCCC and local health departments, health centers, private physicians, and community-based organizations.

“2006: A New Year, A New You” was promoted through local cable programs, advertisements in print media, letters to municipal and county government officials, faith-based organizations, and businesses. As a result, there was a 58% increase in cervical cancer screenings performed through NJCEED in January 2006 (compared to January 2005). Women seeking cervical cancer screenings also received breast and colorectal cancer screenings (if medically recommended). The initial success of “2006: A New Year, A New You” has allowed for expansion of the campaign to screenings for breast, colorectal, and prostate cancers.

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<sup>hh</sup> During the five-year period from 1996 through 2000, Hudson County's average annual cervical cancer incidence rate was 13.4 per 100,000, compared to 10.9 per 100,000 for New Jersey, and Hudson County's average annual cervical cancer mortality rate was 4.2 per 100,000, compared to 3.1 per 100,000 for New Jersey.

**Warren and Sussex County Cancer Coalitions – Cancer Education in Schools:** The Warren and Sussex County Cancer Coalitions have each focused their cancer awareness efforts on school-aged children and adolescents.

The Sussex County Cancer Coalition held a drawing competition at Creative KidCare to promote healthy eating and snack time. The Coalition, in conjunction with Communities Against Tobacco Coalition, has also conducted education sessions during school lunch periods on smoking prevention and skin cancer awareness.

The Warren County Cancer Coalition provides routine education on breast and testicular cancers, melanoma and tanning, and lung cancer and smoking to numerous eighth-grade students in Warren County schools, and has also developed cancer education lesson plans for teachers which can be incorporated into existing health curricula.

Central New Jersey: **Mercer County Cancer Coalition – School Health-PE-Nutrition Conference, “The Cancer Connection:”** The Mercer County Cancer Coalition presented a half-day program for Mercer County’s school nurses and health educators. The conference included information on breast, skin, and lung cancers, the importance of nutrition and physical activity, and resources to help school nurses and health educators develop stimulating lesson plans for students of all ages. Training was provided by a member of the American Cancer Society. Guest speakers included the County Executive and the mayors of several municipalities. Thirty-six school nurses and health educators from several school districts attended the conference and received professional development hours.

Southern New Jersey: **Burlington, Camden, and Gloucester Tri-County Event—“The Big C: Current Trends in Cancer Control:”** Burlington, Camden, and Gloucester counties’ Tri-County Workgroup collaborate to address cancer issues in southern New Jersey. These three counties hosted an educational event for primary care providers in their region in April 2006, The Big C: Current Trends in Cancer Control. Attendees were awarded continuing medical education credits. Speakers included representatives from the OCCP and the Task Force. The event was supported by all three counties’ Cancer Coalitions, hospitals, health departments, and a pharmaceutical company. The workgroup plans to organize other regional events in the future.

### **Use of C/NA Findings**

All 21 county cancer coalitions currently are mandated by OCCP to utilize findings from their respective County Cancer Capacity and Needs Assessment (C/NA),<sup>ii</sup> to prioritize and address cancer needs in their counties. The county cancer coalitions have been developing appropriate initiatives and raising awareness about the C/NA findings among local organizations and local legislators through various mechanisms. These include collaboration with representatives of their county and local health departments, LINC agencies, community and faith-based groups, schools, League of Women Voters, health care providers, mayors, county executives and freeholders, and local and state legislators.

In addition, all coalitions are in the process of developing their own web sites to increase their visibility in their communities, to create opportunities for collaboration, to increase awareness of their missions, to promote their activities, and to highlight cancer-related resources in their counties. For example, the Essex County Cancer Coalition’s web site ([www.umdnj.edu/EssCaWeb/](http://www.umdnj.edu/EssCaWeb/)) describes its mission and goals, provides cancer statistics for the

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<sup>ii</sup> All County Cancer C/NA Report Summaries and Fact Sheets are available online at [www.njcancer.gov](http://www.njcancer.gov).

county based on the C/NA and links to other cancer resources, and maintains a county-wide calendar of cancer-related activities such as screening events and health fairs.

A sample of utilization of the C/NA findings in coalition efforts is described below.

The **Hunterdon County** Cancer Coalition has prioritized sun safety in its endeavors, since the Hunterdon County C/NA identified that the county had high incidence and mortality rates of melanoma. To address the burden of melanoma, the Coalition formed a Skin Cancer Workgroup, which is developing social marketing campaigns and materials addressing sun safety and skin cancer.

The **Somerset County** Cancer Coalition has conducted outreach to hundreds of people (families, children, corporate employees) to provide skin cancer awareness sessions, which incorporated utilization of the Dermaview skin analyzer in conjunction with one-on-one education on the importance of early detection of skin cancer and performing self examinations.

One goal of the *Chronic Illness Coalition of Cape May* is to continue outreach to the uninsured and underinsured population, based on recommendations from its county's C/NA. One outreach activity this Coalition has conducted toward achieving this goal is to increase awareness of the availability of free or reduced-cost cancer screenings. Many gasoline station employees do not have health insurance because their employers do not offer it. Similarly, many real estate agents are uninsured because they are independent agents and are responsible for obtaining their own health insurance. Both gasoline station employees and real estate agents either cannot afford or decide not to pay for health insurance premiums. Thus, the Coalition mailed information on free or reduced-cost cancer screening to gasoline stations and real estate agents in the region.

The **Essex County** C/NA identified oral, cervical, and prostate cancers as priorities, as the county has the highest mortality rates for these cancers among all 21 counties. To begin to increase awareness about oral cancer, the Coalition recruited an oral cancer specialist and collaborated with the Oral Cancer Consortium and the UMDNJ-New Jersey Dental School to conduct a health fair, in conjunction with Oral Cancer Screening Day on April 20, 2006. Over 150 people were educated about cancer prevention and early detection for all seven priority cancers, and were also screened for oral cancer.

Similarly, the **Hudson County** Cancer Coalition's 2006 cancer project, "2006: A New Year, A New You Campaign" described above, was informed by findings from its C/NA.

## EVALUATION

During April–June 2006, the OCCP performed an audit of each coalition to assess its infrastructure and management, fulfillment of state-mandated requirements, and deliverables (mission statement, action plan, organizational chart, quarterly reports, etc.). In addition, all coalitions are required to submit quarterly reports to the OCCP. These reports consist of a narrative report, outlining progress in implementing the coalition's action plan and any coalition-building activities (e.g., recruitment of new members, formation of new partnerships, etc.), and a grant progress report, quantifying progress towards the coalition's goals and objectives. Minutes from quarterly coalition meetings and all committee/workgroup meetings from that period, membership rosters, and budget expenditure reports are submitted with each quarterly report. All 21 county cancer coalitions have submitted narrative reports for the period ending June 2006.

The OCCP reinforces the importance of conducting evaluation with the coalitions. In addition to an annual assessment of its membership, mission, and action plan, coalitions are encouraged to evaluate their activities and are required to conduct process evaluation at each quarterly meeting. Twenty of the 21 coalitions consistently performed process evaluation at each quarterly coalition meeting.



## Section 4 – Outcome Evaluation

Key long-term goals of comprehensive cancer control efforts focus on reducing cancer burden. This is most often measured by incidence and mortality, but also by the occurrence of modification of risk factors such as a reduction in smoking and an increase in physical activity, which are objectives in *Healthy New Jersey 2010*. Changes in risk factor behaviors and cancer screening behavior, as assessed through standardized measures such as the Behavioral Risk Factor Surveillance System (BRFSS), may begin to be discernable in coming years, but are outside the timeframe for this current evaluation period.

The impact of increased outreach through the county cancer coalitions and the New Jersey Cancer Education and Early Detection Program will be addressed in a preliminary fashion in the following section. However, it is anticipated that a more complete assessment of cancer screening, as well as self-reported screening behavior, through sources such as BRFSS, will be conducted in future assessments, as feasible based upon the data available.

### **A. Cancer Screening**

The New Jersey Cancer Education and Early Detection Program (NJCEED) provides free breast, cervical, colorectal, and prostate cancer screening to low-income individuals, those whose income is at or below 250% of the federal poverty level. In addition, eligible individuals must be uninsured or underinsured and aged 40 to 64 years (18 and over for cervical cancer screening). NJCEED receives federal (CDC) funding for breast and cervical cancer screening, sufficient for approximately 12% of the eligible population. Funding that covers an additional 6% of the eligible population is provided by the New Jersey Department of Health and Senior Services (NJ-DHSS). Therefore, the total amount of funding limits breast and cervical screening to approximately 18% of the eligible population. Total funding available for colorectal and prostate cancer screening is less, as there is no federal funding.

Based upon the timing of this report, limited data were available. Thus, a preliminary assessment of only breast cancer screening is provided below, with a discussion of a more in-depth analysis that is anticipated based on additional data becoming available in the future. Furthermore, it is acknowledged that there are many factors that may contribute to increased screening, such as increased advertising by the NJCEED program and other comprehensive cancer control interventions. At the same time, however, health interventions are most successful when multiple approaches are used, and the collaboration between the county cancer coalitions and the 25 NJCEED lead agencies is certainly critical to the success of the NJCEED program. An important aspect of comprehensive cancer control programs is the increased efficiency achieved by enhanced cooperation and decreased duplication of similar efforts, further complicating attributing improvement to single factors.

## NJCEED MAMMOGRAPHY SCREENING<sup>jj</sup>

The NJCEED Program has shown considerable success in mammography screening. Since Fiscal Year (FY) 1996, a total of 63,922 new women have been enrolled in NJCEED — 46.1% Hispanic, 28.4% white, 17.1% black, 4.7% Asian/Asian Pacific Islander, and 10.3% other.<sup>kk</sup> NJCEED reported that the number of women enrolled annually by the 25 NJCEED lead agencies has shown a strong increasing trend, with an average annual increase of 19% in new enrollees. NJCEED has also been successful at focusing on women 40 and above, with 77.5% of enrollees in this age range, and 35% of the total aged 50-64.

**Table 4.1: Counts of New Enrollees in NJCEED by Year\***

Fiscal Year	Number of new enrollees	Total Screening Mammograms Performed Among Women Aged 40–64
2000	4,230	
2001	5,680	7,314
2002	7,313	8,262
2003	6,707	7,034
2004	7,390	9,238
2005	10,460	11,923

\* Data extracted from NJCEED CaST database on March 6, 2006 by NJCEED.

Since FY 1996, NJCEED has performed 76,668 screening mammograms, and of these, 61,299 (80%) were performed since FY 2000. In FY 2005, the most recent year for which complete data are available, 11,923 women aged 40–64 received a screening mammography, the highest number in the program's history. In addition, 75,749 clinical breast examinations were performed from FY 2000 to FY 2006.

The U.S. Census estimates that on July 1, 2004, the number of women in New Jersey aged 40-64 was 1,418,947. NJDHSS estimates that of these women, 83,333 were uninsured and below 250% of the federal poverty level and hence eligible for NJCEED. The number of women screened with mammography in FY 2004 was 9,238 or 11% of the 83,333 eligible women, which is in line with the CDC's funding levels.

A total of 660 cases of invasive cancer or carcinoma *in situ* had been found, of which 427 were invasive and the remaining 233 were lobular carcinoma *in situ*, ductal carcinoma *in situ*, or carcinoma *in situ*. One third of the cancer cases were in women 50-64 years old. As discussed in the 2004 Status Report, further data concerning the trends for lobular carcinoma and carcinoma *in situ* will be important. Epidemiologic data suggest that there is a need for changes in current prevention efforts, such as strategies aimed at reducing the use of continuous combined hormonal replacement therapy by women and reassessing the efficacy of current screening approaches.

<sup>jj</sup> Based on a data provided in a presentation by NJCEED to the Breast Cancer Workgroup on March 13, 2006. It is recognized that these are only preliminary data. More extensive data from NJCEED have been requested by OCCP based upon recommendations from the Evaluation Committee.

<sup>kk</sup> Categories are not mutually exclusive.

## **FUTURE ASSESSMENT OF SCREENING DATA**

The county cancer coalitions play an important role in improving access to screening among the medically underserved. The strong partnerships with the NJCEED lead agencies are vital to effective realization of the missions of both entities. To more fully evaluate their accomplishments toward this end, it would be helpful to review a tabulation of the numbers of persons screened for each cancer over time through the NJCEED program. Future assessments of the Plan's effectiveness in contributing to the goal of increased screening of underserved populations will be facilitated by the availability of quarterly data on the number of persons actually screened and of numbers of screenings funded, both statewide and broken down by NJCEED lead agency. The Evaluation Committee has submitted to the OCCP a detailed request for these data from NJCEED. Such collaboration with NJCEED in the compilation and review of these data would be of considerable value in showing how the Task Force's goals are being accomplished. For instance, these data may be of value for such purposes as evaluating the adequacy of funding, the determinants of the numbers and demographics of persons screened or otherwise assessed by NJCEED, and any longer-term trends and seasonal or local variation in the success of NJCEED in reaching its populations of focus and hence in accomplishing those strategies of the Plan that benefit from NJCEED's efforts.

- ❖ We recommend that the NJDHSS facilitate the development of data that can be used to assess all current cancer screening efforts by NJDHSS programs.

Given the ongoing concern about health disparities in New Jersey, matching these screening data with statewide and county-level demographic data can help determine whether progress is being made toward reaching the targeted proportions of the eligible population.

The OCCP is exploring the feasibility of collecting data from county cancer coalitions on all local screening efforts to better understand the full impact of the coalitions' activities. It should be noted that reasons for changes in screening rates over time, both secular and seasonal, may be multifactorial, and that it may be useful to conduct a formal research project to identify these factors and their relative effects.

## **USE OF SURVEY DATA**

A key goal for comprehensive cancer control is an increase in all screening efforts in each county. The ongoing New Jersey Behavioral Risk Factor Survey (NJ BRFS), which is a component of the national Behavioral Risk Factor Surveillance System (BRFSS) sponsored by CDC, provides estimates of the prevalence of cancer screening and cancer-related risk factors among New Jersey adults (see <http://www.state.nj.us/health/chs/brfss.htm> ). With an adequate sample size, this survey can also provide such estimates at the county level, providing a potentially valuable tool for assessing these screening efforts, but budgetary limitations on the number of interviews may preclude adequate analysis to examine trends due to the limited sample size.

As indicated in the 2004 Status Report, the State Epidemiologist<sup>II</sup> was able to obtain matching funds for the annual BRFSS in 2002, which made it possible to roughly double the sample size of the NJ BRFS (to approximately 1,000 interviews per month) starting in 2003. It thus became possible to establish an annual quota of 500 interviews for each New Jersey county (with Cumberland and Salem Counties combined) plus New Jersey's two largest municipalities

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<sup>II</sup> Eddy Bresnitz, MD, MS

(Newark and Jersey City). This minimum sample size is consistent with the reporting criteria for CDC's SMART BRFSS project (<http://apps.nccd.cdc.gov/brfss-smart/SelMMSAPrevData.asp> ), which provides BRFSS results for selected metropolitan and micropolitan statistical areas with 500 or more respondents. This funding was renewed through fiscal year 2005, making it possible to continue with the doubled sample size through the first half of 2006.

Thus, NJDHSS supported a significant increase in the number of BRFSS interviews beyond that funded directly by the CDC for those time periods. These data from 2005 and 2006 will provide more reliable baseline county-level assessments than were previously available. However, the NJDHSS has not so far allocated supplemental funding for the New Jersey Behavioral Risk Factor Survey in fiscal year 2007.<sup>mm</sup> In the absence of such funding, unfortunately, the annual sample size can be no more than 350 completed interviews per county on average, which does not meet conventional standards for reporting. The sample size is an issue especially relevant to assess county-level cancer control efforts

If the increased sample size were sustained, then NJ BRFS data would prove more useful over time in tracking improvements related to the Plan's activities and in somewhat better identifying populations of focus at the municipal and local levels. However, the sample sizes and relatively wide confidence limits would still restrict interpretation to identifying very large differences. Thus, additional support for an expanded number of interviews is warranted to enable over-sampling of priority population groups (including priority geographic regions), to facilitate analysis of trends over time, and to identify populations for which resources may need to be targeted.

## **B. Short-term Outcomes**

Since January 2005, over 400 reports and other pertinent documents, including membership rosters, meeting minutes, process evaluation forms, have been generated by the following groups to support and document implementation efforts in New Jersey:

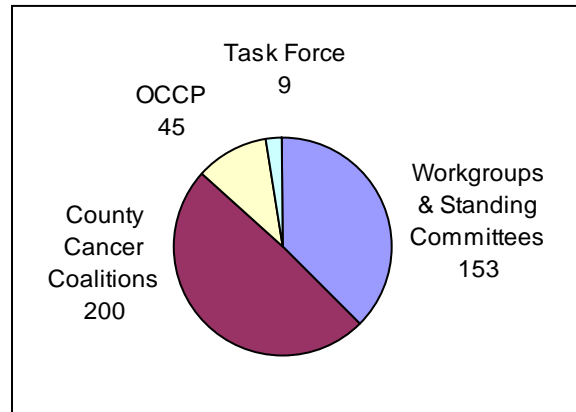
- OCCP and its Consultants
  - Evaluation Team
  - Battelle Centers for Public Health Research and Evaluation
- Task Force Workgroups and Standing Committees
- County Cancer Coalitions

Figure 4.1 below shows an approximate breakdown of the number of reports and documents generated by each major group with the comprehensive cancer control efforts in New Jersey.

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<sup>mm</sup> The NJBRFS does receive supplemental funding (beyond what CDC provides) in much smaller amounts (\$50,000 per year) from the tobacco control program, as well as a pass-through of \$10,000 each in federal funds from the asthma and diabetes programs.

**Figure 4.1 – Number of Reports and Documents in Support of Implementation**



These various documents convey a wealth of information, demonstrating the extent of activities by these groups. A sample of activities of the workgroups, standing committees, and county cancer coalitions is described below.

The **Childhood Cancer** Workgroup planned and implemented the first conference on childhood cancer survivorship in New Jersey. The workgroup partnered with the Lance Armstrong Foundation to host the conference, which was held in May 2005 and drew 120 attendees. Some of the critical issues related to childhood cancer survivorship addressed in this conference include empowerment and survivor rights; educational challenges; fertility issues; pediatric obesity; and late consequences of cure of childhood cancer.

The **Nutrition/Physical Activity** Workgroup has applied for New Jersey to be designated a Fruit and Vegetable State, which carries a \$1M federal appropriation to underwrite a statewide healthy snack effort.

The **Palliation** Workgroup is developing three regional forums to promote a broader definition of palliation, as care that should begin at diagnosis and not just end-of-life care. The focus of the forums is to inform healthcare providers of symptom management utilizing the holistic approach, including complementary and alternative medicine techniques.

The **Breast Cancer** Workgroup is focusing efforts to increase awareness and advance the empowerment of breast cancer population under 40 years.

The **Cervical Cancer** Workgroup collaborated with the NJDHSS on a statewide conference on “HPV Vaccine to Prevent Cervical Cancer: Scientific & Implementation Issues” in May 2006. The Workgroup is currently developing a position statement on the newly FDA-licensed HPV vaccine.

The **Colorectal Cancer** Workgroup held the First Annual New Jersey Colorectal Cancer Screening Conference, “Taking Action to Save Lives,” in September 2005. Some of the key issues addressed during this conference are: understanding and overcoming barriers to colorectal cancer screening in primary care; barriers to screening among physicians, patients, and in the Hispanic population; health communication competencies; and strategies to increase screening. The Colorectal Cancer Workgroup is using the Dialogues for Action model and planning its next conference underwritten through funding from the American Cancer Society.

In conjunction with the Mercer County Cancer Coalition and the NJCEED program, this workgroup helped plan a kick-off event for “Body & Soul: A Celebration of Healthy Living Campaign” in March 2006.

The **Lung Cancer** Workgroup was integral to the successful advocacy efforts for passage of the New Jersey Smoke-Free Air Act. The Lung Cancer Workgroup is now focused on increasing funding for the Comprehensive Tobacco Control Plan and is also engaging the pharmaceutical industry in its proposed oncology treatment plan and the inclusion of tobacco cessation where evidence has demonstrated better outcomes when smoking cessation is initiated.

The **Melanoma** Workgroup has focused on expanding its Train the Trainer project by providing resources to the educational community – school nurses, health and physical education teachers, recreation and dance educators, and coaches – not just on skin cancer, but also on all other school-based cancer education initiatives found in the Plan. Through recent in-kind support by the Mollie Biggane Foundation, this workgroup facilitated the distribution of 2,600 sun safety DVDs to middle schools and high schools throughout New Jersey through the county cancer coalitions.

The **Oral/Oropharyngeal Cancer** Workgroup focuses on increasing oral cancer screening and education to benefit New Jersey as well as across the nation. Recently, the workgroup petitioned and testified before the American Dental Association in an attempt to unbundle reimbursement for oral cancer screening. They are now focused on developing national oral cancer screening guidelines in conjunction with the American Academy of Oral Medicine.

The **Prostate Cancer** Workgroup has increased the network of medical centers in New Jersey involved in the national Barbershop Initiative, which engages the local community through barbershops, healthcare systems, and the NJCEED program to increase awareness about prostate cancer within the African-American population.

The **Advocacy Ad Hoc** Committee’s efforts on the passage of the New Jersey Smoke-Free Air Act came to fruition when the law was enacted in April 2006. Its current efforts include continuing to advocate for the inclusion of casino gaming areas in this law, and for continued funding of cancer initiatives through the budgetary process.

The **Evaluation Committee** submitted an evaluation plan for the first five-year implementation period of the Plan. Its efforts were heavily focused on approval of the County Cancer Capacity and Needs Assessment Report Summaries, which were released in September 2005, as well as compiling statewide recommendations from those summaries.

The **Funding and Resources Committee** has obtained funding from outside organizations, including the 2004 Cooperative Agreement from the Centers for Disease Control and Prevention, and continues to seek funding for various activities and events.

The **Atlantic County** Cancer Coalition, also known as The Atlantic County Healthy Living Coalition, is committed to educating the community and healthcare providers on the importance of a healthy lifestyle through prevention, early detection, treatment, and support services to improve the health of the residents of Atlantic County. The Healthy Lifestyle Committee is coordinating a walk among several towns in the county. A formal presentation was made to city council regarding the walk, which will have media coverage for a proposed 4 month program. Walks will take place Saturday mornings along walking paths with record keeping of all miles walked. The town who walks the most miles wins; an awards ceremony is planned.

The **Bergen County** Cancer Coalition is building a coalition that represents major decision makers in the county and expanding activities through awareness of the cancer continuum: prevention, early detection, treatment, and survivorship. Activities will incorporate the physical, social, spiritual and wellness components of cancer care. In June 2006, the Bergen County Red Bulls soccer team hosted a health fair prior to one of their games. There were educational exhibits, a derma scan, and a cancer screening van. Free tickets were available for 180 children so that they would be able to attend, with a focus on youth issues such as healthy eating, exercise, skin cancer, tobacco use, and cervical and testicular cancer.

The **Burlington County** Cancer Coalition is focused on supporting cancer prevention, education, early detection, treatment and advocacy for all county residents to help reduce the cancer burden. In addition to co-hosting the tri-county event, "The Big C: Current Trends in Cancer Control," in April 2006, this coalition also held a mother/daughter luncheon in May 2006. The luncheon, "What Do We Tell Our Daughters?" hosted by Lourdes Medical Center of Burlington County, was attended by 53 women and focused on breast cancer awareness and education. The Coalition's Health Education work group helped launch the Barbershop Initiative in May 2006.

The **Camden County** Cancer Coalition is working on a "Worksite Wellness" initiative which encourages large employers to offer free cancer screenings and smoking cessation programs. The Camden County Cancer Coalition's Eliminating Health Disparities work group developed and launched their "Get Screened, Stay Healthy, Stay Alive" project, in collaboration with the Camden County Health Department, in April 2006.

The **Cape May County** Cancer Coalition, also known as The Chronic Illness Coalition of Cape May, is educating healthcare providers and citizens about prevention, early detection and support services to improve the lifestyle of Cape May County residents in regards to chronic disease, particularly cancer. The Coalition launched the "Find the 5,000" project to identify the estimated 5,000 Cape May County residents living with an undiagnosed health condition. The Coalition has enlisted the help of the Chamber of Commerce to get small businesses to participate in this campaign; cancer screening posters are being displayed throughout the county. The campaign has attracted media coverage including print and broadcast features.

The **Cumberland County** Cancer Coalition is focused on disseminating findings of its 2004 Cancer Capacity and Needs Assessment; aligning members of the coalition in work groups; and identifying and implementing research tested intervention programs to reduce mortality in Cumberland County. The Coalition is hosting an ongoing smoking cessation program for county residents. Area physicians have been provided with laminated smoking cessation quick-reference cards to hand out in their offices. The Coalition plans to extend the program into the state prison.

The **Essex County** Cancer Coalition is increasing cancer awareness and reducing the impact of cancer on all Essex County residents through improved education, screening, access to treatment and follow-up. The Coalition organized and hosted a one-day Health Fair in April 2006, in conjunction with the Oral Cancer Workgroup and the Oral Cancer Consortium, UMDNJ, and NJCEED. Free oral cancer screenings were provided to over 150 attendees. In addition, since June 2005, the Coalition has maintained a monthly community calendar of cancer-related events (i.e., cancer screenings, education symposiums, and support groups) in and around Essex County (as discussed under "Use of C/NA Findings.") The calendar is continually updated and available electronically on the Coalition's web site ([www.umdnj.edu/EssCaWeb](http://www.umdnj.edu/EssCaWeb)) in



















