### CONNECTICUT CANCER CONTROL PLAN 2001-2004

State of Connecticut Department of Public Health

## **Connecticut Cancer Control Plan 2001-2004**

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### **Table of Contents**

	Page No.
Preliminary Pages	
Table of Contents	ii
List of Tables	iii
List of Graphs	iv
Executive Summary	1
Introduction	6
Part 1: The Burden of Cancer	9
Cancer in the United States	9
Issues and Trends	9
Disparities	10
Cancer in Connecticut	11
Overview of Major Cancer Sites in Connecticut	12
Defining Cancer Control and its Prevention Entities	20
Cancer Control at the Population Level	20
Primary Prevention Initiatives	22
Cancer Risks	22
Lowering Risks	23
Major Risk Factors	23
Genetic Testing and Prevention	29
Secondary Prevention Initiatives	30
Screening	30
Barriers to Early Detection of Cancer	36
Opportunities	37
Part II: Connecticut Cancer Control Plan: Goals, Objectives and	
Interventions: 2001-2004	39
Lung Cancer Control Plan for Connecticut	40
Breast Cancer Control Plan for Connecticut	55
Colorectal Cancer Control Plan for Connecticut	76
Conclusions	90
References	93

### List of Tables

Table 1 Comparison of Various Cancer Prevention Goals and Current Behavior Risk Factor Status of Connecticut Residents		Page No. 8
Table 2	Connecticut's Racial and Ethnic Make-Up	11
Table 3	Age-Adjusted Death Rates for All Cancers, Connecticut Residents, 1993-1997	11
Table 4	Age- Adjusted Invasive Cancer Incidence Rates, Connecticut Residents, 1995	12
Table 5	Breast Cancer Screening Recommendations	32
Table 6	Cervical Cancer Screening Recommendations	33
Table 7	Lung Cancer Screening Recommendations	33
Table 8	Colorectal Cancer Screening Recommendations	34
Table 9	Prostate Cancer Screening Recommendations	35
Table 10	Skin Cancer Screening Recommendations	35
Table 11	Prevention Strategies for Six Cancer Sites	36
Table 12	Breast Cancer Screening Recommendations	64
Table 13	Barriers to Breast Cancer Screening	65
Table 14	Connecticut Breast Cancer Screening Rates (1996-1997)	70
Table 15	Colorectal Cancer Screening Recommendations	82
Table 16	Connecticut Colorectal Cancer Screening Prevalence Rates for Adults 50 and Older	84
Table 17	Comparison of Various Cancer Prevention Goals and Current Behavior Risk Factor Status of Connecticut Residents	91

## List of Graphs

		Page No.
Graph 1	Lung Cancer Incidence for Connecticut Residents	13
Graph 2	Lung Cancer Mortality for Connecticut Residents	13
Graph 3	Breast Cancer Incidence for Connecticut Residents	14
Graph 4	Breast Cancer Mortality for Connecticut Residents	14
Graph 5	Colon Cancer Incidence for Connecticut Residents	15
Graph 6	Colon Cancer Mortality for Connecticut Residents	15
Graph 7	Rectal Cancer Incidence for Connecticut Residents	16
Graph 8	Rectal Cancer Mortality for Connecticut Residents	16
Graph 9	Melanoma Incidence for Connecticut Residents	17
Graph 10	Melanoma Mortality for Connecticut Residents	18
Graph 11	Cervical Cancer Incidence for Connecticut Residents	18
Graph 12	Cervical Cancer Mortality for Connecticut Residents	19
Graph 13	Prostate Cancer Incidence for Connecticut Residents	19
Graph 14	Prostate Cancer Mortality for Connecticut Residents	20
Graph 15	Current Smoking by Age, Connecticut Adults, 1996-1997	24
Graph 16	Current Smoking by Race/Ethnicity, Connecticut Adults, 1996-1997	24
Graph 17	Nutrition Knowledge by Race/Ethnicity, Connecticut Adults, 1997	26
Graph 18	Consumption of High Fat Foods, Connecticut Adults, 1996	26
Graph 19	No Leisure Time Physical Activity, Connecticut Adults, 1989-1996	27

## List of Graphs

Graph 20	Overweight by Body Mass Index, Connecticut Adults, 1989-1996	Page No. 28
Graph 21	Lung Cancer Incidence for Connecticut Residents	45
Graph 22	Lung Cancer Mortality for Connecticut Residents	46
Graph 23	Current Smoking by Age, Connecticut Adults, 1996-1997	47
Graph 24	Current Smoking by Race/Ethnicity, Connecticut Adults, 1996-1997	47
Graph 25	Breast Cancer Incidence for Connecticut Residents	61
Graph 26	Breast Cancer Mortality for Connecticut Residents	62
Graph 27	Mammography and CBE by Race/Ethnicity, Connecticut Women, 40 and Older, 1996-1997	70
Graph 28	Mammography and CBE by Income, Connecticut Women 40 and Older, 1996-1997	70
Graph 29	Colon Cancer Incidence for Connecticut Residents	79
Graph 30	Colon Cancer Mortality for Connecticut Residents	80
Graph 31	Rectal Cancer Incidence for Connecticut Residents	80
Graph 32	Rectal Cancer Mortality for Connecticut Residents	81

### Connecticut Cancer Control Plan 2001-2004 Executive Summary

This is the first phase of the Connecticut Cancer Control plan developed through the Connecticut Cancer Consortium. Four of the major health institutions in the state, State of Connecticut Department of Public Health, University of Connecticut Health Center, Yale University Cancer Center, and the Connecticut Medical Society, recognizing that there was fragmentation related to cancer prevention and control activities in the state and that collaboration is important to achieving its goal for the State plan, organized themselves to form the Connecticut Cancer Consortium. The overall purpose of the Consortium is to coordinate its efforts to reduce the burden of cancer through appropriate surveillance and research goals, effective prevention and control services, program and policy development, and regulatory measures.

Cancer is the second leading cause of death in Connecticut, accounting for about one-fourth of all deaths to residents each year. Six cancer sites were identified to be addressed during this period of plan development. The six cancer sites were chosen based on incidence and mortality in the Connecticut population as well as the existence of scientifically based cancer prevention and control intervention strategies and include: lung, breast, colorectal, cervical, melanoma, and prostate. Because lung, breast, and colorectal are among the most common cancers in Connecticut, these three cancer sites were the primary sites initially addressed by the Connecticut Cancer Consortium. Subgroup committees were developed for each of the three cancer sites and the following goals were formulated.

- 1. Reduce the initiation of tobacco products by youths
- 2. Increase the rate of successful cessation
- 3. Eliminate environmental risk factors for lung cancer including exposure to environmental tobacco smoke
- 4. Increase consumer and clinician knowledge of clinical trials available for prevention and early detection of lung cancer
- 5. Promote clinician knowledge of appropriate use of breast and colorectal cancer screening and follow-up activities
- 6. Promote consumer knowledge of appropriate use of breast and colorectal cancer screening and follow-up activities
- 7. Promote mammography quality assurance
- 8. Promote better understanding of genetic testing for breast cancer and to ensure that test results are kept confidential and not used to discriminate against individuals who are tested

Cancer control encompasses prevention, screening, effective treatment, access to care, support services, survivorship, and end of life issues. For purposes of this plan, however, primary and secondary prevention activities were targeted.

*Primary prevention* is defined as the steps taken to prevent a disease from ever happening by limiting exposure to agents that may cause cancer. Since a majority of

cancers are determined by lifestyle, a principal means of preventing cancer involves changing people's habits. Epidemiologic studies show a positive relationship between specific cancers and identifiable risk factors. Major modifiable risk factors contributing to cancer include tobacco use, inadequate diet, physical inactivity, exposure to ultraviolet radiation, and exposure to occupational and environmental chemicals.

#### Genetic Testing and Prevention

Over the past decade, there has been much learned about genes and how genetic mutations are linked to disease such as cancer. Tests are now available to provide information about an individual's risk or predisposition for developing some forms of cancer. This knowledge raises hopes of saving lives through prevention or early detection, but its also raises legal and ethical concerns for individuals, families and for society. As genetic testing moves from the research stage to public availability, these issues will become increasingly important. Testing is currently available for several genetic mutations. Mutations of the BRCA1 and BRCA2 genes are associated with an increased risk of breast and ovarian cancers. An increased risk for hereditary nonpolyposis colon cancer and familial adenomatous polyposis can also be determined by testing for certain genetic mutations.

Secondary prevention is defined as mass screening of asymptomatic people so that precancerous changes can be detected early enough to prevent cancer or to treat cancer at an early stage when it can be cured or treated successfully. Screening tests appear to be effective for breast, cervical, and colorectal cancer.

### **Key Findings for Cancer Sites**

#### Lung Cancer

Lung cancer is the leading cause of cancer deaths in Connecticut. About 90% of lung cancers may be preventable through abstinence from tobacco. Incidence and mortality rates declined among Connecticut males from 1980- 1994, but increased among women. The age-standardized lung cancer incidence rate in males was 79.1 per 100,000 per year during 1990-1994 as compared to 74.2 per 100,000 per year during 1995- 1997. In contrast, the age standardized lung cancer incidence rate in women was 45.3 per 100, 000 per year during 1990- 1994 as compared to 47.8 per 100, 000 per year during 1995- 1997.

Current cigarette smoking among adults in Connecticut aged 18 and older was 21.8 percent in 1997 as compared with 23.2% for all states within the United States. Women and men in Connecticut had comparable smoking prevalence rates (22.2 vs. 21.4%). Smoking rates in Connecticut, however, varied by age, educational level and ethnicity such that those aged 18-24 years had higher prevalence of smoking than those 35-44, 45-64 and over 65 years (33.7, 25.2, 18.2 vs. 12.5%), and those with less than a high school education had higher rates of smoking prevalence as compared with those with a high school or greater than a high school level of education (29.1, 26.5 vs. 15.8%). Hispanics had higher rates of smoking prevalence as compared with blacks, Asian/Pacific Islanders and whites (30.7, 26.9, 23.2 vs. 20.9%). Prevalence of cigarette smoking among

youths in grades 9 through 12 is high; 35.2% reported smoking during the past month and 17.9% were frequent smokers. It is important to note that prevalence of smoking among high school youths in Connecticut is high and increases in prevalence rates between grades 9 and 12 have been noted such that 26.7% smoked in grade 9 and 45.1% smoked in grade 12.

#### Breast Cancer

Breast cancer is the most common cancer diagnosed among Connecticut women and is the second leading cause of death from cancer. The risk of breast cancer may be modified by lower fat intake, higher fruit and vegetable consumption, increased physical activity, reduced body weight, and reduced alcohol intake. Nearly one-third of Connecticut breast cancers were detected at regional and distant stages, after some metastasis had occurred. Age standardized incidence rates increased in Connecticut from 1980-1984 through 1990-1994, and in 1990-1994 the rate was 115.9 per 100,000. Age standardized incidence rates were 119.3 per 100,000 women between 1995- 1997.

Mammography and clinical breast examination are important in reducing breast cancer mortality, through detection at an early stage. Overall breast cancer screening mammography rates in Connecticut are slightly better than rates reported by all states (22.0% vs. 26.8%). Although many women age 40 and older report that they have had a mammogram and clinical breast examination, the proportion of women who have had a recent mammogram and clinical breast examination (within the past year or two years) is much lower. This finding underscores the fact that women need to be encouraged or reminded to be re-screened at the proper intervals. Moreover, certain subgroups of women, black, Hispanic, and lower income individuals, are less likely to receive mammograms. Thus, these groups need to be targeted for screening.

#### Colorectal Cancer

Colorectal cancer is the third most commonly diagnosed cancer in Connecticut. Age standardized incidence rates decreased for both colon and rectal cancers in men and women in Connecticut from 1980-1984 through 1990-1994, and in 1990- 1994 the colon cancer incidence rate was 42.8 per 100,000 for males and 30.3 per 100,000 for females and the rectal cancer incidence rate was 19.1 per 100,000 for males and 11.4 for females. It appears that rates have continued to decrease for males but have leveled off for females from 1995- 1997 such that the age standardized incidence rate for colon cancer was 37.8 for males and 29.7 for females per 100,000 and age standardized incidence rates for rectal cancer were 17.4 for males and 11.5 for females. It is important to recognize that only 39% of colon cancers and 50% of rectal cancers were diagnosed at the in situ or invasive stage, when the 5 year survival is 90%. In contrast, the five-year survival rate for invasive colorectal cancers diagnosed in Connecticut residents is 62%.

Evidence supports screening for colorectal cancer among persons 50 years of age and older. Currently, Connecticut is below the median for all states for adults aged 50 and older who have not had a sigmoidoscopy within the past 5 years (64.9 vs. 70.0) and for not having had a fecal occult blood test within the past year (75.8 vs. 81.8). Although results from the Behavioral Risk Factor Surveillance Survey indicate that 31% percent of

Connecticut residents have had a fecal occult blood test within the past two years and 35 % have had a sigmoidoscopy within the past five years, only 13.2% have followed the American Cancer Society guidelines for colorectal cancer screening by having a fecal occult blood test within the past year and a sigmoidocopy within the past 5 years. Moreover, certain subgroups are less likely to have colorectal cancer screening. Among those aged 50 and older, non-whites were less likely than whites to have ever received sigmoidoscopy (27.0% versus 46.6% respectively). Results were similar for ever having had a fecal occult blood test, where 39.9% of whites had the test compared with only 20.8% of blacks and 22.8% of Hispanics. Men and women were equally likely to have each test, and utilization of each test increased with age up to the 65 and older age group, where 43.3% had had a fecal occult blood test and 53.8% had had a sigmoidoscopy. Thus, more progress toward colorectal cancer screening is needed within Connecticut.

#### Conclusions and Recommendations

The vision of the Connecticut Cancer Consortium is that, by working together, those involved in cancer-related issues can provide a framework for surveillance and research activities directed toward improving the health of Connecticut citizens.

During this phase of cancer plan development, three priority cancer sites were addressed by the Connecticut Cancer Consortium: lung, breast, and colon/rectum. These cancer sites were chosen because they are among the most common cancers that affect the residents of Connecticut and scientifically based cancer prevention and/or early detection interventions exist. Subgroup committees were formed for each of the cancer sites in order to identify effective prevention and early detection interventions and identify important goals for each cancer site that should be addressed in the next phase of the plan. It is hoped that this document will provide fertile ground for collaboration regarding surveillance and research activities among the various members of the Consortium.

Although Connecticut tends to fare better than other states in the United States regarding cancer risk and screening behaviors, much work remains in order to reduce the burden of cancer within the state. It is important to recognize that disparities exist among various age, racial and ethnic groups in Connecticut regarding cancer risk and screening behaviors. For example, smoking is higher among youth and adults ages 18 to 34 as compared with those over age 35. In addition, smoking is higher among black and Hispanic racial /ethnic minority groups. Breast cancer screening rates are lower among Hispanic women. Similarly, colorectal cancer screening is less for non-whites as compared to whites. An important next step in understanding the disparities within the state is to examine the geographical differences related to cancer outcomes such as incidence and mortality so these high-risk areas can be targeted for more intensive cancer control interventions.

The Consortium has identified goals, objectives, strategies, and tactics for each cancer site. Because resources are limited, priorities regarding each cancer site are identified so that efforts can be directed toward these goals initially. The priorities below were established based on the health priorities set forth by the Connecticut Department of

Public Health Assessment, Healthy People 2010 and data from the Connecticut Department of Public Health Cancer Surveillance Program, Behavioral Risk Factor Surveillance Survey and Youth Risk Behavior Survey describing the behavioral cancer risk factors of Connecticut residents.

- Lung cancer is the major cause of cancer death in both men and women in the state of Connecticut. The most important factor to decrease the burden of lung cancer is to prevent the initiation of smoking and also to promote smoking cessation among those who smoke. While the percentage of smoking adults has declined over the past ten years, smoking among youth is on the rise. Almost all smokers take up the habit before they are twenty. Youth smoking in Connecticut is high and efforts toward prevention of smoking and smoking cessation in this group should be targeted as a priority.
- Breast cancer is the most common cancer in Connecticut women and the second leading cause of cancer death. Although the proportion of Connecticut women having ever had a mammogram and clinical breast examination is high, rates for ongoing screening are much lower. Therefore, efforts directed toward increasing the proportion of women, especially among low income and racial and ethnic minority groups, who obtain repeat screening should be targeted as a priority.
- Colorectal cancer is the third most commonly diagnosed cancer in Connecticut and while detection and treatment of early stage cancers reduces mortality it is underutilized. Colorectal cancer screening has not received much attention. Because colorectal cancer screening has the potential to dramatically decrease mortality, increased attention should be directed toward improving screening among Connecticut residents.

#### **CONNECTICUT CANCER PLAN: 2001-2004**

#### Introduction

Many types of cancer can be prevented, and the prospects for surviving cancer are better than ever and continue to improve. Early detection and improved treatments are allowing more people who have been diagnosed with cancer to live longer and better.

The development of many cancers is related to personal lifestyles, behaviors, and the environment. Major risk factors contributing to cancer include the use of or exposure to tobacco products, inadequate diet, physical inactivity, exposure to ultraviolet radiation and the presence of cancer causing chemicals in the environment.

Cancer incidence rates are also influenced by the use of and the availability of tests for identifying the disease in its earliest stages. Regular screening examinations can detect cancer at a point when treatment is more likely to be successful.

Connecticut is fortunate to have excellent cancer treatment and research facilities, which provide the most advanced care. In addition, coordinated efforts at the state and community levels are dedicated to reducing the burden of cancer.

In this era of health care cost containment and limited funding, existing resources must be integrated and maximized if continued cancer prevention and control is to be achieved. A comprehensive approach is needed to identify statewide capacity for cancer prevention and control and to develop leadership needed to act on that capacity. This includes creating a partnership to identify and implement priorities and strategies and to evaluate outcomes.

Effective partnering requires organizations and individuals to make a sustained commitment to work together toward a goal. Such cooperation yields accomplishments not possible by agencies and organizations working independently. The unique skills and strengths of diverse individuals and organizations are necessary to create and initiate innovative approaches to the complex issues presented by cancer.

Four of the major health institutions in the state, State of Connecticut Department of Public Health, University of Connecticut Health Center, Yale University Cancer Center, and the Connecticut Medical Society, recognizing that there was fragmentation in the state related to cancer prevention and control activities and that collaboration is important to achieving its goal for the State plan, organized themselves to form the Connecticut Cancer Consortium. The overall purpose of the Consortium is to coordinate its efforts to reduce the burden of cancer through appropriate surveillance and research goals, effective prevention and control services, program and policy development, and regulatory measures. This Consortium is committed to developing and implementing a state-wide cancer prevention and control plan.

*Seven major assumptions* for the Cancer Prevention and Control plan have been outlined by the Consortium. The state wide plan will:

- Emphasize primary and secondary prevention.
- Be compatible with the goals and objectives of three existing documents: State of Connecticut's 1998 Health Assessment, the 1998 Cancer Report of the New England Coalition for Health Promotion and Disease Prevention (NECON) and the Healthy People 2010 of the US Department of Health and Human Services (See Table 1).
- Address cancers that pose the greatest burden to the state's population, either by incidence or mortality or disparity of populations.
- Emphasize those cancers for which procedures and practices are recognized and generally well accepted by the public and health care providers for preventing and controlling the disease.
- Take into account the many activities already underway in the state of Connecticut to prevent and control cancer, as well as recent public policy directives and opportunities (such as the tobacco settlement, and Department of Defense grants for cancer) that may significantly increase the availability of funds for cancer prevention and control programs.
- Promote effective collaboration, cooperation, and coordination of activities among other institutions and parties that will become part of this plan.
- Be a dynamic document reflecting the changing potential of cancer prevention and control efforts and the needs of Connecticut residents.

Six cancer sites have been identified to be addressed during this period of plan development. The six cancer sites chosen are based on incidence and mortality in the Connecticut population as well as the existence of scientifically based cancer prevention and control intervention strategies and include: lung, breast, colorectal, cervical, melanoma, and prostate. Because lung, breast, and colorectal are among the most common cancers in Connecticut, these three cancer sites will be the primary sites initially addressed by the Connecticut Cancer Consortium.

This document provides information about the Cancer Control Plan for Connecticut. Part one describes the burden of cancer both in the United States and in Connecticut, provides a definition of cancer control, and discusses issues related to cancer prevention and early detection. The second part of this document provides specific goals, objectives, and interventions for the primary cancer sites addressed by the Connecticut Cancer Consortium and provides suggestions for future development and implementation of the Connecticut Cancer Control Plan. Data related to Connecticut cancer incidence and mortality was obtained from the Connecticut Department of Public Health Tumor Registry and Vital Records Mortality Files. Data related to cancer behavioral risk factors was obtained from the Connecticut 1996-1997 Behavioral Risk Factor Surveillance Survey and the 1997 Youth Risk Behavior survey coordinated by the Centers for Disease Control and Prevention (Connecticut Department of Public Health, 2000) (see Appendix 2).

Table 1: Comparison of Various Cancer Prevention Goals and Current Behavior Risk Factor Status of Connecticut Residents

Cancer Site	Connecticut DPH Priorities	Healthy People (HP) 2010 (2)	Connecticut Rates according to BRFSS or YRSS* (3)
Breast	Improvement in rates of breast cancer screening and follow up	Increase the proportion of women age 50 and over to 70% who received a mammogram within the past 2 years	Mammography ever screening rates: White: 82.4% Black: 75% Hispanic: 65% Income less than 25K: 75% Mammography ACS guidelines 40 and over (51%) HP guidelines 50 and over (68%)
Colorectal	Improvement in rates of colorectal cancer screening and follow up	Increase the proportion of adults age 50 and older to 50% who receive a fecal occult blood test with the preceding two years and who have ever received a sigmoidoscopy	Adults who have met ACS guidelines: 13.2% Adults who have met HP guidelines: FOBT past yr 24% FOBT ever: Whites: 39.9% Blacks: 20.8% Hispanic: 22.8% Sigmoidoscopy ever 45% Whites: 27% Non-whites: 47%
Lung (Adult)	Prevention and cessation of tobacco use	Reduce the proportion of adults (18 and older) who use tobacco products to 13% by 2010	Current adult smoking: 21.7% White: 20.7% Black: 26.7% Hispanic: 31.2% Unemployed: 45%
Lung (Youth*)	Prevention and cessation of tobacco use	Reduce the proportion of youth who use tobacco products in grades 9 through 12 to 21% by 2010	Current student smoking: 35.2% Grade 12 students 45%

<sup>\*</sup> Youth data is obtained from YRSS and adult data is obtained from BRFSS. Data set information is explained in Appendix 2.

<sup>1=</sup>State of Connecticut, Department of Public Health (1999).

<sup>2=</sup>Healthy People 2010 (Retrievable online).

<sup>3=</sup>Connecticut Department of Public Health (2000).

#### Part I: The Burden of Cancer

#### Cancer in the United States

Cancer is the second leading cause of death in the United States. During 1999, an estimated 1,221,800 persons in the United States were diagnosed with cancer; 563,100 persons were expected to die from cancer (Landis, Murray, Bolden & Wingo, 1999). These estimates did not include most skin cancers, and new cases of skin cancer are expected to exceed 1 million per year. One-half of new cases of cancer occur in people aged 65 and over (Ries, Kosary, Hankey et al., 1999).

About 491,400 Americans who get cancer in a given year, or 4 in 10 patients, are expected to be alive 5 years after diagnosis. When adjusted for normal life expectancy (accounting for factors such as dying of heart disease, injuries, and diseases of old age), a relative 5 year survival rate of 60% is seen for all cancers (Landis, Murray, Bolden & Wingo, 1999). This rate means that the chance of a person recently diagnosed with cancer being alive in 5 years is 60 percent of the chance of someone not diagnosed with cancer. Five year relative survival rates commonly are used to monitor progress in the early detection and treatment of cancer and include persons who are living 5 years after diagnosis, whether in remission, disease free, or under treatment.

#### Issues and Trends

Cancer death rates for all sites combined decreased an average of 0.6 percent per year from 1990 to 1996 (Wingo, Ries, Giovino et al., 1999). This decrease occurred after rates had decreased by 0.4 percent per year from 1973 to 1990 (Wingo, Ries, Rosenberg, Miller & Edwards, 1998). Death rates for male lung, female breast, prostate, and colorectal cancers decreased significantly during the 1990-96 period (Wingo, Ries, Giovino et al., 1999). The lung and bronchus, prostate, female breast, and colon and rectum were the most common cancer sites for all racial and ethnic populations in the United States and together they accounted for approximately 54 percent of all newly diagnosed cancers (Landis, Murray, Bolden & Wingo, 1999).

In addition to the human toll of cancer, the financial costs of cancer are substantial (Brown, Hodgson & Rice, 1996). The overall annual costs for cancer are estimated at \$107 billion, with \$37 billion for direct medical costs (the total of all health care expenditures), \$11 billion for costs of illness (the cost of low productivity due to illness), and \$59 billion for costs of death (the cost of lost productivity due to death). Treatment for lung, breast, and prostate cancers alone accounts for more than half of the direct medical costs.

### **Disparities**

Cancer death rates vary by gender, race, and ethnicity (Wingo, Ries, Giovino et al., 1999). Male cancer death rates peaked in 1990 at 220.8 per 100,000 and female death rates peaked a year later at 142.2 per 100,000. After the peak year, through 1996, male cancer deaths for all sites decreased on average by 1 percent per year, and female death rates decreased on average by 0.4 percent per year. There were significant decreases in mortality for lung, prostate, brain, and other nervous system cancers in males and a significant decrease in breast cancer mortality for females (Wingo, Ries, Giovino et al., 1999). Among males, lung cancer death rates have declined since 1990. In contrast, lung cancer death rates have continued to increase among females. Since 1987, more females have died from lung cancer than breast cancer.

African Americans are about 34 percent more likely to die of cancer than are whites and more than two times more likely to die of cancer than are Asian/Pacific Islanders, American Indians, and Hispanics (Landis, Murray, Bolden & Wingo, 1999). African American women are more likely to die of breast and colon cancers than are women of any other racial and ethnic group, and they have approximately the same lung cancer mortality rates as white women. African American men have the highest mortality rates of colon and rectum, lung, and prostate cancers. Age adjusted lung cancer death rates are approximately 40 percent higher among African American males than white males. Little difference in age adjusted lung cancer death rates has been observed between African American and white females. The recent decrease in deaths from breast cancer in white females is attributed to greater use of breast cancer screening in regular medical care. However, new cases of breast cancer in African American females continue to increase, and deaths continue to increase as well, in part, because breast cancer is diagnosed at later stages in African American females (Landis, Murray, Bolden & Wingo, 1999). Data on colorectal cancer show a decline in new cases and death rates in white males and females, stable new case rates in African Americans and a continued rise in death rates in African American males. Five year survival rates are 64 percent in whites and 52 percent in African Americans (1989-1994). Early detection and treatment play a key role in these survival rates.

Hispanics have higher rates of cervical, esophageal, gall bladder, and stomach cancers. New cases of female breast and lung cancers are increasing among Hispanics, who are diagnosed at later stages and have lower survival rates than whites. Similarly, some specific forms of cancer affect other ethnic groups at rates higher than the national average (for example, stomach and liver cancers among Asian American populations and rectum cancer among Alaska Natives). Minority racial and ethnic groups have lower survival rates than whites for most cancers (Landis, Murray, Bolden & Wingo, 1999). Differences among the races represent both a challenge to understand the reasons and an opportunity to reduce illness and death and to improve survival rates.

#### Cancer in Connecticut

Cancer is the second ranked leading cause of death nationwide and in Connecticut. Similar to the United States, cancer incidence and mortality rates vary by race, ethnicity, and gender (Connecticut Department of Public Health, 1999). Table 2 provides information about the various racial and ethnic groups in Connecticut.

Table 2 Connecticut's Racial and Ethnic Make-up		
Whites		
*Hispanic includes all races Source: 1990 Census		

Among Connecticut residents in 1993-1997, African Americans had the highest rate of deaths due to cancer followed by whites, Native Americans, and Hispanics (see Table 3). Asian Americans and Pacific Islanders had the lowest rate of cancer deaths among the groups to be considered, but cancer was still their leading cause of death (Connecticut Department of Public Health, 1999).

Table 3
Age-Adjusted Death Rates for All Cancers, Connecticut Residents, 1993-1997

Race/Ethnicity (1)	Number of Deaths	Age Adjusted Death Rate (2)	Relative Risk (3) (Minority/White)
Total	35, 446	160.8	
African American	2, 138	199.2	1.3
Hispanic (4)	576	86.6	0.5
Asian American/PI	130	67.6	0.4
Native American (5)	39	128.2	0.8
White	33, 119	159.0	1.0

Sources: Connecticut Department of Public Health (1999), Connecticut Department of Public Health, Vital Records Mortality Files, U.S. Census Bureau Population Estimates, PE-65, 9/4/98.

1= There may be inaccuracies when estimating mortality rates by race/ethnicity because racial groupings (African American, Asian American/Pacific Islander, Native American, White) include persons of Hispanic ethnicity. Less than 1% of the mortality data are not classified by race or ethnicity. 2= rates are per 100,000 persons based on race and ethnicity specific population estimates. Age adjusted rates were calculated by the direct method using the 1970 U.S. standard million. 3= Relative risk is estimated to be the ratio of the minority group rate to the white rate. 4= Hispanic persons may be of any race. 5= Native American include American Indian and Alaska Native.

Estimated invasive (malignant) cancer incidence rates by gender among African Americans, Hispanics, and white Connecticut residents in 1995 are shown in Table 4. For all three racial ethnic groups, males had higher incidence rates than females. Among males, African Americans had higher incidence rates and whites the lowest, whereas among females, the opposite was true (Connecticut Tumor Registry, unpublished data). Because of the small numbers of invasive cancers among Asian Americans and Native Americans, data are not presented.

Table 4
Age-Adjusted Invasive Cancer Incidence Rates, Connecticut Residents, 1995

Race/Ethnicity (1)	Number of Cases	Age Adjusted Rate (2)	Relative Risk (3) Minority/White
African American	542	604.2	1.3
Males			
Hispanic Males (4)	263	479.2	1.0
White Males	7, 951	474.1	1.0
African American	389	294.8	0.8
Females			
Hispanic Females	246	306.5	0.8
White Females	7, 872	370.7	1.0

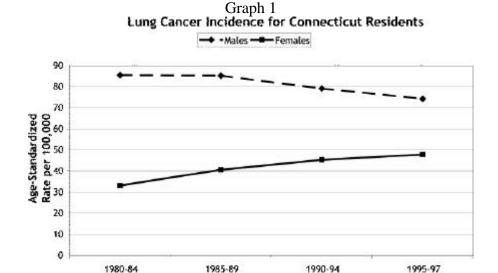
Sources: Connecticut Department of Public Health (1999), Connecticut Tumor Registry.

1= Racial groupings (African American and White) include persons of Hispanic ethnicity. 2= rates are per 100,000 persons based on race and ethnicity specific population estimates. Age adjusted rates were calculated using the age distribution of the total 1970 U.S. population as the standard. 3= Relative risk is estimated to be the ratio of the minority group rate to the white rate. 4= Hispanic persons may be of any race.

### Overview of Major Cancer Sites in Connecticut

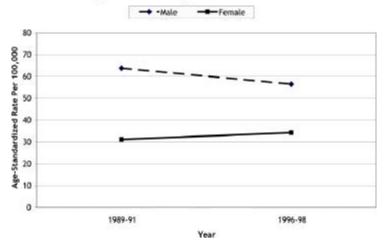
#### Lung Cancer

Lung cancer is the leading cause of cancer deaths in Connecticut. About 90% of lung cancers may be preventable through abstinence from tobacco. As the graphs below demonstrate, incidence and mortality rates declined among Connecticut males from 1980- 1997, but increased among women. The age-standardized incidence rate for lung cancer rate in males was 74.2 per 100,000 per year during 1995- 1997. In contrast, the age standardized lung cancer incidence rate in women was 47.8 per 100,000 per year during 1995- 1997.



Graph 2
Lung Cancer Mortality for Connecticut Residents

Years



Age- standardized incidence rates per 100,000 for lung cancer were higher for African American males (104.8) as compared with white males (77.9) between 1990 and 1995. In contrast, white females had a higher age standardized incidence rate per 100,000 (46.7) as compared with African American females (37.2) during the same time.

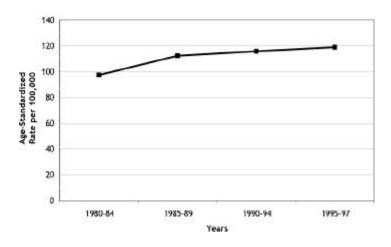
#### Breast Cancer

Breast cancer is the most common cancer diagnosed among Connecticut women and is the second leading cause of cancer deaths. The risk of breast cancer may be modified by lower fat intake, higher fruit and vegetable consumption, increased physical activity, reduced body weight, and reduced alcohol intake. Nearly one-third of Connecticut breast cancers were detected at regional and distant stages, after some metastasis had occurred. Mammography and clinical breast examination are important in reducing breast cancer mortality, through detection at an early stage. As the graphs below

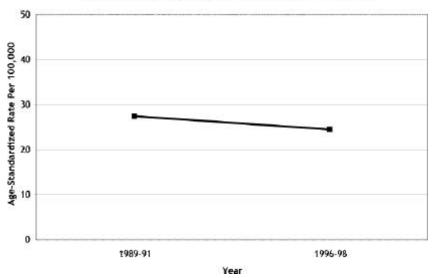
indicate, age standardized incidence rates increased in Connecticut from 1980-1984 through 1990-1994, and in 1990-1994 the rate was 115.9 per 100,000. Age standardized incidence rates have continued to increase such that the rate was 119.3 per 100,000 women between 1995- 1997. These increases may be due to increased utilization of screening programs among women. The Connecticut death rate for breast cancer is comparable to death rates in the United States (Centers for Disease Control, 1999a).

Graph 3

Breast Cancer Incidence for Connecticut Residents



Graph 4
Breast Cancer Mortality for Connecticut Residents



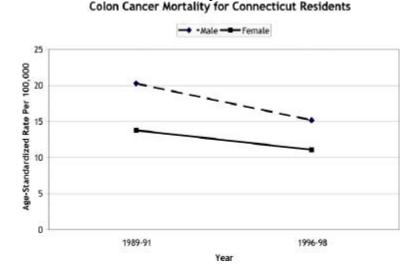
Breast cancer is one of only a few cancers that is associated with higher socioeconomic status. For most cancers, incidence rates are higher among those with a lower socioeconomic status. The higher breast cancer incidence among those with a higher socioeconomic status is due in part to reproductive history; that is, larger numbers of pregnancies and earlier age at first pregnancy are protective against breast cancer and tend to be less common in higher social classes. Social class differences are also involved

in African American-white breast cancer differences, although post-menopausal rates may be higher in whites than African American even within social classes (Baquet, Horm, Gibbs, et al, 1991). Differences in the age-standardized incidence rates per 100,000 vary among African American and white women in Connecticut such that African American women (89.8) had a lower incidence rate as compared with white women (119.5) between 1990-1995.

#### Colorectal Cancer

Colorectal cancer is the third most commonly diagnosed cancer in Connecticut. Evidence also supports screening for colorectal cancer among persons 50 years of age and older. As the graphs below indicate, age standardized incidence rates decreased for colon cancer in men and women in Connecticut from 1980- 1994, and in 1990- 1994 the colon cancer rate was 42.8 per 100,000 for males and 30.3 per 100,000 for females. It appears that rates have continued to decrease for males but have leveled off for females from 1995- 1997 such that the age standardized incidence rate for colon cancer was 37.8 for males and 29.7 for females per 100,000.

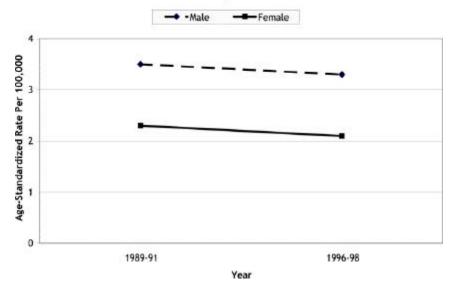
Graph 5



Age- standardized incidence rates per 100,000 for colon cancer were slightly higher for African American males (49.2) as compared with white males (42.0) between 1990 and 1995. No differences were evident between African American (30.1) and white (30.4) females.

Similar to colon cancer, the graphs below demonstrate that the age standardized incidence rates for rectal cancer decreased for men and women in Connecticut from 1980-1984 through 1990-1994, and in 1990-1994 the rectal cancer incidence rate was 19.1 per 100,000 for males and 11.4 for females. The rates have continued to decrease for men but have leveled off for women such that the age standardized incidence rates per 100,000 for rectal cancer were 17.4 for males and 11.5 for females.

Graph 8
Rectal Cancer Mortality for Connecticut Residents



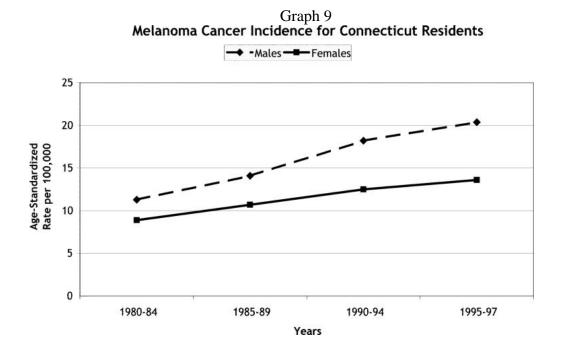
16

Age- standardized incidence rates per 100,000 for rectal cancer were slightly higher for white males (19.3) as compared with African American males (13.2) between 1990 and 1995. Similarly, white females (11.5) had slightly higher incidence rates as compared with African American females (9.1).

It is important to recognize that only 39% of colon cancers and 50% of rectal cancers were diagnosed at the in situ or invasive stage, when the 5 year survival is 90%. In contrast, the five-year survival rate for invasive colorectal cancers diagnosed in Connecticut residents is 62% (Connecticut Tumor Registry, 2000).

#### Melanoma

Melanoma of the skin is a growing public health problem, and in many cases may be prevented by modifying behavior (avoiding sun exposure) starting in childhood. As the graphs below indicate, age standardized incidence rates increased for both sexes in Connecticut from 1980-1984 through 1990-1994, and in 1990-1994 the rates were 18.2 and 12.5 per 100,000 population in males and females, respectively. Incidence varied by town, with higher than expected incidence in certain shore towns. Age standardized incidence rates continue to increase during 1995- 1997 such that rates were 20.3 per 100, 000 for males and 13.6 per 100,000 for females.



17

Graph 10
Melanoma Cancer Mortality for Connecticut Residents

30

000'001 30

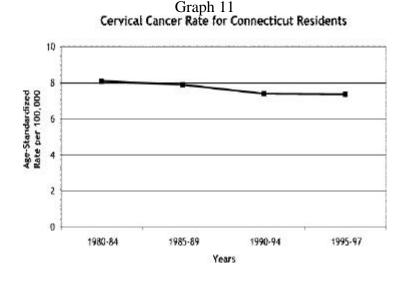
1989-91

1996-98

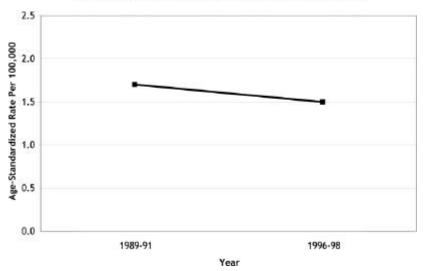
# Cervical Cancer

Invasive cervical cancer is largely preventable through screening to detect pre-invasive lesions. Social class affects the risk of developing lesions that progress to invasive cancer. As the graph below indicates, incidence rates in Connecticut declined from 1980 to 1994, and in 1990-1994 the age standardized incidence was 7.4 per 100,000 population. For the same period, crude incidence rates were higher for black women than for white women (12.8 and 8.8/100,000, respectively). Age specific incidence rates in 1990-1994 rose through ages 45-49 years, with no clear pattern at older ages. The 1994 age-standardized death rate was 2.1 per 100,00, nearly twice the year 2000 objective. Age standardized incidence rates remain unchanged from 1995- 1997; 7.3 per 100, 000 population.

Year



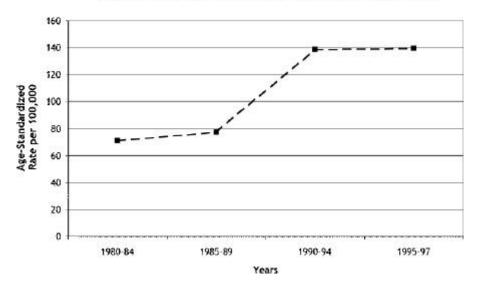
Graph 12 Cervical Cancer Mortality for Connecticut Residents



#### Prostate Cancer

Prostate cancer is the most common type of cancer among men in Connecticut. As the graph below indicates, age standardized incidence rates have been increasing from 71.3 per 100,000 in 1980-1984 to 138.7 per 100,000 in 1990-1994 and were 139.3 per 100,000 in 1995- 1997. The increase in age standardized incidence rates is most likely due to earlier diagnosis in asymptomatic men by the increased use of the prostate specific antigen screening test.

Graph 13
Prostate Cancer Incidence for Connecticut Residents



Prostate Cancer Mortality for Connecticut Residents

50

90 40

10 1989-91

1996-98

Graph 14
Prostate Cancer Mortality for Connecticut Residents

Similar to national trends, the age standardized incidence rate per 100,000 population is much higher for African American males (217.1) as compared with white males (137.0).

### **Defining Cancer Control and Its Prevention Entities**

Cancer control is a broad array of organized activities at local, state, regional, and national levels that have an impact on reducing the human burden of cancer. It encompasses prevention, screening, effective treatment, access to care, support services, survivorship, and end of life issues (Armstrong, 1992). For purposes of this plan, however, primary and secondary prevention activities are targeted.

*Primary prevention* is defined as the steps taken to prevent a disease from ever happening by limiting exposure to agents that may cause cancer (Armstrong, 1992). Since a majority of cancers are determined by lifestyle, a principal means of preventing cancer involves changing people's habits. For example, eliminating tobacco use would decrease the risk of developing lung cancer.

Secondary prevention is defined as mass screening of asymptomatic people so that precancerous changes can be detected early enough to prevent cancer or to treat cancer at an early stage when it can be cured or treated successfully (Armstrong, 1992). These include the use of mammography, Pap tests, and physical examination of the colon, rectum, testes, oral cavity, and skin.

### Cancer Prevention at the Population Level

We currently have sufficient knowledge of cancer causes and prevention to reduce cancer burden in the United States by over 50 percent (Willett, Colditz & Mueller,

1996). As public awareness of cancer continues to rise, we must be ready to move forward with a strategy that effectively utilizes our understanding of cancer prevention. The following section will summarize that strategy.

Although an overall reduction in cancer burden requires a reduction in both cancer mortality and cancer incidence, the strategy proposed focuses on primary prevention and secondary prevention. Most public health initiatives aimed at reducing cancer burden have focused on reducing cancer mortality by improving the treatment of disease. While efforts to improve survival are critical, prevention and early detection of the disease must also become a priority if we are to reduce cancer burden significantly.

A comprehensive cancer strategy that creates a prevention oriented environment that makes choosing risk reduction behaviors easier is important. It is not enough to assume that individuals who are educated about their cancer risk will modify behavior to lower their risk (U.S. Department of Health and Human Services, 1994). Barriers to behavioral change exist not only at the individual level, but also at the community level and within the broader social milieu. As social epidemiologists have pointed out, broad social movements are needed to stimulate and sustain change in health behavior at the population level (Atwood, Colditz & Kawachi, 1997). Because our society is a heterogeneous one, composed of persons of different racial, ethnic, and socioeconomic backgrounds, there is a need to develop well supported, broad based public health programs that target culturally diverse population groups; such programs help to cultivate a social environment that promotes policy initiatives and social norms supportive of health. It is only through such large scale actions that barriers to healthy behavior (including economic, social, political, cultural, and psychological barriers) will be eliminated at the population level (Atwood, Colditz & Kawachi, 1997; Richmond & Kotelchuck, 1984). From the standpoint of primary prevention of cancer, small changes in behavior across the entire population are likely to have large effects on disease risk. This phenomenon, whereby a strategy leading to a small shift in the population distribution of a risk factor leads to a larger decrease in disease burden than a strategy focusing only on "high risk" individuals, is sometimes called the prevention paradox (Rose, 1985). For instance, increasing the physical activity level of everyone in the population by a relatively small amount will likely have a larger effect on reducing population incidence of colon cancer than would a larger increase in activity among only the most sedentary in the population. Thus, a widespread cancer plan that targets population level barriers to healthy behaviors and that will be integrated into the social environment through health care organizations and providers, state and federal government, industry, and local communities is proposed (Richmond & Kotelchuck, 1984).

The role of health care organizations and providers in cancer prevention and early detection involves making primary and secondary prevention a priority in both the health care setting and the community. Insurers and health maintenance organizations are instrumental in determining the amount of provider time, funding, and research oriented toward preventive services. By mandating allocation of resources to preventive services, health care organizations could strengthen cancer prevention and early detection while

reducing their overall costs. In addition, health care providers themselves may lead communities in making prevention and early detection a priority (U. S. Preventive Services Task Force, 1996).

As the health care system makes cancer prevention and early detection a priority, government and industry may serve as regulatory agencies to ensure that all individuals have access to preventive services. They may pass regulatory legislation, provide workplace wellness programs, or create public-private partnerships to promote health. The prevention initiatives of municipal government and small businesses will differ greatly from those of state or federal government and industry leaders. However, all levels of government and industry need to make prevention a priority if cancer prevention and health promotion are to be integrated into the social environment.

Like the roles of health care organizations, government, and industry, the role of the community in cancer prevention is diverse. Local communities may support and enforce regulatory legislation, provide the manpower for prevention initiatives, or promote healthy activities and policies. A prevention oriented environment cannot be created without local, hands-on support at the community level.

Implementation of a widespread cancer prevention strategy will depend on the efforts of health care providers and organizations, regulatory agencies, and communities. However, these groups cannot work in isolation. The barriers to cancer prevention are many, and targeting them at a population level will require collaborative effort. Given the limited resources often available for prevention, collaboration offers agencies the opportunity to share not only expertise, but also financial and material resources. In addition, agencies working together at the various levels of the social environment will further our goal of fully integrating cancer prevention into the social milieu. This is best exemplified by comprehensive school health education, in which school systems collaborate with voluntary health care organizations and universities to deliver a high quality health curriculum.

### **Primary Prevention Initiatives**

#### Cancer Risks

Cancer risk factors are the internal and external factors that may increase an individual's chances of developing cancer in his or her lifetime. Internal predispositions are genetic, or are a direct result of the aging process. An individual can rarely escape the internal influences that cause cancer. External risk factors are cancer risks related to exposure to, or ingestion of, substances that can cause or have been linked to the development of cancer. Many external influences are associated with lifestyle choices and behaviors and can be entirely eliminated or controlled such as tobacco use, inadequate dietary patterns, physical inactivity, unprotected exposure to ultraviolet rays, and exposure to various other environmental and occupational chemicals.

Anyone can develop cancer. Cancer researchers use the word risk two different ways- lifetime risk and relative risk. Lifetime risk refers to the probability that an individual will develop cancer or die from it over the course of his or her lifetime. Relative risk is a measure of the strength of the relationship between risk factors and a particular cancer. It compares the risk of developing cancer in persons with a particular exposure or trait to the risk in persons who do not have this exposure or trait.

### Lowering risks

Epidemiologic studies show a positive relationship between specific cancers and identifiable risk factors. Major modifiable risk factors contributing to cancer include tobacco use, inadequate diet, physical inactivity, exposure to ultraviolet radiation, and exposure to occupational and environmental chemicals.

Existing scientific evidence suggests that one-third of all cancer deaths occur each year due to smoking and another one-third of cancer deaths are due to dietary factors. More than two-thirds of cancer in Connecticut could be prevented by not smoking, making appropriate nutrition and dietary choices, and engaging in adequate physical activity.

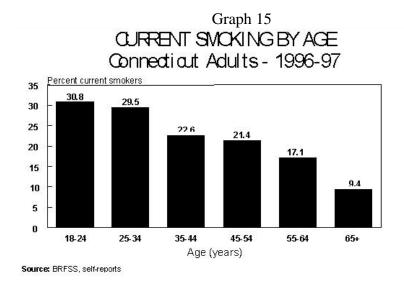
Regular screening examinations by a health care professional can result in the detection of cancers of the breast, colon, rectum, cervix, prostate, testes, oral cavity, and skin at earlier stages, when treatment is more likely to be successful. Self examination for cancers of the breast, skin, and testes may also detect cancers at earlier stages. These screening accessible cancers account for nearly half of all new cancer cases. The five year relative survival rate for these cancers is about 81 percent. If all Americans participated in regular cancer screenings, this rate could surpass 95 percent (American Cancer Society, 2000).

### Major Risk Factors

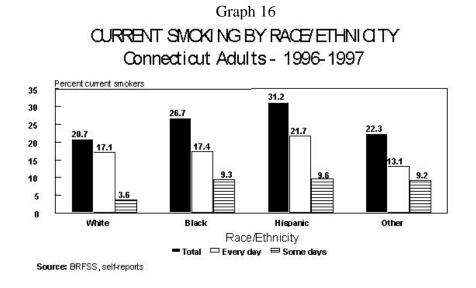
**Tobacco use** is the most preventable cause of premature death in Connecticut. Tobacco is the leading external, modifiable cancer risk factor. Smoking cigarettes, cigars or pipes and using spit tobacco cause one-third of all cancer related deaths nationwide and in Connecticut. Smoking is responsible for 87 percent of all lung cancers and is also associated with cancers of the mouth, pharynx, larynx, esophagus, pancreas, cervix, kidney, and bladder (American Cancer Society, 2000).

Current cigarette smoking among adults in Connecticut aged 18 and older was 21.8 percent in 1997 as compared with 23.2% for all states within the United States. Women and men in Connecticut had comparable smoking prevalence rates (22.2 vs. 21.4%). Smoking rates in Connecticut, however, varied by age, educational level and ethnicity. The graph below shows current smoking by age in Connecticut residents. Connecticut adults age 18-24 years had higher prevalence of smoking than those 35-44, 45-64 and over 65 years. Smoking prevalence is higher in those with less than a high school education as compared with those with a high school or higher than a high school

level of education (29.1, 26.5 vs. 15.8%) (Connecticut Department of Public Health, 2000).



The graph below presents information about current smoking in Connecticut residents by race and ethnicity. As the graph demonstrates, Hispanics had higher rates of smoking prevalence as compared with blacks, Asian/Pacific Islanders and whites (30.7, 26.9, 23.2 vs. 20.9%).



Prevalence of cigarette smoking among Connecticut youths in grades 9 through 12 is high; 35.2% reported smoking during the past month and 17.9% were frequent smokers (Centers for Disease Control and Prevention, 1999). It is important to note that prevalence of smoking among high school youths in Connecticut is unacceptably high and increases in prevalence rates between grades 9 and 12 have been noted such that

26.7% smoked in grade 9 and 45.1% smoked in grade 12 (Connecticut Department of Public Health, 2000).

Non-smokers are also at risk from exposure to environmental or second hand smoke. Environmental smoke is the smoke that is given off between puffs and that are exhaled by the smoker. When individuals are exposed to environmental smoke they absorb carcinogens similar to smokers (American Public Health Association, 1998).

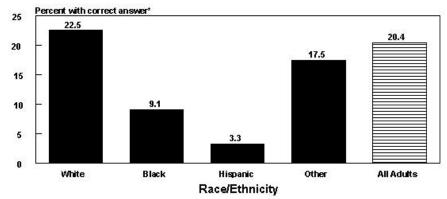
In 1993, the U.S. Environmental Protection Agency declared second hand smoke a human carcinogen (cancer causing agent) that contains more than 4,000 chemical compounds. These chemicals can result in cancer and other chronic conditions for the exposed non-smoker. Each year approximately 3,000 non-smoking adults die of lung cancer as a result of breathing the smoke of other's cigarettes (American Public Health Association, 1998, U.S. Department of Health and Human Services, 1993).

**Nutrition and diet** are also external, modifiable risk factors. Scientific studies have shown an association between nutrition and diet and at least one-third of all cancers. The National Cancer Institute defines nutrition as "ingesting and synthesizing food for growth and normal body functions and diet as the quantity and types of food that people eat (National Cancer Institute, 1996). Dietary related cancers may include breast, colorectal, endometrial, lung, oral, bladder, cervix, esophageal, prostate, stomach and liver.

Many dietary factors can affect cancer risk: types of food consumed, food preparation methods, portion sizes, food variety, and balanced diet. The 1999 ACS Guidelines for Nutrition and Cancer Prevention cite four broad recommendations to reduce the risk of cancers related to diet: 1) eating a high portion of foods from plant sources (fruits, vegetables, grain products and beans), 2) limiting amounts of high fat foods particularly from animal sources (limit meats, especially the higher fat choices), 3) being physically active and achieving and maintaining a healthy weight, and 4) limiting consumption of alcoholic beverages, if you drink at all (American Cancer Society, 1999). The single most important dietary factor for lowering cancer risk is to eat five or more daily servings of fruits and vegetables.

About 30% of Connecticut adults and 33% of students reported consuming 5 or more servings of fruits and vegetables a day, indicating over two-thirds of Connecticut residents did not follow recommendations. Only about one in every five adults (20%) know that the recommended number of servings of fruits and vegetables was 5, and those who did were more likely to report consuming 5 servings (51%) than those that did not (25-42%). As the graph below indicates, Blacks (9%) and Hispanics (3%) were least likely to know the correct answer (Connecticut Department of Public Health, 2000).

Graph 17
NUTRITION KNOWLEDGE BY RACE/ETHNICITY
Connecticut Adults - 1997

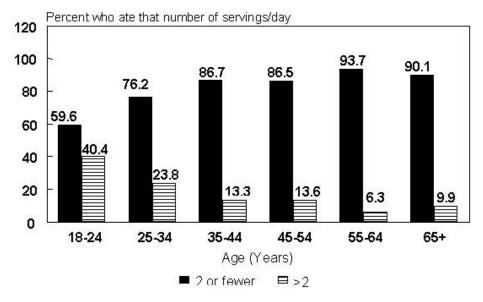


Source: BRFSS, self-reports; unknowns included
\*Answered "5" to number of servings of fruits and vegetables recommended

Two-thirds of Connecticut students and 83% of adults reported consuming 2 or fewer servings of high fat foods a day. As the graph below indicates, consumption of high fat foods was highest among those less than 34 years of age (Connecticut Department of Public Health, 2000).

Graph 18

## CONSUMPTION OF HIGH FAT FOODS Connecticut Adults - 1996



Source: BRFSS, self-reports based on 13 questions

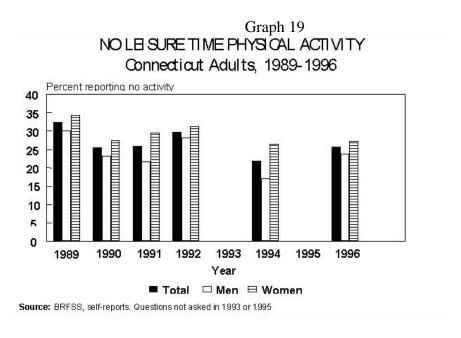
**Physical inactivity and being overweight** are other external, modifiable risk factors. Regular physical activity, combined with a diet including fruits and vegetables and reduced fat helps achieve and maintain a healthful body weight.

Researchers are studying the role of physical activity and its relation to reduced cancer risk through enhancing the immune system, shortening the time it takes to move food through the intestines, and altering body composition and hormone levels.

In women, obesity is associated with increased risk of the gallbladder, breast (for post menopausal women), cervix, endometrium, uterus, and ovary cancer. Among men, obesity is associated with an increase risk of colon and prostate cancers.

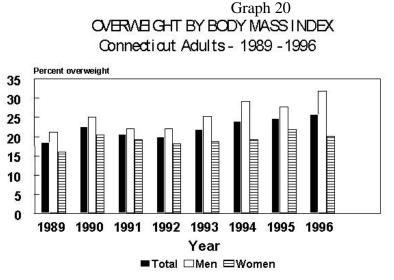
The 1996 U.S. Surgeon General's report on Physical Activity states that the risk of premature mortality from colon cancer can be reduced by regular physical activity (U.S. Department of Heath and Human Services, 1996).

Based on studies showing the minimum level of activity needed to achieve health benefits, several agencies including the Centers for Disease Control and the American Cancer Society recommend 30 minutes of moderate-intensity physical activity each day (Connecticut Department of Public Health, 2000). Only 21% of Connecticut adults and students reported getting the recommended exercise at least 5 days a week (although data have certain limitations), suggesting that nearly 80% were at increased risk for cancer due to lack of activity. As the graph below indicates, over one-fourth of all adults reported engaging in no leisure time physical activity.



For adults, several measures based on body mass index (BMI) were used in assessing overweight status. Using the pre- 1998 criteria for overweight (men BMI  $\geq$  27.8; women BMI  $\geq$  27.3), 28% of Connecticut adults were overweight. In addition, 29%

of high school students perceived themselves to be overweight. The figure for adults is likely an underestimate, as validation studies have shown people underestimate their weight, and actual measurements indicate over one-third of adults are overweight (Connecticut Department of Public Health, 2000). The prevalence of self reported overweight in Connecticut adults has increased over time (see graph below). Using guidelines published in 1998 that differentiate between obesity (BMI > 30) and overweight (BMI= 25-30), over half of the adults in the state were overweight or obese, including 14% who were obese. Black and Hispanic adults were more likely to be obese than non-Hispanic whites.



Source: BRFSS, self-reports; cutoffs of 27.3 for women and 27.8 for men. Unknowns included in analysis:

**Ultraviolet radiation** is the primary cause of skin cancer, which is the most common cancer in the nation (U.S. Department of Health and Human Services, 1999). There are three major types of skin cancer: basal cell carcinoma, squamous cell carcinoma, and melanoma. Malignant melanoma causes 75 percent of all deaths from skin cancer. The disease can spread to other organs, most commonly to the lung and liver (U.S. Department of Health and Human Services, 1999).

Although anyone can get skin cancer, individuals with certain internal and external factors are particularly at risk, these include light skin color, personal and family history of skin cancer, chronic exposure to the sun, history of sunburn(s) early in life, certain types and a large number of moles and freckles.

Sunburn(s) during childhood and adolescence have been associated with an increased risk of skin cancer, including melanoma, the deadliest form. Many young people are putting themselves at risk for skin cancer later in life by not protecting their skin now. Studies have shown that young people are among those who are protecting themselves the least (U.S. Department of Health and Human Services, 1999).

Simple lifestyle choices to reduce skin cancer risks include protecting one's skin from the sun. Persons should seek shade and avoid the strongest midday sun as much as possible, wear protective clothing including a hat, shirt, and pants, and use sun screen

with a sun protective factor (SPF) of 15 or greater that offers both ultraviolet A and ultraviolet B protection.

Tanning beds are not a safe alternative to direct sun exposure. They emit mostly ultraviolet A rays which have been shown to play a role in skin cancer (U.S. Department of Health and Human Services, 1999).

**Environmental** risk factors refer to specific sources of carcinogens, including air, water, and soil contaminants (Commonwealth of Massachusetts, 1998). Environmental risks include exposure to ultraviolet radiation, pesticides, radon, and some food and beverages, and other synthetic chemicals. Most environmental risks are determined by lifestyle choices (smoking, diet); others occur from community and workplace settings. There seems to be a synergistic effect between some environmental factors. For example, cigarette smokers exposed to asbestos have higher lung cancer rates (Ginsberg, Vokes & Raben, 1997).

Occupational carcinogenic chemicals found in the workplace are also in the environment, although workers may have a more intense and prolonged exposure to the substances (National Cancer Institute, 1996). It is difficult to confirm definite causal relationships with environmental carcinogens since it can take up to 30 years for exposure to result in specific health effects. There is often a lack of information about persons exposed, level of exposure and possible interactions with other carcinogens in the environment. Steps to reduce or eliminate known exposures is the most effective means of preventing cancers associated with environmental carcinogens (Commonwealth of Massachusetts, 1998).

**Family history and inherited gene mutation** also play a role in the development of cancer. About 5% to 10% of cancers are clearly hereditary, in that an inherited faulty gene predisposes the person to a very high risk of particular cancers.

#### Genetic Testing and Prevention

Over the past decade, there has been much learned about genes and how genetic mutations are linked to disease such as cancer. Tests are now available to provide information about an individual's risk or predisposition for developing some forms of cancer. This knowledge raises hopes of saving lives through prevention or early detection, but its also raises legal and ethical concerns for individuals, families and for society (Jacobs, 1998; Jacobs & Deatrick, 1999). As genetic testing moves from the research stage to public availability, these issues will become increasingly important.

Nationally, genetic testing issues are addressed by groups such as the Human Genome Project's working group on Ethical, Legal, and Social Implications (ELSI). The ELSI group funded a project to develop guidelines to protect information stored in genetic data banks. Their efforts resulted in proposed federal legislation called the Genetic Privacy Act. The American Society of Human Genetics has created an Ad Hoc Committee on Insurance Issues in Genetic Testing to address these issues. In addition, the

National Cancer Institute is working with the National Center for Genome Research to address the scientific and social issues that surround the evolving technology for genetic testing (Florida Cancer Control and Research Advisory Committee, 1997; Giarelli & Jacobs, 2000).

Several states have enacted laws to protect the privacy of genetic information, prohibit insurers from requiring or requesting genetic test results and denying coverage based on test results, or using test results to determine rates and benefits. Connecticut has enacted genetics legislation and is one of 33 states that have laws restricting health insurance discrimination and one of only 19 states that have legislation addressing employment discrimination (National Cancer Institute, 1999).

Technically, all cancers are genetic because they are caused by an alteration in cells' genetic material. However, it is believed that 5 to 10 percent of cancers are inherited (caused by a mutation passed from one generation to another).

Testing is currently available for several genetic mutations. Mutations of the BRCA1 and BRCA2 genes are associated with an increased risk of breast and ovarian cancers. An increased risk for hereditary nonpolyposis colon cancer and familial adenomatous polyposis can also be determined by testing for certain genetic mutations.

Genetic counseling and informed consent are essential components of genetic testing programs. Individuals and families considering genetic testing need to understand the ramifications of their decision, how to understand and interpret the test results, and how the results will be used (Jacobs & Deatrick, 1999).

Individuals who test positive for genetic mutations will not necessarily develop cancer, and a negative test result does not mean that they will not develop cancer. A positive result may indicate a need for more frequent screening, i.e. more frequent mammograms and clinical breast exams for women at high risk for breast cancer, or lifestyle changes, i.e., high fiber, low fat diet for those at high risk for colon cancer. Some women with a strong family history of early onset breast cancer who test positive for BRCA1 or BRCA2 mutations consider prophylactic mastectomies. Prophylactic removal of ovaries or chemoprevention interventions such as use of tamoxifen are also considered for women who are carriers of certain BRCA mutations. These decisions require extensive counseling and medical consultation.

Negative test results may provide peace of mind, but the possibility of a false negative result needs to be understood. Family members who have negative test results may feel guilty if others in their family receive positive test results. For these and other reasons, counseling plays a critical role in genetic testing.

### **Secondary Prevention Initiatives**

*Screening* is the detection of disease among people who do not have symptoms. Screening for disease is considered effective if it meets several distinct criteria. First, it

must demonstrate the ability to reduce cancer related morbidity and mortality. Thus, for a screening test to be effective, the specific cancer must be potentially curable if detected early and the test must be able to detect the cancer at an early stage when it can be treated with less intensity and lower cost (Kramer and Screening Editorial Board of the Physician Data Query, 1995). Second, the effectiveness of a screening test depends on having high sensitivity and specificity; that is, people who have the disease have a high likelihood of testing positive and people who do not have the disease must have a high probability of testing negative (Hulka, 1988). Third, screening tests must be affordable, not only so that they are accessible to individuals, but also so that the costs of screening entire populations do not outweigh the benefits (Ransohoff & Lang, 1991). Finally, cancer screening cannot be effective unless the tests are acceptable to and used by the population at risk and unless they are repeated at intervals appropriate to detect cancer (Anderson, & May, 1995).

Screening and early detection become particularly problematic when our ability to diagnose a disease outpaces our ability to treat it effectively. Patients may come to a clinic with some awareness of the benefits of screening tests, but they know little about the potential risks or negative consequences of screening. Knowing that one has a disease before symptoms appear but when treatment may not be available may lead to emotional distress and needless suffering. Policymakers are wary of "creating disease in the absence of symptoms" while practitioners find it difficult to explain to patients that screening is a two-edged sword that may bring with it as many questions as answers (Harris & Leininger, 1995; Morrison, 1992).

An effective screening program has many dimensions. There are six components that must be addressed successfully for a program to have an impact on morbidity and mortality. These components include: public and patient education, provider referral, availability of services, access to services, quality assurance, and surveillance and evaluation of screening activities and outcomes.

Screening for cancer is a moving target, in that the state of knowledge about different kinds of cancer is continually evolving. When discussing screening recommendations, recommendations from the National Cancer Institute, American Cancer Society, and the United States Preventive Services Task Force are often cited.

Tables 5 through 10 show the differences and similarities in screening guidelines among these groups. Screening tests appear to be effective for three of the six cancer sites proposed by the Connecticut Cancer Plan, breast, cervical, and colorectal, whereas primary prevention strategies can be proposed for all six (see Table 11).

## Table 5 Breast Cancer Screening Recommendations

## Recommendation from U.S. Preventive Services Task Force

- Mammogram: Every 1-2 years for women age 50-69. There is insufficient evidence to recommend for or against routine mammography for women age 40-49 or 70 and older, although recommendations for high-risk women age 40-49 and healthy women 70 and older may be made on other grounds.
- Clinical Breast Exam: Every 1-2 years for women age 50-69. There is insufficient evidence to recommend for or against routine clinical breast exam for women aged 40-49 or 70 and older, although recommendations for high-risk women age 40-49 and healthy women 70 and older may be made on other grounds. There is insufficient evidence to recommend for or against the use of clinical breast exam alone.
- **Breast Self Exam:** There is insufficient evidence to recommend for or against the teaching of breast self exam.

## Recommendation from the National Cancer Institute

- **Mammogram:** Women age 40 and older should have a screening mammogram every 1-2 years. Women who are at increased risk for breast cancer should seek medical advice about when to begin having mammograms and how often to be screened.
- Clinical Breast Exam: A clinical breast exam should be performed at the same time as the mammogram.
- **Breast Self Exam:** Studies have not shown that breast self exam reduced the number of deaths from breast cancer. Therefore, it should not be used in place of a clinical breast exam and mammography.

## Recommendation from American Cancer Society:

- Mammogram: Every year for women age 40 and older.
- Clinical Breast Exam: Every year for women age 40 and older. Every three years for women age 20-39.
- Breast Self Exam: Every month for women age 20 and older.

## Table 6 Cervical Cancer Screening Recommendations

## Recommendation from U.S. Preventive Services Task Force:

• Routine screening for cervical cancer with Pap testing is recommended for all women who have been sexually active and who have a cervix. Pap smears should begin with the onset of sexual activity and should be repeated at least every three years. There is insufficient evidence to recommend for or against an upper age limit for Pap testing, but recommendations can be made on other grounds to discontinue regular testing after age 65 in women who have had regular previous screenings in which the smears have been consistently normal. There is insufficient evidence to recommend for or against routine screening with cerviography or colposcopy, or screening for human papilloma virus infection, although recommendations against such screenings can be made on other grounds.

### Recommendation from the National Cancer Institute:

• Women who are, or have been, sexually active or have reached the age of 18, should have Pap tests and physical exams regularly. Women may want to discuss with their doctor how often to have the test. There is no known upper age limit at which Pap test cease to be effective. Older women should continue to have regular physical exams, including pelvic exams and Pap tests. Women who have had a hysterectomy should talk with their doctors about whether to continue to have regular Pap tests. If the hysterectomy was performed for treatment of a precancerous or cancerous condition, the end of the vaginal canal still needs to be sampled for abnormal changes. If the uterus (including the cervix) was removed because of a noncancerous condition such as fibroids, routine Pap tests may not be necessary.

### Recommendation from American Cancer Society:

• A Pap test should be performed annually with a pelvic exam in women who are, or have been, sexually active or have reached the age of 18. After three or more consecutive annual exams with normal findings, the Pap test may be performed less frequently at the discretion of the physician.

# Table 7 **Lung Cancer Screening Recommendations**

## Recommendation from U.S. Preventive Services Task Force:

• Routine screening with chest radiography or sputum cytology in asymptomatic persons is not recommended. All persons should be counseled against tobacco use.

#### Recommendation from the National Cancer Institute:

• The National Cancer Institute is studying whether regular chest radiography will help detect cancer in both men and women. Chest radiography is often used to diagnose the disease once symptoms occur, but its usefulness in finding cancers before symptoms occur is unknown. Routine screening is not recommended.

#### Recommendation from American Cancer Society:

• Routine screening is not recommended.

## Table 8 Colorectal Cancer Screening Recommendations

## Recommendation from U.S. Preventive Services Task Force:

• Screening is recommended for all persons age 50 and older with annual fecal occult blood testing or sigmoidoscopy (period unspecified) or both. There is insufficient evidence to determine which of these screening methods is preferable or whether the combination of FOBT and sigmoidoscop[y produces greater benefits than does either test alone. There is insufficient evidence to recommend for or against digital rectal examination, barium enema or colonoscopy, although recommendations against such screening in average risk persons may be made on other grounds. Persons with a family history of hereditary syndromes associated with a high risk of colon cancer should be referred for diagnosis and management.

## Recommendation from the National Cancer Institute:

- Fecal Occult Blood Testing: Studies show that a FOBT performed every 1-2 years in people between the ages of 50-80 decreases the number of deaths due to colorectal cancer.
- **Sigmoidoscopy:** Stuides suggest that fewer people may die of colorectal cancer if they have regular screening by sigmoidoscopy after the age of 50.
- **Digital Rectal Exam:** The evidence does not suggest that digital rectal exam is effective in decreasing mortality from colorectal cancer.
- Barium Enema: There is not yet any information on the use of barium enema as a screening test.
- Colonoscopy: There is not yet any information on the use of colonoscopy as a screening test.

## Recommendation from American Cancer Society:

Beginning at age 50, men and women should have **one** of the following:

- **Fecal Occult Blood Testing and Sigmoidoscopy:** if normal repeat FOBT annually, and flexible sigmoidoscopy every 5 years.
- Colonoscopy: if normal, repeat every 10 years.
- **Double-Contrast Barium Enema:** if normal, repeat every 5-10 years.
- **Digital Rectal Exam:** should be done at the same time as a sigmoidoscopy, colonoscopy, or double contrast barium enema.

## Table 9 Prostate Cancer Screening Recommendations

## Recommendation from U.S. Preventive Services Task Force:

• Routine screening for prostate cancer with digital rectal examinations, prostate specific antigen or transrectal ultrasound is not recommended.

### Recommendation from the National Cancer Institute:

• The National Cancer Institute is supporting research to learn more about screening men for prostate cancer. The research will help determine whether the blood test for prostate specific antigen along with digital rectal examination can help reduce the death rate from the disease. At present, it is unclear whether routine screening of men who are not at unusually high risk will prove to save lives and outweigh the extra surgery, radiation, and complications of therapy for large numbers of patients, many of whom do not have aggressive or life threatening tumors. Therefore, routine screening for prostate cancer is not recommended.

## Recommendation from American Cancer Society:

• Both prostate specific antigen and digital rectal examination should be offered annually, beginning at age 50 years, to men who have at least a 10 year life expectancy, and to younger men who are at high risk. Information should be provided to patients regarding potential risks and benefits of intervention.

## Table 10 Skin Cancer Screening Recommendations

## Recommendation from U.S. Preventive Services Task Force:

• There is insufficient evidence to recommend for or against routine screening for skin cancer by primary health care providers or counseling patients to perform periodic skin self examinations. A recommendation to consider referring patients at substantially increased risk of malignant melanoma to skin cancer specialists for evaluation and surveillance may be made on other grounds. Counseling patients at increased risk of skin cancer to avoid excess sun is recommended, based on proven efficacy of risk reduction, although effectiveness of counseling has not been well established. There is insufficient evidence to recommend for or against sunscreen use for the primary prevention of skin cancer.

#### Recommendation from the National Cancer Institute:

• Routine examination of the skin increases the chance of finding skin cancer early. Most melanomas that appear on the skin can be seen by the naked eye. Usually, there is a lengthy period when the tumor expands beneath the top layer of the skin but does not invade deeper skin layers. This period allows for early detection and full recovery if the tumor is discovered before spreading deeper.

#### Recommendation from American Cancer Society:

• Recognition of changes in skin growths or the appearance of new growths is the best way to find early skin cancer. Adults should practice skin exam regularly and suspicious lesions should be evaluated by a physician. Because of the possible link between severe sunburns in childhood and greatly increased risk of melanoma in later life, children, in particular, should be protected from the sun. Use of a sunscreen with a sun protective factor of 15 or higher is recommended.

## Table 11 Prevention Strategies for Six Cancer Sites

**Lung:** Lung cancer is the leading cause of cancer death in men and women. It is also the most preventable cancer. Smoking tobacco, whether cigarettes, cigars, or a pipe, accounts for more than 80% of lung cancers.

**Breast:** Breast cancer is the second leading cause of cancer deaths in women. It is possible that breast cancer may be prevented through regular exercise, maintaining a healthy weight, and using estrogen-regulating drugs (such as tamoxifen). Mammography and clinical breast exam can find early breast cancer that is curable.

*Colorectal*: Colorectal cancer is the third leading cause of death in men and women. Since removal of early stage polyps of the colon can prevent this cancer, screening is important. In addition, regular physical exercise, eating fruits, vegetables, and whole grain foods and limiting high-fat foods may help to prevent colorectal cancer.

*Cervical*: Cervical cancer may be prevented by avoiding multiple sex partners, by delaying first sexual experience and by using a condom during sexual intercourse to provide protection from HPV infection that can develop into cancer. Regular PAP tests can detect cervical cancer early when it can be successfully treated.

*Melanoma*: Prevention is a key, by limiting exposure to the sun, using protective clothing and sunscreen when in the sun, and avoiding tanning parlors and sun lamps. Understanding key warning signs and following skin examinations guidelines can help detect melanoma early when it is most curable.

**Prostate**: Prostate cancer is the second leading cause of cancer death in men. Eating a diet low in fat may help prevent it. Digital rectal exam and PSA testing can find prostate cancer early. However, since treatment choices are uncertain, mass screening is not recommended at this time.

## Barriers to Early Detection of Cancer

Barriers to early detection of cancer are numerous and include: lack of physician recommendation, cultural barriers, inadequate or inaccessible information, inadequate insurance coverage, poverty, lack of transportation, and lack of continuity of care (Cooley & Jennings-Dozier, 1998; Report of the New England Task Force for Health Promotion and Disease Prevention, 1998).

Minorities and people of lower socioeconomic status often have reduced access to health care services because of lack of insurance, lack of transportation, or due to cultural barriers. An individual's knowledge and beliefs about what causes illness and how it can best be treated also influence whether and what type of care is sought (Aday & Anderson, 1974). Evidence shows that people of lower socioeconomic status may have little awareness of, or belief in, the importance of early cancer detection and treatment, resulting in diagnosis of later stage cancers that require more invasive therapy and have poorer prognoses (Farley & Flannery, 1989).

Financial barriers, such as lack of insurance, may be an obstacle to health care access and obtaining screening tests for early detection of cancer. People without insurance are often unable to participate in screening or to seek care for suspicious

symptoms, particularly if they have no resources to follow through with treatment when cancer is diagnosed. When they do seek care, it is often when the disease has progressed to an untreatable stage. The numbers of uninsured in Connecticut has increased. Concurrently, employee based heath insurance has decreased. The uninsured include several groups: 1) individuals with low incomes who do not qualify for Medicaid; 2) employees- usually of small businesses- who are not offered health insurance or who can not afford the premiums and 3) people with medical conditions who are unable to get insurance. Most of the uninsured cannot afford to pay for health care. Moreover, those who are underinsured in Connecticut are thought to represent a greater proportion of the population than was previously thought (State of Connecticut, Department of Public Health, 1999). Caring for the uninsured and underinsured remains an ongoing challenge. Federally funded programs, such as the Breast and Cervical Cancer Early Detection Program, offer free or low cost screening and diagnostic services to women who cannot afford to pay. However, the program does not cover all diagnostic procedures, nor does it cover treatment. Hospitals in the areas participating in the program provide uncompensated care, as they do for many medically indigent people.

## **Opportunities**

As the 21<sup>st</sup> century approaches, Connecticut is challenged by the cancer care needs of a population that is growing more racially and ethnically diverse. Analyses conducted both nationally and regionally point to the striking differences in the health status among racial and ethnic minorities. Invasive cancer incidence rates were highest among African American males followed by Hispanic and white males, white females, Hispanic females, and African American females in Connecticut (Connecticut Department of Pubic Health, 1999). Nationwide, overall cancer survival rates have improved due to earlier diagnosis and better treatments but research indicates that African Americans tend to be diagnosed with certain cancers at later stages and consequently have lower survival rates compared with whites (Institute of Medicine, 1999).

Socioeconomic status factors play an important role in early detection and treatment of certain types of common cancers like breast and cervical. Because low income people of any race or ethnicity tend to have less access to medical care, they are less likely to be diagnosed with cancer at an early stage when prognosis for treatment is best.

Evidence suggests that several types of cancer can be prevented and that the prospects for surviving cancer continue to improve. The ability to reduce cancer death rates depends, in part, on the existence and application of various types of resources. First, the means to provide culturally and linguistically appropriate information on prevention, early detection, and treatment to the public and to health care professionals are essential. Second, mechanisms or systems must exist for providing people with access to effective preventive services and treatment. Where suitable, participation in clinical trials for prevention and early detection should also be encouraged. Third, a mechanism for maintaining continued research progress and for fostering new research is essential. In particular, mechanisms need to be developed where Consortium members can work

together to promote surveillance and research goals identified as important to attain the goals set forth in this cancer control plan. Genetic information that can be used to improve disease prevention strategies is emerging for many cancers and may provide the foundation for improved effectiveness in clinical and preventive health care services. To provide new opportunities for cancer prevention and control in the future, there is a continuing and vital need to foster new, innovative research on both the causes of cancer (including genetic and environmental causes) and on methods to translate biologic and epidemiologic findings into effective prevention and control programs for use by government and community organization to further reduce the Nation's cancer burden.

# PART 2: CONNECTICUT CANCER CONTROL PLAN: GOALS, OBJECTIVES, AND INTERVENTIONS 2001-2004

This is the first phase of a Cancer Prevention and Control plan for Connecticut. The Connecticut Cancer Consortium is committed to the development of a Cancer Prevention and Control Plan for Connecticut based on effective interventions that can be used to promote the health and well being of Connecticut residents. The purpose of the Connecticut Cancer Consortium is to bring together members from four of the major health institutions in the state so that efforts can be coordinated to reduce the burden of cancer through surveillance and research goals, evaluation of effective prevention and cancer control services, and promotion of program, policy and regulatory measures. An overarching concern of the Connecticut Cancer Consortium is to address health disparities that exist in cancer prevention and early detection among racial and ethnic minorities in the state.

During this phase of cancer plan development, three priority cancer sites were addressed by the Connecticut Cancer Consortium: lung, breast, and colorectal. These cancer sites were chosen because they are among the most common cancers that affect the residents of Connecticut and scientifically based cancer prevention and/or early detection interventions exist. Subgroup committees were formed for each of the cancer sites in order to identify effective prevention and early detection interventions and identify important goals for each cancer site that should be addressed in the next phase of the plan. This part of the document provides information about the subgroup committee process, effective prevention and early detection interventions and identifies cancer control goals for each cancer site. It is hoped that this document will provide fertile ground for collaboration regarding surveillance and research activities among the various members of the Consortium.

## Subgroup Committee Process and Activities

Subgroup committees were formed for each cancer site. Members of these groups were chosen to participate in the committees because they were recognized as experts in lung, breast, or colorectal cancer, represented the Connecticut Cancer Consortium participating agencies, and were committed toward developing a cancer control plan for the state. Each subgroup committee functioned in a different way. The lung cancer subgroup committee had e-mail communication and held two group meetings to develop goals and then revise and approve the plan. The breast cancer subgroup committee had e-mail communication and held one group meeting to develop the plan. Revisions were done via e-mail communication or phone contact. The colorectal cancer subgroup committee had e-mail communication to develop and revise the plan. Group discussions centered on effective interventions for each cancer site and goals that were most important to address within each cancer site. Multiple goals were identified for each cancer site by the subgroup committee members. Priorities for cancer control were established for each cancer site based on cancer behavioral risk factor data provided through the Connecticut Department of Public Health, Behavioral Risk Factor Surveillance Survey and Youth Risk Behavior Survey coordinated by the Centers for Disease Control and Prevention (Connecticut Department of Public Health, 2000).

## LUNG CANCER CONTROL PLAN FOR CONNECTICUT

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## LUNG CANCER CONTROL PLAN FOR CONNECTICUT

## Goal 1: To reduce the initiation of tobacco products by youths

## *Objectives:*

- Increase awareness of the dangers of tobacco use by youths
- Reduce access to tobacco products by youths
- Increase number of youths that never start smoking
- Change social norms about smoking

#### *Interventions:*

- Include effective educational curricula and peer driven programs in K-12 schools and communities that focus on tobacco-use prevention.
- Distribute appropriate prevention messages through existing youth oriented community based channels, such as organized athletics, youth councils, scouts.
- Work with local authorities to conduct merchant and community education program.
- Work with law enforcement agencies to reduce illegal tobacco sales and distribution of tobacco products.
- Raise the price of tobacco high enough to give smokers a financial incentive to quit and to arrest the onset of youth smoking.
- Conduct mass media campaigns that educate youths about the dangers of cancer and tobacco use and encourage youths to be smoke free.
- Prohibit the use of tobacco on school property and at school sanctioned programs.

- Monitor prevalence of youth smoking through the Youth Risk Factor Survey.
- Monitor consumption of tobacco using Connecticut excise tax information.
- Monitor the enforcement of state laws that eliminate cigarette vending machines in areas frequented by youths such as, arcades, recreation facilities, schools, and community centers.
- Monitor illegal tobacco sales to youth.
- Solicit broad based support and participation in implementing Connecticut Lung Cancer Control Plan.
- Secure funding for ongoing monitoring of surveillance of smoking and health effects.

# Goal 2: To increase the rate of effective cessation among tobacco users in Connecticut who want to quit the use of tobacco

## Objectives:

- To provide support for tobacco users who want to quit
- Target interventions toward high risk smokers such as ethnic minorities and pregnant women

#### *Interventions:*

- Work with communities carrying out effective community based, incentive driven cessation programs for tobacco users who want to quit.
- Increase awareness of cessation resources in each community.
- Encourage support for tobacco users who want to quit by providing smoking cessation programs and incentives in Connecticut worksites.
- Develop activities to increase the number of health care providers who counsel patients to quit smoking through training of health care practitioners.
- Mandate that all health insurers including Medicaid, cover the cost cessation counseling and cessation products- both nicotine and non-nicotine based.
- Establish a telephone call line for those who wish to quit tobacco use.
- Increase access to cessation programs in substance abuse facilities.
- Reach out to high-risk women, including pregnant women, through WIC programs and prenatal facilities.

- Inventory community based resources available in Connecticut for smoking cessation.
- Monitor prevalence of adult smoking through the Behavioral Risk Factor Surveillance Survey.
- Monitor use of telephone quit lines.
- Solicit broad based support and participation in implementing Connecticut Lung Cancer Control Plan.
- Secure funding for ongoing monitoring of surveillance of smoking and health effects.

# Goal 3: Eliminate environmental risk factors for lung cancer including tobacco smoke

## *Objectives:*

 Increase the proportion of schools, restaurants, day care centers, malls and worksites with tobacco free environments

#### *Interventions:*

- Work with legislators to enact a comprehensive clean indoor air law that prohibits smoking or limits smoking to separately ventilated areas.

## Evaluation Criteria:

- Monitor legislative initiatives.
- Solicit broad based support and participation in implementing Connecticut Lung Cancer Control Plan.

# Goal 4: To increase consumer and clinician knowledge of clinical trials available for prevention and early detection of lung cancer

## *Objectives*:

- To increase awareness among providers of cancer care and consumers of the importance of participation in clinical trials in providing state of the art prevention and early detection in lung cancer
- To provide statewide dissemination of cancer prevention and early detection clinical trials available for lung cancer

#### *Interventions:*

- Launch a statewide campaign focusing on the value of clinical trials to cancer prevention and early detection.
- Publicize the availability of educational resources about clinical trials for cancer prevention and early detection.
- Support information distribution to consumers and clinicians about clinical trials that are available in the state for prevention and early detection.

- Inventory research that is being done related to prevention and early detection clinical trials.
- Inventory educational resources that are available for consumers and clinicians regarding cancer prevention and early detection trials.
- Develop an internet web site that serves as a source of up to date information regarding cancer prevention and early detection opportunities available in Connecticut.

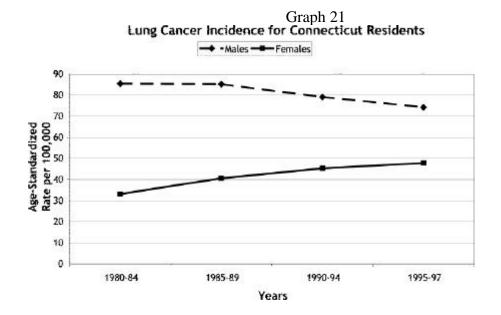
## **LUNG CANCER**

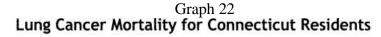
## Background

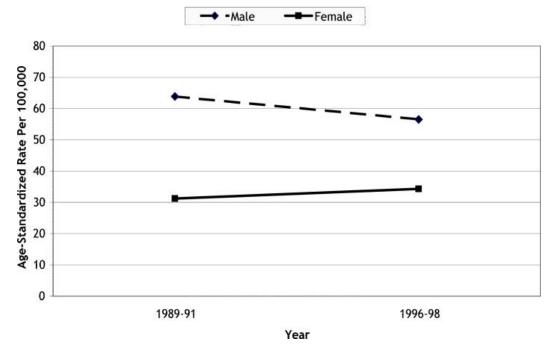
More new information is becoming available about the adverse health consequences of tobacco use. The association between tobacco use and lung cancer is one of the most widely studied and clearly defined relations among cancer studies (U.S. Department of Health and Human Services, 1991). If the current effectiveness of smoking control programs were doubled, by the year 2015 there would be up to a 50% reduction in lung cancer rates (U.S. Department of Health and Human Services, 1991). Increasingly, major attention is focusing on three groups of tobacco users: youth, adults who want to quit using tobacco and pregnant women.

Tobacco use is the leading preventable cause of death in Connecticut and in the United States (State of Connecticut, Department of Public Health, 1999). Smoking is the primary cause of 87% of all lung cancer deaths and 30% of all cancer deaths. Lung cancer overtook breast cancer as the leading cause of cancer deaths among women in 1987. Smoking rates for men have decreased in the past three decades but appear to have plateaued in the 1990's (Wingo et al., 1999). The mortality rate for women, however, continued to rise steeply mirroring the increase in smoking among women (Wingo et al, 1999).

Lung cancer is the leading cause of cancer deaths in Connecticut. As the graphs below demonstrate, incidence and mortality rates declined among Connecticut males from 1980- 1994, but increased among women. The age-standardized lung cancer incidence rates in males were 79.1 per 100,000 per year during 1990-1994 as compared to 74.2 per 100,000 per year during 1995- 1997. In contrast, the age standardized lung cancer incidence rates in women were 45.3 per 100,000 per year during 1990- 1994 as compared to 47.8 per 100,000 per year during 1995- 1997.







Age standardized incidence rates per 100,000 population for lung cancer were higher for African American males (104.8) as compared with white males (77.9) between 1990 and 1995. In contrast, white females had a higher age standardized incidence rate per 100,000 (46.7) as compared with African American females (37.2) during the same time.

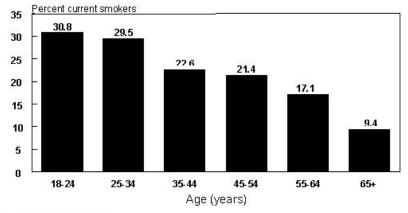
About 90% of lung cancers can be prevented through abstinence from tobacco. Current cigarette smoking among adults in Connecticut aged 18 and older was 21.8 percent in 1997 as compared with 23.2% for all states within the United States (Centers for Disease Control and Prevention, 1999). Women and men in Connecticut had comparable smoking prevalence rates (22.2 vs. 21.4%). Smoking rates in Connecticut, however, varied by age, educational level and ethnicity. The graph below shows current smoking by age in Connecticut residents. Connecticut adults aged 18-24 years had higher prevalence of smoking than those 35-44, 45-64 and over 65 years (see graph 3). Smoking prevalence was higher in those with less than a high school education as compared with those with a high school or higher than a high school level of education (29.1, 26.5 vs. 15.8%) (Connecticut Department of Public Health, 2000).

The graph below presents information about current smoking in Connecticut residents by race and ethnicity. As graph 4 demonstrates, Hispanics had higher rates of smoking prevalence as compared with blacks, Asian/Pacific Islanders and whites (30.7, 26.9, 23.2 vs. 20.9%).

Graph 23

CURRENT SWCKING BY AGE

Connecticut Adults - 1996-97

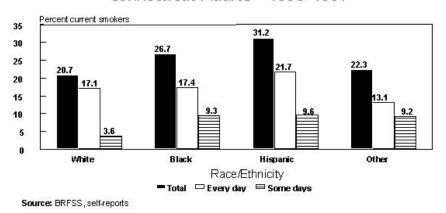


Source: BRFSS, self-reports

Graph 24

CURRENT SMCKING BY RACE/ETHNICITY

Connecticut Adults - 1996-1997



Environmental tobacco smoke (also called passive smoke- the smoke that non-smokers breathe) is a human lung carcinogen responsible for approximately 3,000 lung cancer deaths in the United States among non-smokers. Because there are no safe levels of exposure to environmental tobacco smoke, public policies to protect people from the effects of passive smoke are important (American Cancer Society, 2000).

The use of smokeless tobacco (chewing or spitting tobacco, oral and nasal snuff) is a cause of oral cancer. For example, the risk of oral cancer for women who do not smoke but who use snuff chronically is 50 times greater than for non-users (American Cancer Society, 2000).

In addition to deaths from cancer, tobacco contributes significantly to deaths from cardiovascular disease (coronary artery disease, stroke, and high blood pressure), lung disease (chronic bronchitis, emphysema, and asthma), low birth weight, and burns.

## Smoking among young people

Almost all smokers take up the habit before they are twenty. Every day, 3000 United States teenagers start smoking: their average age is 13 or 14 years. The earlier they start smoking, the harder it will be to quit later and the more likely they will die prematurely (Chassin & Presson, 1990).

While the percentage of smoking adults has declined over the past ten years, smoking among youth is on the rise (Wingo et al., 1999). Easy access to tobacco products by youth is a major public health problem. Seventy-two percent of teenage smokers say they purchase their own cigarettes in spite of the fact that it is illegal to sell tobacco to youths under 18 (Centers for Disease Control, 1996; DiFranza & Tye, 1990).

Prevalence of cigarette smoking among Connecticut youths in grades 9 through 12 is high; 35.2% reported smoking during the past month and 17.9% were frequent smokers. It is important to note that prevalence of smoking among high school youths in Connecticut increases in prevalence rates between grades 9 and 12 such that 26.7% smoked in grade 9 and 45.1% smoked in grade 12 (Connecticut Department of Public Health, 2000). Moreover, in contrast to the trend that Connecticut tends to fare better than other states regarding early detection and screening behaviors for breast and colorectal cancer, current cigarette smoking among adolescents remains high and is comparable to all other states (35.2 vs. 36.4) (Centers for Disease Control, 1999a).

## Review of Intervention Studies

Since smoking is the major factor in lung cancer incidence, smoking prevention and cessation interventions and tobacco control interventions should receive the highest priority in lung cancer control efforts. In order to identify the most effective smoking prevention and cessation interventions, a review of the literature was conducted using a PUBMED search from 1975 to April 2000 (Parsa, Wang, Schulman & Germana, 2000). Key words, such as smoking cessation program, preventive lung cancer, lung cancer Connecticut and environment lung cancer were used to compile a preliminary list of appropriate interventions. Citations were also analyzed within the reference section of articles as well as several meta-analysis and review articles. The citation list was then categorized by type of intervention: community based and self help, workplace, hospital based, media based, and those directed toward women, minorities, and children. Findings from this review of literature are highlighted.

## Community-based and self-help smoking cessation interventions

Many different approaches have been used in community based and self help smoking cessation programs. Wheeler (1988) suggests that behavioral factors are the most crucial for success in a low cost community wide smoking cessation campaign using a combination of the American Lung Association's (ALA) 20 day self conducted

"Freedom from smoking" program and television coverage of anti-smoking messages. In another similar study, Daughton and colleagues (1986) reports that 31% of the participants remained cigarette free for at least 1 year by the use of the ALA "Freedom from smoking" self help manuals, nicotine gum, and brief and repeated professional supervision. Shuster (1996) mentions that minimal contact smoking cessation programs in addition to the manual "Freedom from smoking for you and your family" caused a 15% quit rate. McFall (1993) applied a variant of the ALA's "Freedom from smoking in 20 days" within a televised smoking cessation program which showed that smokers who preferred written materials tended to use newsletters. All studies confirm that use of written materials from the ALA are easy to distribute and are cost effective.

Regarding community wide smoking cessation contests, Elder and colleagues (1991) found that use of "Up in smoke" cessation in the form of a lottery with the "quit and win" approach was associated with a quit rate of 20%. This method could be cost effective on a large scale. In an extensive study, Bains (1998) performed a literature review of population-based smoking cessation interventions with incentives and calculated a 23% mean rate of quitting at 1 year follow up. Therefore, for smokers of a community, use of incentives could provide another cost effective solution in addition to the commonly used smoking cessation programs.

## Workplace smoking cessation interventions

Total prohibition of smoking and enforcement of a smoking ban at all workplaces is the most effective solution in causing a high quit rate among smokers. Petersen and colleagues (1988) found that prohibition of smoking in all work areas at an insurance company produced a 93% reduction among those who smoked at least 2 packs of cigarettes daily. Mankani, Garabrant and Homa (1996) examined the effectiveness of nicotine patches in a 70 day treatment regimen at the workplace and measured a 9% abstinence rate after 11 months of follow up. On a larger scale, Fisher (1994) reported an estimate that smoking cessation rates among 98 participants in cessation clinics at pilot and test sites in addition to 350 randomly sampled respondents among all 877 employees at those test sites ranged from 21 to 41% for a worksite oriented program. Similarly, Omenn (1988) compared three programs: multiple component program (MCP), relapse prevention program (RPP) and the American Cancer Society's quitter's guide (ACSQG) among 13, 171 employees who were currently smoking and measured short term quit rates of the following: MCP- 61%, RPP- 37%, ACSQG- 12%. Overall long term quit rates for his study ranged from 16% to 26%.

Use of incentives within the workplace is not as effective as in the general community; still, incentives increase quit rates beyond those typically observed in the worksite. Klesges (1988) looked at 107 employees at five worksites and concluded that 16% quit smoking in the competitive setting which was still more effective than the noncompetitive settings where the quit rate was 7%. Jason (1997) found that among employees of 38 workplaces, 26% of participants who were provided support and incentives were abstinent relative to 16% of those who were only provided self help materials at 12 month follow up. Finally, Sloan (1990) used a year long multiple lottery quit smoking contest among 73 employees to achieve a continuous 1 year abstinence rate

of 32.8%. On the other hand, Glasgow and colleagues (1993) concluded that the use of incentive and no incentive smoking cessation programs among about 1100 smokers at 19 moderately sized worksites showed the incentive program to have no significant improvement over the non-incentive one.

## Hospital based smoking cessation interventions

Successful interventions have been used in the hospital setting using physicians, residents, primary care nurses, nurse practitioners, and pharmacists. Ockene and colleagues (1988) mentions that a three hour training program for 50 internal medicine residents at an university medical center significantly improved their ability to promote smoking cessation. Dawley (1984) mentioned that use of a hospital smoking cessation treatment program among 15 hospital employees and 2 patients produced a 53% success rate. Similarly, Montner (1994) reports that a training program for 34 residents at a hospital serving a predominantly black inner city area increased the rate of advising black patients to quit smoking. Andrews (1999) reports that use of a primary care nurse delivered intervention in a tobacco cessation HMO program resulted in 30.5% of the enrollees quitting tobacco use.

## Media based smoking cessation interventions

Numerous media approaches have been used in smoking cessation programs. Cummings (1987) found a newspaper mediated quit smoking program in Buffalo New York achieved a 4% quit rate for at least one week. Although the intervention through the newspaper did not show comparable quit rates to that of television, using the print media could be a very inexpensive way of disseminating anti-smoking information.

A combination of media interventions with other methods such as self-help manuals can enhance effectiveness. Salina (1990) reports that using self help manuals in conjunction with either a 20 day televised series advertising anti-smoking literature or a television series on quitting techniques plus social support contributed to a 30% abstinence rate in group participants versus a 19.5% rate in non-group participants. Valois (1996) developed a strategy called "Cablequit" which involved a 6 week community cable television smoking cessation program in addition to thirteen 30 minute long "live" sessions, each of which was followed by a 30 minute "live" telephone call in support segment. Warnecke (1992) noted that smokers who registered for a cessation program that comprised 20 televised segments plus the ALA's "Freedom from smoking in 20 days" manual had a 6% 24 month adjusted cessation rate, relative to 2% within smokers who did not receive the treatment. Use of a televised version of the ALA brochure "Freedom from smoking in 20 days" encouraged more blacks, females and those with incomes less than \$13,000 annually to join the smoking cessation program.

## Smoking cessation programs in special populations

A variety of smoking cessation interventions have been tested in women, children and adolescents and ethnic minority groups. Interventions tested within each of these groups are highlighted. Aaronson (1985) found that a smoking cessation program with a home correspondence format that included 7 weekly mailings and a telephone answering machine adjunct for all pregnant women who were attending a HMO prenatal clinic led

to a 28.5% cessation rate. Manfredie (1999) estimated that 14.5% of smokers affiliated with prenatal, family planning, and pediatric services in 12 public health clinics quit when exposed to a multicomponent motivational smoking cessation intervention. Freels (1999) targeted 722 low income female smokers with a high school education or less in the Chicago metropolitan area and found that smokers who were older, black, or at higher stages of readiness were more likely to quit when exposed to a targeted smoking cessation intervention with both television and booklet components. O'Loughlin (1997) found that the "Yes, I quit" smoking cessation course in women within a low income, low education community had a 22.3% quit rate after a six month period. For pregnant women in an urban setting, Price and colleagues (1991) applied a special video program based on female perceptions of smoking effects during pregnancy to one group while another group received the ALA'a "Freedom from smoking for you and your baby", and a third group received physician advice. There was a 6% overall quit rate for this study.

Because of the rising prevalence of smoking among children and adolescents, interventions directed toward smoking prevention and cessation are critical within this group. Farkas (1996) reported that the earlier parents quit smoking, the less likely their children will become smokers. Prince's (1995) study looked at a six session peer led smoking intervention program for high school age youth in comparison to the same program led by adults within a cohort of 93 students. Results of this study demonstrated a significant reduction in smoking rates among those who received the peer led intervention.

Racial and ethnic minorities experience a greater burden of tobacco related illness. Successful interventions seem to be more difficult to achieve in certain populations, especially among black Americans, Hispanics, and Native Americans. Therefore, smoking cessation interventions targeted toward these various groups are essential (Cataldo, Cooley & Giarelli, 2000). Resnicow (1997) examined the effects of a culturally sensitive, low intensity smoking cessation intervention with a printed guide, video, and a telephone booster call or health education materials which did not directly address tobacco use on a group of low socio-economic black American and found no significant results. Boyd (1998) reports that the impact of radio and television advertisements with a community outreach in 14 black American communities was effective in reaching the underserved population at risk. Fisher (1998) concludes that a 24 month community intervention in black American neighborhoods in St. Louis and Kansas City was effective in these neighborhoods. In another study, Voorhees (1998) found that a multimodal culturally sensitive intervention was more effective than self help interventions in 22 urban black American churches. Nevid (1996) found that at 1 year follow up among 48 male and 45 female Hispanic subjects, the culturally specific, multicomponent behavioral smoking intervention which had a 8% quit rate was not different from the low intensity, enhanced self help group interventon which had a quit rate of 7%. Finally Hensel and colleagues (1995) reported a 21% quit rate at 12 months follow up in a population of Alaska Native Indians after use of a tobacco cessation program using behavioral modification classes and transdermal nicotine patches.

## Clean indoor air

As more has become known about the effects of environmental tobacco smoke, more and more businesses have restricted smoking on site. Government worksites, private worksites, and restaurants, day care centers and home based day care are required to have designated smoking areas (Centers for Disease Control, 1999b; Connecticut Public Health Code, 2000).

## Taxes

Data from research on the relationship between cigarette prices and cigarette consumption support the conclusion that substantial increases in cigarette excise taxes reduce smoking, especially among youths (Lynch & Bonnie, 1994). Moreover, the revenues from these taxes can be used to fund anti-tobacco initiatives within the state. Evidence exists that state tobacco control programs can make a difference in tobacco use. For example, California has been a leader in implementing an aggressive tobacco control program and demonstrated a decline in cigarette consumption that was over 50% faster than the national average (Pierce, Gilpin, Emory, et al., 1998). Multifaceted state tobacco control programs are best for reducing tobacco use. Key elements of a State tobacco control program should include: antismoking education, prevention and cessation programs, an independent oversight committee, infrastructure and competitive grants available to community organizations and schools, and educational programs that reach out to the youngest child and continue to reinforce health promoting messages (Centers for Disease Control, 1999c; Glanz, 1998).

The potential exists for significant investment in tobacco prevention and control activities through the use of excise taxes, state settlements or through potential federal and state legislation. In order for comprehensive tobacco control programs to attain their maximal effectiveness, however, it is critical that funding from sources earmarked for tobacco prevention and control be directed to those efforts and not diverted to other causes (Advocacy Institute, 2000).

## Federal, state, and local laws on youth access to tobacco

It is illegal for youths to purchase tobacco in Connecticut. The minimum age for sale is 18 years and any person who sells to minors can be fined up to \$200.00. Revocation and/or suspension of licenses can occur for violation of this law. Tobacco vending machines must be located where minors cannot access them unless the machines are supervised (Centers for Disease Control, 1999b).

## Summary

Smoking is the leading cause of preventable death in the United States, causing an estimated 420,000 deaths per year (Centers for Disease Control, 1993). Every day, an estimated 3000 young persons start smoking and of those who continue smoking regularly, approximately 50% will eventually die from smoking related illness (Centers for Disease Control, 1995a). Estimated medical care costs attributed to smoking totaled \$50 billion in 1993 (Centers for Disease Control, 1994). A male smoker incurs approximately \$9,000 more in medical care costs over his lifetime than a male who has

never smoked, and a female smoker incurs approximately \$10,000 more than a female nonsmokers (US\$ 1990) (Hodgson, 1992).

The National Cancer Institute has conducted over 15 years of research on strategies to reduce the cancer deaths attributed to tobacco in this country. The limited impact of clinic-based cessation programs together with increasing recognition of the importance of environmental factors in smoking behaviors, have led to broadening tobacco control strategies to include interventions in community organizations, the health care system, schools and work sites (Centers for Disease Control , 1999c). These are designed to affect public opinion on tobacco use and health.

Research suggests that reducing youth access to tobacco results in lower smoking rates (Lynch & Bonnie, 1994). Given the irrefutable data linking tobacco use to serious health effects, it is appropriate to prevent tobacco use among youths and to develop educational behavior and social change strategies for smoking cessation for all smokers who want to quit.

Clinical trials related to prevention and early detection of lung cancer

There is a need for greater willingness among health care providers and the public to support clinical trials. Enrollment in a clinical trial or National Cancer Institute approved protocol often affords consumers the best therapy available. Yet many eligible patients are unwilling to participate in clinical trials and physicians may neglect to refer them to appropriate and available protocols. In general, those who participate in cancer clinical trials tend to be white, younger and have advanced disease (Friedman, 1987). Reasons for consumer refusal to participate included concerns about experimentation, toxicity and cost. Physician refusals tended to reflect a preference for specific alternative therapy (Hunter, Frelick, Feldman et al., 1987).

In response to this evidence, the National Cancer Institute Office of Cancer Communications initiated an information dissemination and educational program in 1988 to foster physician, patient and general public acceptance of and participation in clinical trials. The American Cancer Society has also strongly endorsed clinical trials participation as a means of improving cancer care by sponsoring workshops and developing a public education program (Lawrence, 1990).

Although many clinical trials have focused on treatment of cancer, clinical trials aimed at prevention and early detection of cancers are also needed. Prevention and early detection is particularly important in lung cancer because most adults with lung cancer present with advanced stages of disease. Several potentially promising areas have been identified for prevention and early detection of lung cancer including chemoprevention and the use of spiral computerized tomography scans in those at high risk for developing lung cancer.

Chemoprevention is defined as the use of specific natural or pharmacologic agents to prevent or reverse the process of developing invasive cancer (Greenwald & McDonald, 1997; Hong, 1999). Epidemiologic studies have shown a relationship

between the intake of several vitamins and the incidence of different types of cancer. For example, an inverse relationship exists between the intake of foods high in vitamin A (specifically the retinoids/carotenoids), raw fruits and vegetables vitamin E supplements and the incidence of lung cancer (Mayne et al., 1994; Mayne, Redlich & Cullen, 1998). In order to clearly understand the role of chemopreventive strategies, clinical trials using micronutrients aimed at lung cancer are underway.

Although clinical trials conducted during the 1970's did not show that screening for lung cancer reduced mortality, recent evidence from the Early Lung Cancer Action Project challenges this notion (Fontana et al., 1986; Smith, 1999; Tockman, 1986). The Early Lung Cancer Action Project was designed to evaluate the use of low radiation dose CT scans as a potential screening method for detecting early stage lung cancer in those at high risk for the disease. Adults aged 60 years and over, with at least a 10 year pack history of cigarette use and no previous cancer were selected as participants in this study. Preliminary results from the study suggest that yearly screening with low dose radiation CT scans increased the diagnosis of lung cancer at earlier and potentially more curable stages (Henschke et al., 1999). Furthermore, sharing the results from the scans may provide motivation for patients to quit smoking. In a follow up study, 23% of participants who looked at their scans reported that they stopped smoking and an additional 23% reported that they cut back (Sussman, 2000). Although these results are promising, long term follow up and further studies are needed.

## Summary

Although prevention of smoking, promoting smoking cessation and efforts directed toward tobacco control remain the most effective strategies to combat the development of lung cancer, new strategies are emerging that offer promise in helping to decrease the incidence and also identify lung cancer at earlier stages when curative treatment may be effective. In order to evaluate the potential usefulness of these new prevention and early detection modalities, clinical trials examining their efficacy are needed.

## BREAST CANCER CONTROL PLAN FOR CONNECTICUT

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## BREAST CANCER CONTROL PLAN FOR CONNECTICUT

# Goal 1: Promote clinician knowledge of appropriate utilization of breast cancer screening and follow up activities

## Objectives:

- Increase numbers of primary care providers who recommend mammograms to their eligible patients
- Promote use of reminder or tracking systems to help identify those who need screening and/or follow up
- Increase medical education in the area of breast cancer public education, screening, detection and follow up
- Establish a formal agreement among pertinent health care professionals in the state as to who should be responsible for notifying women of the need for repeat mammograms and follow up for abnormal results

#### Interventions:

- Promote and conduct continuing medical education programs and/or training conferences in breast cancer education among all pertinent health care providers (primary care physicians, nurse practitioners, physician assistants).
- Determine baseline data as to the number of pre-existing programs being offered in targeted educational institutions.
- Promote through existing channels of the health professional organizations, innovative systems and/or the latest in computer technology for the use of tracking and reminder systems for breast cancer.
- Disseminate information about current trends, significant data and research findings, risks, incidence mortality data of Connecticut residents.
- Work cooperatively to establish a formal protocol in the state to ensure that women are being notified of need for follow up and abnormal results of mammogram.
- Identify leaders in model tracking and reminder systems for breast cancer screening and follow up.
- Develop a formal protocol for repeat mammograms and notifying women of abnormal results.

- Evaluate the number of actual professional educational programs organized and implemented and the number of participants attending programs.
- Evaluate the number of health care provider schools (physicians, nurses, physician assistants) and training programs offering comprehensive breast cancer education.
- Prepare articles for publication in newsletters, journals and existing communications of the health professionals target groups.

# Goal 2: Promote consumer knowledge of appropriate utilization of breast cancer screening and follow up activities

## Objectives:

- Increase knowledge and change attitudes of all women with regard to the importance of breast cancer screening
- Promote outreach activities within communities across the state to increase awareness about breast cancer screening
- Provide adequate resources to enable all women in need of diagnostic follow up to receive care in a timely manner
- Target interventions toward high risk groups such as older adults, minority and low income women

#### *Interventions:*

- Develop and maintain an inventory of breast cancer screening and diagnostic services by type, cost, location, and eligibility criteria.
- Inform the public about the availability of breast cancer screening and diagnostic services and how to obtain them.
- Publish resource information on the internet about locally available breast cancer screening programs.
- Encourage local health agencies to make screening services available during existing community events and in cooperation with churches, civic groups and businesses.
- Conduct a community assessment of knowledge, attitudes and behavior representative of high-risk target groups. Data will be used to ensure effectiveness and appropriateness of community education.
- Recruit and convene statewide advocacy group to address public issues related to breast cancer.

- Establish collaborative agreements with pertinent agencies for intervention implementation are established.
- Publish report of community assessment.
- Inventory breast cancer screening and diagnostic services.
- Develop an Internet site that disseminates breast cancer information.
- Solicit broad based support and participation in implementing breast cancer control plan.
- Monitor breast cancer screening rates through the Behavioral Risk Factor Surveillance Survey.

## Goal 3: Promote mammography quality assurance

## Objectives:

- Promote continuing education programs for physicians and allied health professionals involved in mammographic screening
- Promote uniform reporting procedures of mammogram results from radiologic facilities to referring physicians and referring physicians to patients
- Submit, support and testify for pertinent legislative initiatives in the area of mammography quality assurance
- Develop with community health centers statewide a triage network for mammography screening as well as diagnostic testing and follow up for patients with abnormal mammogram results
- Develop a tracking and reminder system at selected facilities for patients in target populations with an abnormal mammogram or in need of repeat screening

## Interventions:

- Work with the Radiological Society of Connecticut Inc and the Connecticut Society of Radiologic Technologists to facilitate the organization, implementation and sponsorship of professional education programs.
- Conduct continuing education for radiologist and radiologic technologists simultaneously, as often as possible, to assist in developing a cooperative venture that supports a team approach.
- Work collaboratively with the Radiological Society of Connecticut Inc to encourage and provide technical assistance and information regarding ACR accreditation and MQSA compliance.
- Inform facilities of a formal protocol established by pertinent agencies/organizations in the state to refer public inquiries for mammography only to facilities in compliance with MOSA.
- Recruit and convene advocacy group to investigate relevant issues and submit and report legislative initiatives.

- Monitor the number of educational programs that are provided.
- Monitor the number of mammography units in the state which are in compliance with MQSA.
- Monitor the number of accredited facilities within the state.
- Monitor number of legislative bills submitted and legislation passed.

# Goal 4: Promote better understanding of genetic testing for breast cancer and ensure that test results are kept confidential and not used to discriminate against individuals who are tested.

## Objectives:

- Increase provider understanding of genetic testing
- Promote patient and family understanding of genetic testing and its ramifications
- Protect confidentiality of genetic test results

#### Interventions:

- Promote genetic counseling as a required component of all genetic testing programs.
- Convene a statewide advisory panel to establish standards for genetic testing programs.
- Establish systems to protect confidentiality of genetic test results.
- Provide professional educational programs related to genetic testing and its ramifications.

- Monitor the legal and ethical implications of genetic testing.
- Monitor the number of educational programs for health care professionals.
- Develop an inventory of genetic testing programs offered within the state and identify whether genetic counseling is provided as a component of the program.

## **Breast Cancer**

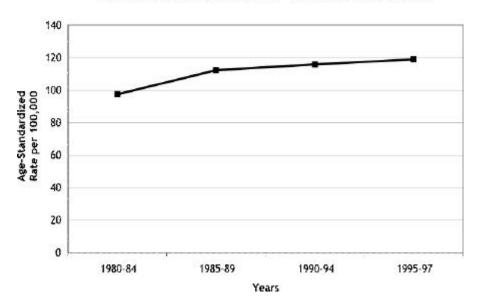
## **Background**

The incidence of breast cancer has increased over the past twenty years, due in part to more women undergoing screening examinations. Despite the increasing incidence, however, the mortality rate has remained relatively constant. This stable mortality rate probably reflects the effects of early detection and treatment, which have somewhat offset the rising incidence of the disease. Very recent data have, in fact, shown a decrease in breast cancer deaths among white women for the first time, although not among black women (Dignam, 2000).

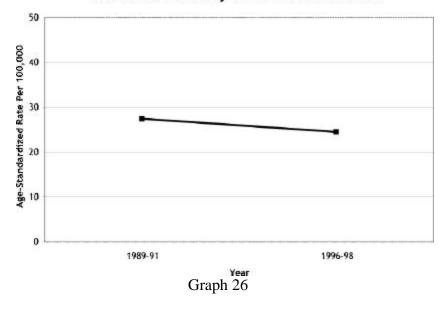
Breast cancer is the most common cancer diagnosed among Connecticut women and is the second leading cause of cancer deaths. The risk of breast cancer may be modified by lower fat intake, higher fruit and vegetable consumption, increased physical activity, reduced body weight, and reduced alcohol intake. Nearly one-third of Connecticut breast cancers were detected at regional and distant stages, after some metastasis had occurred. Mammography and clinical breast examination are important in reducing breast cancer mortality, through detection at an early stage. As the graph below indicates, age standardized incidence rates increased in Connecticut from 1980-1984 through 1990-1994, and in 1990-1994 the rate was 115.9 per 100,000. Age standardized incidence rates have leveled off for both black and white women such that rates were 119.3 per 100,000 women between 1995- 1997.

Graph 25

Breast Cancer Incidence for Connecticut Residents



## **Breast Cancer Mortality for Connecticut Residents**



Age is the most important risk factor for breast cancer. The risk of being diagnosed with invasive breast cancer increases by more than 15 fold between 30 and 70 years of age (Harris & Leininger, 1995). Over 78% of breast cancer occurs in women over 50 years old; over 50% occurs in women over 60. Two other important factors are family history of breast cancer and a personal history of breast cancer. An inherited susceptibility is linked to breast cancer in about 5 to 10% of cases (King, Rowell & Love, 1993). Family clusters of breast cancer have been reported in the cancer literature. A women's lifetime risk of breast cancer is increased by any maternal or paternal family history of breast cancer. The risk is greater if breast cancer is diagnosed in a first degree relative (mother, sister or daughter). Roughly half of the estimated hereditary breast cancer may be due to mutations in the two breast cancer susceptibility genes BRCA1 and BRCA2. Both genes along with a number of other genes associated with breast cancer are located on chromosome number 17. The estimated prevalence in the United States of the BRCA1 mutation that results in breast cancer is about 0.2% and the BRCA2 mutation is less common (Hoskins, Stopfer, Calzone, et al., 1995). Finally, white women have a higher risk of being diagnosed with breast cancer than do black women (Dignam, 2000).

Secondary risk factors for breast cancer include delivery of a first child after age 30, never having given birth, history of endometrial or colon cancer, early menarche, obesity in post-menopausal women, and late menopause. Fat consumption, oral contraceptive use, hormone replacement therapy, and alcohol use are other possible, but not proven, risk factors.

Women diagnosed at a later stage have lower overall survival rates than those diagnosed at an earlier stage. Black women generally have more advanced breast cancer at the time of diagnosis; in addition, their survival rates are lower at any given stage of diagnosis (King, Rowell & Love; 1993, Qualters, Lee, Smith & Aubert, 1992). Although the incidence of breast cancer is lower among black women, a higher percentage of black women with breast cancer die from it than white women (Dignam, 2000).

Until breast cancer can be prevented, the only way to reduce its mortality will continue to be through early detection and timely treatment. Assuring that all women receive appropriate and necessary follow up is a complex undertaking that requires a multifaceted, comprehensive plan. Such an approach involves three major components: screening, follow up, and quality assurance. Genetic screening may assume a more important role in the future. Therefore, issues related to genetic screening will also be highlighted.

## Screening

Research has demonstrated that early detection through regular screening mammograms and a breast examination by a trained clinician can reduce mortality from breast cancer by about 30% among women over age 50 (Department of Health and Human Services, 1994). Monthly breast self examinations are a third recommended screening method, although limited research has been done on their efficacy in lowering mortality from breast cancer (O'Malley & Fletcher, 1987; Morrison, 1991). Results after ten years from a British non-randomized trial did not show a decrease in mortality (Ellman, Cox & Richardson, 1993).

Among women aged 50 to 69, regular mammography alone can decrease mortality by about 33 percent (Elwood, Cox & Richardson, 1993; Fletcher, Black, Harris, Rimer & Shapiro, 1993; Forrest & Alexander, 1995). Regular mammography is capable of detecting cancers too small to be found on clinical breast examination (US General Accounting Office, 1990). The effectiveness of mammography in detecting breast cancer among women 50 years of age and older is generally accepted. Most expert groups recommend annual or biennial mammograms for this group (see Table 12).

Because some studies have shown no impact in mortality among women under 50, considerable controversy surrounds recommendations for mammography screening among younger women (Shapiro, 1994). The American Cancer Society and a consensus conference of the American College of Radiology with twelve medical organization recommend beginning mammography when a women is in her forties; the American College of Physicians and the U.S. Preventive Services Task Force make such a recommendation only for a women with a family history of breast cancer, and the National Cancer Institute recently dropped its guidelines and recommends only that younger women make informed decisions with the help of their physicians (O'Malley, 1995). These recommendations for women in the decade between 40 and 49 are intended for the average risk, asymptomatic woman; a woman in the high risk category should decide with her physician at what point to begin regular mammography screening.

Despite strong epidemiologic evidence that screening for breast cancer with mammography and clinical breast examination can reduce mortality rates, most women are not screened according to recommended guidelines (Smith & Haynes, 1992). The National Health Interview Survey found that in 1990 only 63% of women over the age of 40 reported ever having a mammogram; this rate does indicate, however, a doubling from

the 1987 rate (Breen & Kessler, 1994). Only 28.6% of the women surveyed adhered to screening guidelines specific to their age and intended to continue doing so.

## Table 12 Breast Cancer Screening Recommendations

## Recommendation from U.S. Preventive Services Task Force

- Mammogram: Every 1-2 years for women age 50-69. There is insufficient evidence to recommend for or against routine mammography for women age 40-49 or 70 and older, although recommendations for high-risk women age 40-49 and healthy women 70 and older may be made on other grounds.
- Clinical Breast Exam: Every 1-2 years for women age 50-69. There is insufficient evidence to recommend for or against routine clinical breast exam for women aged 40-49 or 70 and older, although recommendations for high-risk women age 40-49 and healthy women 70 and older may be made on other grounds. There is insufficient evidence to recommend for or against the use of clinical breast exam alone.
- **Breast Self Exam:** There is insufficient evidence to recommend for or against the teaching of breast self exam.

## Recommendation from the National Cancer Institute

- **Mammogram:** Women age 40 and older should have a screening mammogram every 1-2 years. Women who are at increased risk for breast cancer should seek medical advice about when to begin having mammograms and how often to be screened.
- Clinical Breast Exam: A clinical breast exam should be performed at the same time as the mammogram.
- **Breast Self Exam:** Studies have not shown that breast self exam reduced the number of deaths from breast cancer. Therefore, it should not be used in place of a clinical breast exam and mammography.

## Recommendation from American Cancer Society:

- Mammogram: Every year for women age 40 and older.
- Clinical Breast Exam: Every year for women age 40 and older. Every three years for women age 20-39.
- Breast Self Exam: Every month for women age 20

## Public Education

Many studies have been conducted to identify both the barriers to screening and the educational interventions needed to overcome these barriers. Common barriers to breast cancer screening are listed in Table 13. Subgroups of women with poorer utilization rates, including those of lower educational or socioeconomic status, those who are older or minority women, may have special barriers. The most important barriers are lack of a health care provider's recommendation that a woman have a screening mammogram and a woman's belief that mammograms are unnecessary unless she has symptoms (Bastani & Marcus, 1991; Rimer, 1995). A survey of underserved women in six sites across the nation found reasons for not receiving screening (lack of knowledge regarding screening and who should be screened, lack of recommendation by health professional, and no time) to be similar reasons stated by all women (The National Cancer Institute Cancer Consortium for Underserved Women, 1995). This suggests that

many interventions will work across population groups. Fear of radiation, of finding cancer, and of embarrassment have also been reported, particularly among black and Hispanic women (Fox & Stein, 1991).

# Table 13 Barriers to Breast Cancer Screening

- Cost
- Lack of perceived risk
- Pain
- Lack of awareness
- Embarrassment
- Access
- Anxiety over results
- Communication barriers
- Lack of a recommendation by a health care provider

Many older women underestimate their true risk of the disease, particularly if they do not have a family history of breast cancer, do not understand that risk increases with age, and do not know that most breast cancer is non-familial. Thus, a lack of understanding that risk increases with age and that screening is most effective for women at higher risk may lead to increased worry among younger women and a lack of utilization among older women (Harris et al., 1991).

Older, poorer, less educated working women, and women with less knowledge of breast cancer risk factors and screening guidelines, are all less likely to have a clinical breast examination, as are those with little contact with health care providers. Overall, research indicates that factors related to socioeconomic status are predictors of not receiving screening for breast cancer. Inaccurate beliefs about the disease also contribute to low screening rates (Lerman et al., 1992; Burg, Lane & Polednak, 1990).

Efforts to educate women about the need for breast cancer screening have varied in their ability to overcome these barriers and increase screening rates. Some successful attempts to persuade women of the necessity of screening mammograms have used nurse practitioners, videotapes, and tailored letters from physicians to their patients (Bastani, Marcus, Maxwell, Das & Yan, 1994; Rothman, Salovey, Turvey & Fishkin, 1993; Skinner, Strecher & Hospers, 1994). Others have involved individualized telephone counseling with patients (King, Rimer, Scay, Balshem & Engstrom, 1994). Comprehensive campaigns that target not only individual women but also their communities, physicians, legislators, and the health care system have been more successful than those aimed primarily at women at risk (Ansell, Lacey, Whitman, Chen & Phillips, 1994; Lane, Polednak & Burg, 1992).

Educational campaigns must be targeted to the appropriate audience, whether that be physicians or women. Some studies have suggested expending more effort in targeting health education campaigns to older women because this is the group with the highest potential gain from breast cancer screening (Rimer et al., 1992).

## Provider Referral and Promotion

Women report that the most important reason to have a mammogram was a physician's recommendation (Fox & Stein, 1991; Horton, Romans & Cruess, 1992). In the 1990 National Health Interview Survey, however, over 30 percent of women reported that their physician had not advised them to have a screening mammogram (Lerman et al., 1992). Surveys of physicians report that the barriers to their recommending mammography to patients include its cost, their belief that the examination is unnecessary, and concerns about radiation exposure (American Cancer Society, 1990).

Factors such as physician's gender, specialty, practice setting, and year of medical school graduation influence the rate at which they refer women for mammography. As knowledge, attitude, and cost barriers fall, organizational barriers, chiefly found in primary care office environments, will probably assume a more dominant role in determining how many eligible women receive mammography on a regular basis (Gann, Melville & Luchman, 1993). Intervention programs need to be developed that target physicians with the greatest deficiencies in breast cancer screening performance and knowledge, including older physicians in primary care settings and medical specialists (Turner et al., 1992). Older women are those most in need of screening, and also most likely to have chronic disorders that require them to be under the care of specialists. It is thus extremely important that these specialists recommend screening to age appropriate patients.

#### Access

The expense of screening mammography is seen as a major barrier by physicians but its effect on women is less clear (O'Malley, 1995). Other important barriers include lack of time, especially for women who work full time, inconvenience of the times during which screenings are offered, and living more than 45 minutes from a screening site (Schechter, Vanchieri & Crofton, 1990). To increase screening rates, mammography needs to be available at low or no cost to women, be offered at work sites, and be located in accessible areas.

## Follow up of Abnormal Screening Results

For screening to result in a reduction in breast cancer mortality, all abnormalities must be appropriately followed up. As screening rates increase, the number of abnormalities will also increase. Delays in diagnosing breast cancer are a major reason for malpractice claims and result in the most costly awards (Katz, Hislop, Thomas & Larson, 1993). There is strong medical evidence that delays in diagnosing cancer and thus initiating treatment lowers the chance of survival.

The components of appropriate follow up care depend on the results of both the clinical breast examination and the mammogram. Follow up of breast abnormalities may

include a diagnostic (as opposed to a screening) mammogram, fine needle aspiration, core biopsy, x-ray localization, ultrasound, and surgical removal of the lump or cyst. Timely follow up demands considerable coordination among primary care physicians, obstetrician- gynecologists, radiologists, surgeons, public health nurses, social workers, health educators, and their office support staffs.

For a number of reasons, follow up for evaluation and treatment is often not completed. Rates of non-compliance differ dramatically depending on the medical setting and socioeconomic status and ethnicity of women. Lack of understanding by the patient about the next steps often contributes to incomplete follow up, as does inconsistent sharing of information among providers about tests that are required. Often follow up issues include accessibility to providers who can perform the procedures, the training level of professionals conducting the tests, quality equipment to perform procedures, as well as staff to interpret findings (North Carolina Department of Environment, Health and Natural Resources, 1996). Developing strategies to address barriers to follow up is essential in increasing survival from this disease.

### Patient Education

Abnormal screening tests sometimes have negative psychosocial consequences and may result in failure to comply with further screening tests and treatment. Women who have abnormalities found on screening mammogram often suffer from anxiety, depression, and fear of cancer, even if the cancer is not ultimately diagnosed (Paskett & Rimer, 1995). Psycho-educational interventions tailored to the unique needs of these women may reduce distress and promote continued adherence to follow up recommendations (Fox & Stein, 1991).

The process of motivating women to return for follow up begins with communicating abnormal test results (Paskett & Rimer, 1995). Such communications should balance needed information about the suspicion of breast cancer with reassurance about the relationship between early detection and cure (Lerman et al., 1992). The method of informing patients is also an important component of notification; proven strategies should be used to minimize patients' stress while optimizing their potential to follow through with recommendations.

## Provider Referral and Promotion of Follow up

Clear and appropriate communication is essential to facilitating timely and accurate diagnostic care. Compliance with follow up appears to increase when the wait for a follow up is fifteen days or less, thus minimizing patient distress, and when the instructions for follow up are clear and understandable to the patient (Manfredi, Lacey, & Warnecke, 1990; Paskett & Rimer, 1995). Because the follow up procedures for breast abnormalities require an array of professionals, a woman is unlikely to receive continuing care from the same practitioner at the same site. Rather, she is likely to encounter different specialties at different sites, such as community health centers, health maintenance organizations, local health departments, and primary care and specialists offices. Well designed systems to assure adequate responses to abnormal tests would decrease the number of patients lost to follow up and would likely increase survival. Such

systems should foster communication across different specialties and make adequate provision for informing women of the next steps they must take to obtain adequate care.

Physician recommendations are critical to motivating women to return for appropriate follow up (Paskett & Rimer, 1995). An office systematic tracking or reminder system is important for following women with abnormal results and for being able to assess compliance rates within a practice. Finally, women have reported provider insensitivity and clinic waiting as a barrier (Paskett & Rimer, 1995).

## Breast cancer screening in Connecticut

Because women's health is one of the established priorities for the State of Connecticut Department of Public Health, programs related to breast and cervical cancer control have been established (Connecticut Breast and Cervical Cancer Prevention and Control Coalition, 1994). The State of Connecticut Department of Public Health has been awarded funds by the Centers for Disease Control and Prevention (CDC) to develop the Connecticut Breast and Cervical Cancer Early Detection Program (CBCCEDP). The grant is part of the CDC National Breast and Cervical Cancer Program. Fifty states, three territories, the District of Columbia, and nine American Indian tribes and tribal organizations participate in this program. CDC provides national program leadership in collaboration with other federal agencies, professional, national, voluntary, and consumer organizations. Enactment of the Breast and Cervical Cancer Mortality Prevention Act of 1990 authorized CDC to implement many of the activities recommended in the National Strategic Plan for the Early Detection and Control of Breast and Cervical Cancers through partnerships with state health agencies and other national organizations.

The first funding period from CDC's cooperative agreement was a four year and seven month commitment that began March 1, 1995 and ended September 29, 1999. The CBCCEDP submitted a reapplication and received funds for an additional cycle of federal funding from October 1, 1999 through September 29, 2004. On July 1, 1996 the program was allocated money from the State of Connecticut Governor's Budget and has been allocated level state funding each year. In 1999, the CBCCEDP was allocated \$1,913,441 in state funds and \$1,466,00 in federal funds.

The goal of the program is to reduce breast and cervical cancer morbidity and mortality by diagnosing breast and cervical cancer at earlier stages. Progress is being made toward this goal by providing screening and diagnostic services to women in Connecticut who are 40 and over for mammograms and age 19 and over for Pap tests. Mammograms are also available for women age 35-39 if risk factors or symptoms for breast cancer are present. Women must also be at or below 200% of the federal poverty level and have no health insurance or health insurance that does not cover these services.

Activities supported under this program include screening and diagnostic services, referral for treatment, case management, tracking and follow up of clients, professional education for providers of services, community outreach, quality assurance, statewide professional education, public education and promotional activities to increase awareness

of the benefits of early detection. Specific procedures provided through this program include screening and diagnostic mammograms, breast biopsies, ultrasounds, fine needle aspirations, PAP tests, colposcopies, colposcopy-directed biopsies and surgical consultations. Office visits, which include a clinical breast examination and a pelvic examination, are also covered. As of June 2000, 12, 435 women have been screened for breast cancer (clinical breast examination, mammography, or both) and 2,617 of these women were recommended for diagnostic follow up. To date, 2,546 women completed their diagnostic follow up and, of these women, 91% have received a definitive diagnosis. The remaining women were either lost to follow up or refused further testing (State of Connecticut Department of Public Health 1998; personal communication, Joan Simpson, June 15, 2000).

Currently, eighteen primary health care facilities and multiple facilities provide statewide breast and cervical cancer screening. Statewide and community based public education campaigns have been conducted to bring program information directly to women in target populations through intensive outreach efforts linked with grass root organizations as well as the general population. To support the campaign, educational videos and informational posters and brochures have been developed and distributed statewide. In addition, emphasis is being placed on developing professional education programs for physicians, physician assistants, nurses, nurse practitioners, radiologic technologists and cytotechnologists to ensure high quality breast and cervical care in Connecticut.

All program activities are supported by the Connecticut Breast and Cervical Cancer Prevention and Control Coalition established by the CBCCEDP. The coalition consists of an array of experts in the area of cancer prevention and treatment and is chaired by the CBCCEDP Project Director. Members serve in an advisory capacity as well as on subcommittees and task forces as needed in program development, operations and implementation.

## Breast Cancer Screening Rates in Connecticut

Overall breast cancer screening rates in Connecticut are slightly better than rates reported by all states (22.0% vs. 26.8%) (Connecticut Department of Public Health, 2000). Although many women age 40 and older report that they have had a mammogram and clinical breast examination, the proportion of women who have had a recent mammogram and clinical breast examination (within the past year or two years is much lower (see Table 14). This finding underscores the fact that women need to be encouraged or reminded to be re-screened at the proper intervals.

Table 14 Connecticut Breast Cancer Screening Rates (1996-1997)

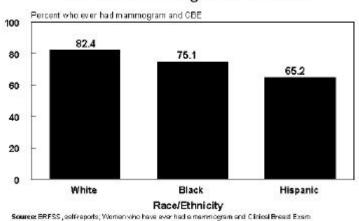
Breast cancer screening	Rate	N
CBE & M age 40+ ever	81.5%	1423
CBE & M age 40+ past yr	51.1%	1423
CBE & M age 50+ past 2 yr	68.3%	895

Source: BRFSS

Moreover, as the graphs below demonstrate certain subgroups of women, black, Hispanic, and those with lower income, are less likely to receive mammograms. Thus, these groups need to be targeted for screening.

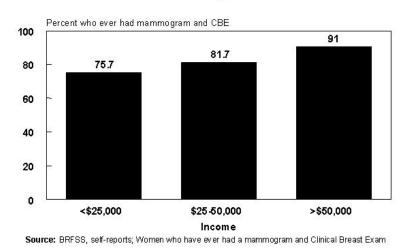
Graph 27
MAMMOGRAPHY AND OBE BY RACE/ETHNICITY

Connecticut Women Ages 40+ - 1996-97



## MAMMOGRAPHY AND CBE BY INCOME

Connecticut Women Ages 40+ - 1996-97



Graph 28

## Review of Intervention Studies

Although screening with mammography can decrease the mortality associated with breast cancer, the use of this screening method is not used often enough (Kerlikowske, Grady, Rubin, Sandrock & Ernster, 1995). It is unclear if the failure of women to seek screening is due to formidable barriers such as low income or low education or underserved women or rather the deployment of ineffective clinical or community based interventions (National Cancer Institute Cancer Screening Consortium for underserved women, 1995). Furthermore, it is becoming increasingly difficult to evaluate measures because of an increasing adoption of mammography screening throughout comparison cities (Zapka, Costanza, Harris, et al., 1993; Urban, Taplin, Taylor et al., 1995). That is, the percentage of women between the ages of 50 to 69 who obtain mammograms has increased since the 1980's from 20 to 40% (Cancer Control Supplements, 1987 and 1992). Therefore, as overall screening rates increase, targeted activities aimed at population subgroups may be warranted (Zapka, Costanza, Harris, et al., 1993; Urban, Taplin, Taylor et al., 1995; Rakowski, Ehrich, Rubenstein et al., 1998; Skinner, Strecher & Hospers, 1994).

Many of the barriers/perceptions to obtaining mammograms are race specific (Crane, Leakey, Rimer, 1998; Dibble, Vanomi & Miakowski, 1997). Latina women, for example, view embarrassment, perceived respect and politeness of provider, family involvement, anxiety over results, and radiation exposure as significant obstacles to screening. African American women view lack of knowledge, cost, lack of perceived susceptibility, fear of pain, and fatalism toward cancer as obstacles, though they do have a significantly more positive attitude toward screening than white or Latina women. Older women regard a lack of knowledge of procedure and need for it as well as a lack of symptoms as barriers to screening.

A literature search was done in Medline, for the years 1984 to 2000, to identify clinical interventions to promote early detection of breast cancer. Key words were breast cancer, breast cancer interventions, mammography, screening, cancer screening, and community interventions. Studies were selected if they attempted to increase the use of mammography or clinical breast examinations among women over the age of 40 with randomization. Twenty-four trials and 3 systematic reviews were evaluated (Parsa, Wang, Schulman & Germana, 2000). Promising clinical interventions for mammography and breast examinations are highlighted in the following section.

## Mammography

### **Physician Recommendations**

Physician recommendations, irrespective of setting, are the strongest predictors of mammography use (May, Kiefe, Runkhouser & Fouad, 1999; National Cancer Institute Breast Cancer Screening Consortium, 1990). Unfortunately, most physicians do not recommend screening. Less than half of the women who see their doctor report having a recommendation (Paskett, McMahon, Tatum et al., 1998). Most women who receive a recommendation, however, adhere to it while those who do not receive one do not seek a mammogram (Slenker & Brant, 1989; Reeves & Remington, 1999). An increase in the

rate of physician recommendations, then, should have an enormous impact on mammography and clinical breast examination rates among women over the age of 40.

Physician reminder systems have been observed in academic settings to increase mammography and clinical breast examination rates in women over the age of 40 who do not receive an annual mammogram (Mandelblatt & Danetcky, 1995). Mandelblatt et al (1995) found that the most effective means of increasing physician recommendation is to include a reminder for the physician in the patients' medical record. In this way the more pressing problems which the physician faces will not cause the physician to forget recommending mammography. She emphasizes that the strategy must be performed repeatedly for the positive effect to be maintained.

Community based and office based physician reminders have been shown to increase mammography and clinical breast examinations rates in women over the age of 40 who do not receive an annual mammogram by 20% and 15% respectively (Mandelblatt & Danetcky, 1995), although some reports conclude that the effectiveness of office system interventions are uncertain (Dietrich, O'Connor, Keller et al., 1992; Kinsinger, Harris, Qaqish, Strecher & Kaluzny, 1998). These strategies, such as exam room prompts, checklists, computer generated reminders, education, feedback of screening rates, or nurse generated reminders had modest effects at increasing cancer screening in primary care settings (Paskett, Tatum, D'Agostino et al., 1998; Cheney & Ramsdell, 1987; Korn, Schlossberg & Rich, 1988; Tierney, Hui & McDonald, 1986; Davidson, Fletcher, Tetchin & Duh, 1984). Feedback of screening rates to the physician was reported to be just as effective as physician reminder systems yet are much more expensive (Mandelblatt & Danetcky, 1995).

The training of non-physicians to identify women who do not receive an annual mammogram and subsequently to offer screening using standing orders seems to be an extremely effective strategy to increase breast screening rates (Margolis, Lurie, McGovern, Tyrell & Slater, 1998). The effectiveness of this type of intervention is undecided among white women (Margolis, Lurie, McGovern, Tyrell & Slater, 1996). These types of interventions demonstrate that training lay health workers is effective, probably because they are more flexible and culturally sensitive to women than are physicians.

### *Telephone Interventions*

The most practical, effective means of increasing mammography screening rates is to mail a written recommendation and follow up with a telephone call. In all telephone interventions reviewed, the written recommendation group did not have a significant increase in mammography screening rates nor did a written follow up (Crane, Leakey, Rimer et al., 1998; Taplin, Barlow, Ludman et al., 2000; Ludman, Curry, Meyer & Taplin, 1999; Taplin, Anderman, Grothaus, Curry & Montano, 1994; Davis, Lewis, Rimer, Harvey & Kiplan, 1997). Yet a telephone reminder following a written invitation did significantly increase mammography rates. Motivational telephone follow ups are just as effective as telephone reminders, therefore much effort or time does not need to be

invested into these telephone calls (Taplin, Barlow, Ludman et al., 2000; Taplin, Anderman, Grothaus, Curry & Montano, 1994).

### **Educational Interventions**

Distribution of educational materials does not significantly increase mammography rates unless such services are tailored to the specific ethnic groups or are accompanied by a facilitator in the development and implementation of an office system (Paskett, McMahon, Tatum, et al., 1998; Dietrich, O'Connor, Keller, et al., 1992). The latter of these approaches demonstrates the effectiveness of combining the limited number of interventions available to produce the desired effects. It may very well be that women may become accustomed to a certain strategy and no longer respond. Varying the implementation and/or combining strategies may cause women to respond more readily.

### Tailored Interventions

Tailored interventions have been endorsed as the most promising means of increasing breast cancer screening. Due to the increasing rate of screening irrespective of applied interventions, to further increase screening rates it has been suggested that efforts must tailor interventions to particular sub-populations (Rakowski, Ehrich, Goldstein, et al., 1998). Yet Rakowski and colleagues (1998), the only tailored intervention found, failed to show a significant difference between the stage of change matched interventions and the generic intervention. The stage matched intervention, however, was significantly better than no intervention.

### Community Organizations

Community organization has also been viewed as a promising approach to increase screening practices. This may entail the formation of local physician planning groups, informational mailings, and the physician reminder systems. Yet none of the studies reviewed showed any significant increase in screening rates between the intervention cities and the control cities (Urban, Taplin, Taylor, et al., 1995; Taylor, Taplin, Urban, et al., 1996). One systematic review did find that a multistrategy approach similar to a community organization intervention is the best approach to increase screening rates in inner city areas (Sin & Leger, 1999).

### **Breast Examinations**

Only two randomized trials have looked at screening by self examination (Jatoi, 1999). Neither of the studies showed a significant difference in breast cancer incidence or mortality. Yet the self examination group had a significant increase in the number of excisional biopsies.

No randomized trials have been done to date that compare screening by a physician with no screening. Yet there are mammography studies that also include a physician exam component. Four of eight mammography studies that Jatoi (1999) investigated showed between 59% and 74% of the breast cancer cases were detected by physical examination.

## Quality Assurance for Breast Cancer Screening and Follow Up

### Screening

Mammography with or without a clinical breast examination is the only screening technology clearly tied to reductions in breast cancer mortality. The screening must be of high quality if it is to be effective. Several interrelated factors are critical to quality: professionals who are well trained to perform clinical breast examinations and to refer women appropriately for mammography; proper interpretation of the images; accurate and prompt reporting of the interpretation to both the clinician and the patient; and having definitive outcome data provided to the diagnostician to assess the accuracy of the tests. It is also vital for mammography equipment to be properly maintained by qualified personnel with a quality assurance program in place (Department of Health and Human Services, 1994).

## Follow-up

The components of quality assurance and follow up include: 1) provide well trained professionals to conduct the procedures, 2) develop clear protocols for when and what procedures are to be used, and 3) promote communication among the professionals performing the diagnostic procedures so that care can be coordinated for each patient.

Recent concerns about the quality of mammography have made headlines. With women being encouraged to obtain screening, health care providers have a responsibility to ensure that mammography poses a low radiation risk and is of optimal quality. Furthermore, health care providers must ensure that all aspects of mammography, including personnel involved in positioning clients and interpreting films, reports, and clinical outcomes of positive mammograms are part of an overall chain of quality assurance.

The Mammography Quality Standards Act (MSQA) of 1992 authorized the Food and Drug Administration (FDA) to establish nationwide baseline quality standards. The regulations require that all facilities which provide, process, or interpret mammograms meet quality standards. These include standards for personnel engaged in mammography: the interpreting physician, the medical physicist, and the radiologic technologist. Essentially, the regulations require these providers to have licenses, be board certified or have specialized training in mammography, meet minimum practice requirements, and receive continuing education (State of Connecticut, Department of Public Health, 1998). In addition, the facility must use only dedicated mammography x-ray machines. Each facility needs to maintain a quality assurance program that ensures consistently high quality images with minimum exposure. Tests are done to monitor all radiographic equipment (processors, films, image receptors). A written report of results must be signed by the interpreting physician and sent to the health care provider. It is clear that the intent of these standards is to provide universal access to quality mammography.

## Genetic Testing and Breast Cancer

Technically, all cancers are genetic because they are caused by an alteration in cells' genetic material. However, it is believed that 5 to 10 percent of cancers are inherited (caused by a mutation passed from one generation to another) (Florida Cancer Control and Research Advisory Committee, 1997).

Testing is currently available for several genetic mutations. Mutations of the BRCA1 and BRCA2 genes are associated with an increased risk of breast and ovarian cancers. As genetic testing becomes more available, legal, ethical and psychosocial issues associated with testing need to be addressed.

## Counseling and Psychosocial Issues

Genetic counseling and informed consent are essential components of genetic testing programs. Individuals and families considering genetic testing need to understand the ramifications of their decision, how to understand and interpret the test results, and how the results will be used (Jacobs & Deatrick, 1999).

Individuals who test positive for genetic mutations will not necessarily develop cancer, and a negative test result does not mean that they will not develop cancer. A positive result may indicate a need for more frequent screening, i.e. more frequent mammograms and clinical breast exams for women at high risk for breast cancer, or lifestyle changes, i.e., high fiber, low fat diet for those at high risk for colon cancer. Some women with a strong family history of early onset breast cancer who test positive for BRCA1 or BRCA2 mutations consider prophylactic mastectomies. These decisions require extensive counseling and medical consultation (Florida Cancer Control and Research Advisory Committee, 1997).

Negative test results may provide peace of mind, but the possibility of a false negative result needs to be understood. Family members who have negative test results may feel guilty if others in their family receive positive test results. For these and other reasons, counseling plays a critical role in genetic testing

## Summary

There is a broad array of programs currently underway in Connecticut to address many of the issues that relate to breast cancer screening, follow up and quality assurance. Future challenges exist to improve breast cancer screening rates in Connecticut. Although the proportion of Connecticut women having ever had a mammogram and clinical breast examination is high, rates for ongoing screening are much lower. Therefore, efforts directed toward increasing the proportion of women who obtain repeat screening should be targeted. Moreover, certain sub groups of women, black, Hispanic, and those with lower income, are less likely to receive mammograms. Thus, these groups should be targeted for screening.

### COLORECTAL CANCER CONTROL PLAN FOR CONNECTICUT

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## COLORECTAL CANCER CONTROL PLAN FOR CONNECTICUT

## Goal 1: Promote clinician knowledge of appropriate utilization of colorectal cancer screening and follow-up activities

### Objectives:

- Inform clinicians of screening recommendations for colorectal cancer and effectiveness of screening modalities
- Increase numbers of primary care providers who recommend colorectal cancer screening to their eligible patients
- Promote use of reminder or tracking systems to help identify those who need screening and/or follow up
- Increase medical education in the area of colorectal cancer public education, screening, detection and follow up

### Interventions:

- Promote and conduct continuing medical education programs and/or training conferences in colorectal cancer education among all pertinent health care providers (primary care physicians, nurse practitioners, physician assistants).
- Determine baseline data as to the number of pre-existing programs being offered in targeted educational institutions.
- Promote through existing channels of the health professional organizations, innovative systems and/or the latest in computer technology for the use of tracking and reminder systems for colorectal cancer screening.
- Disseminate information about current trends, significant data and research findings, risks, incidence, and mortality data of Connecticut residents.
- Work cooperatively to establish a formal clinical protocol in the state to ensure that women and men are being notified of need for follow up and abnormal results of colorectal cancer screening.

### Evaluation Criteria:

- Convene a technical advisory group to monitor and disseminate scientific information about colorectal cancer screening.
- Evaluate the number of actual professional educational programs organized and implemented and the number of participants attending programs.
- Evaluate the number of health care provider schools (medical, nursing, physician assistant) and training programs offering comprehensive colorectal cancer education.
- Prepare articles for publication in newsletters, journals and existing communications of the health professionals target groups.
- Identify leaders in model tracking and reminder systems for colorectal cancer screening and follow up.
- Development of a formal clinical protocol for repeat colorectal cancer screening and follow up of abnormal test results.

# Goal 2: Promote consumer knowledge of appropriate utilization of colorectal cancer screening and follow up activities

### Objectives:

- Increase knowledge and change attitudes of women and men with regard to the importance of colorectal cancer screening and the need to request it
- Increase consumer knowledge of risk factors associated with colorectal cancer
- Increase the percentage of women and men who have fecal occult blood testing and sigmoidoscopy screening tests
- Promote use of tracking systems to inform women and men of the need for follow up and/or rescreening
- Reduce barriers to colorectal screening for all women and men 50 years of age and older
- Target interventions toward high risk groups such as minority groups

#### *Interventions:*

- Recruit and convene statewide technical advisory group to address public issues related to colorectal cancer.
- Promote public education about colorectal cancer, its risk factors and screening recommendations.
- Conduct a community assessment of knowledge, attitudes and behavior representative of high-risk target groups. Data will be used to ensure effectiveness and appropriateness of community education.

### Evaluation Criteria:

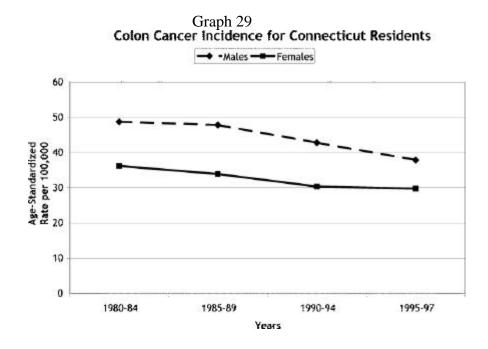
- Publish report of community assessment.
- Develop an Internet site that disseminates cancer information.
- Solicit broad based support and participation in implementing colorectal cancer control action plan.
- Monitor colorectal cancer screening rates through the Behavioral Risk Factor Surveillance Survey.
- Evaluate the extent to which state laws and regulations foster the use of colorectal cancer screening.

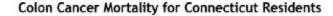
### **Colorectal Cancer**

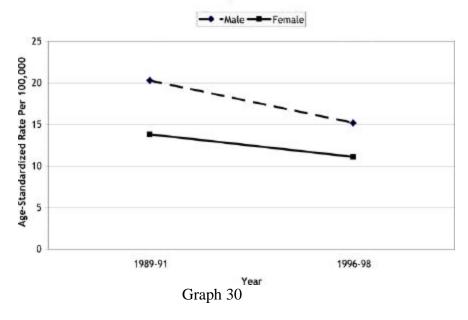
## Background

Risk factors for colorectal cancer include a family history of the disease, a history of large adenomatous colon polyps, and possibly poor diet and sedentary lifestyle. About 15 percent of all colorectal cancer patients have a family history of the disease in a first degree relative (DeCosse, Tsioulias & Jacobsen, 1994). People with a first degree relative with colorectal cancer have a two to three fold greater risk than persons with no family history; that risk is increased further if the relative with colorectal cancer was younger than 55 at the time of diagnosis (Ransohoff & Lang, 1991, Fuchs, Giovannucci, Colidtz, et al., 1994). A positive family history is considered by many to be a reason for aggressive screening, starting several years earlier than the age at which the relative was diagnosed with colorectal cancer (Eddy, Nugent, Eddy et al., 1987; Levin & Murphy, 1992).

Colorectal cancer is the third most commonly diagnosed cancer in Connecticut. Evidence also supports screening for colorectal cancer among persons 50 years of age and older. As the graphs below indicate, age standardized incidence rates decreased for colon cancer in men and women in Connecticut from 1980-1984 through 1990-1994, and in 1990-1994 the colon cancer rate was 42.8 per 100,000 for males and 30.3 per 100,000 for females. It appears that rates have continued to decrease for males but have leveled off for females from 1995- 1997 such that the age standardized incidence rate for colon cancer was 37.8 for males and 29.7 for females per 100,000.

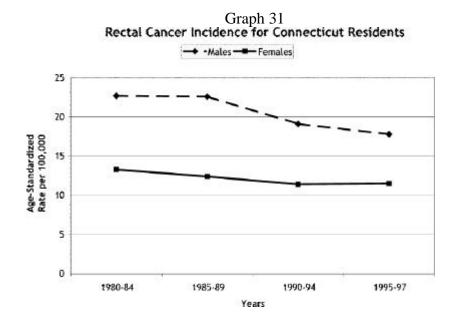




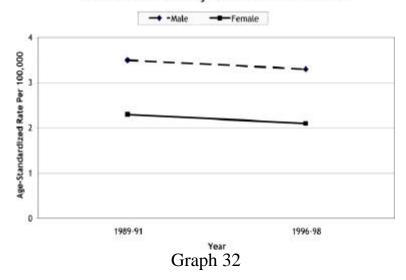


Age standardized incidence rates per 100,000 population for colon cancer were slightly higher for African American males (49.2) as compared with white males (42.0) between 1990 and 1995. No differences were evident between African American (30.1) and white females (30.4).

Similar to colon cancer, the graphs below demonstrate that the age standardized incidence rates per 100,000 population for rectal cancer rate was 19.1 per 100,000 for males and 11.4 for females. The rates continued to decrease for men, but have leveled off for women such that the age standardized incidence rates per 100,000 for rectal cancer were 17.4 for males and 11.5 for females.



### **Rectal Cancer Mortality for Connecticut Residents**



It is important to recognize that only 39% of colon cancers and 50% of rectal cancers were diagnosed at the in situ or invasive stage, when the 5 year survival is 90%. In contrast, the five-year survival rate for invasive colorectal cancers diagnosed in Connecticut residents is 62% (Connecticut Tumor Registry, 2000).

## Screening

There is now strong evidence that screening reduces colorectal cancer mortality. Table 15 provides information about current screening recommendations from various organizations. First, most agree that colorectal cancer develops slowly from adenomatous polyps and that, once a neoplasm has become cancerous, it generally does not metastasize until the cancer is relatively large (Muto, Bussey & Morson, 1975). This slow and orderly growth of colorectal polyps provides a long period during which they can be detected and removed before metastasizing. Second, compelling evidence indicates that fecal occult blood testing and sigmoidoscopy can detect some early cancers and large polyps (CDC, 1995). Recent studies suggest that colonoscopic screening can detect advanced colonic neoplasms in asymptomatic adults, many of which would not be detected with sigmoidoscopy (Imperiale, Wagner, Lin et al., 2000; Lieberman, Weiss, Bond, et al., 2000). Future studies are needed to more clearly determine the role of colonoscopy in routine screening.

There are two primary procedures currently available for screening for colorectal cancer: fecal occult blood testing and sigmoidoscopy. Such screening is for asymptomatic populations rather than for people with a history of polyps who should be under surveillance by a health care provider. Persons with one or more first degree relatives who have had colorectal cancer, especially if they had it before age 55, are at high risk and should also be screened more frequently. These procedures, and the supporting evidence for their effectiveness in detecting cancers early and reducing mortality, are discussed below.

## Table 15 Colorectal Cancer Screening Recommendations

### Recommendation from U.S. Preventive Services Task Force:

• Screening is recommended for all persons age 50 and older with annual fecal occult blood testing or sigmoidoscopy (period unspecified) or both. There is insufficient evidence to determine which of these screening methods is preferable or whether the combination of FOBT and sigmoidoscop[y produces greater benefits than does either test alone. There is insufficient evidence to recommend for or against digital rectal examination, barium enema or colonoscopy, although recommendations against such screening in average risk persons may be made on other grounds. Persons with a family history of hereditary syndromes associated with a high risk of colon cancer should be referred for diagnosis and management.

### Recommendation from the National Cancer Institute:

- **Fecal Occult Blood Testing:** Studies show that a FOBT performed every 1-2 years in people between the ages of 50-80 decreases the number of deaths due to colorectal cancer.
- **Sigmoidoscopy:** Stuides suggest that fewer people may die of colorectal cancer if they have regular screening by sigmoidoscopy after the age of 50.
- **Digital Rectal Exam:** The evidence does not suggest that digital rectal exam is effective in decreasing mortality from colorectal cancer.
- Barium Enema: There is not yet any information on the use of barium enema as a screening test.
- Colonoscopy: There is not yet any information on the use of colonoscopy as a screening test.

### Recommendation from American Cancer Society:

Beginning at age 50, men and women should have **one** of the following:

- **Fecal Occult Blood Testing and Sigmoidoscopy:** if normal repeat FOBT annually, and flexible sigmoidoscopy every 5 years.
- Colonoscopy: if normal, repeat every 10 years.
- **Double-Contrast Barium Enema:** if normal, repeat every 5-10 years.
- **Digital Rectal Exam:** should be done at the same time as a sigmoidoscopy, colonoscopy, or double contrast barium enema.

## Fecal Occult Blood Testing

The type of fecal occult blood testing used most commonly in the United States is one that examines for blood present in a fecal sample. False negative results can occur if a neoplasm does not bleed or if it bleeds less than the test can measure (Simon, 1985). False positive results can be caused by diet or other sources of bleeding (Herzog, Holtenmuller, Preiss et al., 1982). Clinical trials of fecal occult blood testing are underway. In one study that has published mortality results, a 33 percent reduction in colorectal cancer mortality was found (Mandel, Bond, Church et al., 1993). However, the overall, positive rate was 10% so that the vast majority of positive fecal occult blood test results were false positives. Because each positive result was evaluated with a colonoscopy or barium enema, false positive results refelected the poor specificity of this screening test (Mandel, Bond, Church et al., 1993). A recent case-control study showed that a mortality reduction of approximately 25 percent may be obtained with yearly fecal occult blood testing (Selby, Friedman, Quesenberry & Weiss, 1992).

Despite encouraging news from both the case-control study and the clinical trial, two characteristics of fecal occult blood testing suggest that its use will be problematic: the test's relatively low level of sensitivity (i.e. false negative rate) and lack of specificity (i.e. false positive rate). The high rate of false positives results in high costs for follow up and anxiety among patients. The sensitivity of fecal occult blood tests for large adenomatous polyps (1-2 cms) is only about 11 percent; for larger polyps (over 2 cm) or early cancer it is only about 29 percent (Ahlquist, Wieand, Moertel et al., 1993). In one study, the fecal occult blood test was positive in only about 30 percent of patients with large, extensive, asymptomatic colorectal cancer tumors (Ahlquist, McGill, Fleming et al., 1989). These data suggest that some neoplasms do not bleed or do not bleed regularly. To the extent that neoplasms do not bleed, it is impossible for a fecal occult blood test to detect them. Many of the polyps that appear to be detected by fecal occult blood tests- certainly the small ones- probably are not bleeding and are detected by chance (Ransohoff & Lang, 1990; Simon, 1990; Lang & Ransohoff, 1994). Fecal occult blood testing alone cannot adequately screen for all colorectal cancers.

## Sigmoidoscopy Screening

Sigmoidoscopy is an endoscopic screening procedure that examines the lower colon using a flexible tube. Although there is no evidence from a randomized clinical trial that sigmoidoscopy can reduce mortality from colorectal cancer, two recent case-control studies reported that periodic sigmoidoscopy, as infrequently as every 5 to 10 years, can reduce the mortality from cancer within reach of the sigmoidoscope by 70 percent (Selby, Friedman, Quesenberry & Weiss, 1993; Selby, Friedman, Quesenberry & Weiss, 1992). If such reduction is confirmed in other studies, sigmoidoscopy screening would be among the most beneficial of cancer screening methods.

Given the findings of these two studies, the case is strong for implementing sigmoidoscopic screening (Ransohoff & Lang, 1993). The frequency of optimal sigmoidoscopic screening is still unclear; it appears that it should be performed every 3 to 10 years for asymptomatic people who are fifty and older (Ransohoff & Lang, 1993). The challenge is not merely to adjust recommendations but to encourage the use of a procedure that has not been widely accepted by patients, physicians, and payers, and to anticipate substantial costs if screening becomes widespread.

Clinicians must decide whether to implement sigmoidoscopy screening, which has been largely ignored even though it has been recommended by many authoritative organizations for over a decade.

Screening strategies may at some point be influenced by significant advances in molecular biology. Sidransky and colleagues (1992) have demonstrated a technique to measure some molecular markers of colon neoplasms in the stool. The specific test thus far developed may or may not be useful in detecting early cancer or large polyps, but the technique is promising. Another use of the technique assesses underlying genetic risk in a similar way that information about family history is presently used (Powell, Petersen, Krush et al., 1993).

Even though major health organizations have recommended screening for colorectal cancer such screening is underutilized. Currently, only about 7 to 15 percent of age eligible persons have received sigmoidoscopy screening according to recommended schedules, and there is only a slightly greater rate for yearly fecal occult blood test screening (McPhee & Bird, 1990; Lillard, Manning, Peterson, et al., 1986; Harris, Leininger, Qaquish, Kaluzny & Strecher, 1994). The National Health Interview Survey does indicate a slight upward trend in rates from 1987 to 1992 (Breen & Kessler, 1994; Anderson & May, 1995). However, one-third of the 1992 respondents age 50 and older had never heard of proctoscopic screening for colorectal cancer (Anderson & May, 1995). In comparison, screening with mammography or Pap smears has a roughly 50 to 70 percent compliance rate among eligible persons (Lillard, Manning, Petersen, et al., 1986; McPhee, Richard & Solkwitz, 1986).

## Colorectal Cancer Screening in Connecticut

Currently, Connecticut is below the median for all states for adults aged 50 and older who have not had a sigmoidoscopy within the past 5 years (64.9 vs. 70.0) and for not having had a fecal occult blood test within the past year (75.8 vs. 81.8) (Centers for Disease Control, 1999). Although results from the Behavioral Risk Factor Surveillance Survey indicate that 31% percent of Connecticut residents have had a fecal occult blood test within the past two years and 35% have had a sigmoidoscopy within the past five years, only 13.2% have followed the American Cancer Society guidelines for colorectal cancer screening by having a fecal occult blood test within the past year and a sigmoidocopy within the past 5 years (see Table 16) (Connecticut Department of Public Health, 2000).

Table 16 Connecticut Colorectal Cancer Screening Prevalence Rates for Adults Age 50 + (1997)

Screening test	Males	Females	Total
FOBT past 2 yrs	29.4	32.4	31.3
Sigmoidoscopy past 5 yrs	37.9	32.8	35.1
FOBT past yr +			
Sigmoidoscopy past 5 yrs	13.6	13.0	13.2

Source: BRFSS

Moreover, certain subgroups are less likely to have colorectal cancer screening. Among those aged 50 and older, non-whites were less likely than whites to have ever received sigmoidoscopy (27.0% versus 46.6% respectively). Results were similar for ever having had a fecal occult blood test, where 39.9% of whites had the test compared with only 20.8% of blacks and 22.8% of Hispanics. Men and women were equally likely to have each test, and utilization of each test increased with age up to the 65 and older age group, where 43.3% had had a fecal occult blood test and 53.8% had had a sigmoidoscopy (Connecticut Department of Public Health, 2000). Thus, more progress toward colorectal cancer screening is needed within Connecticut.

## Barriers to Screening

Little research has been done on barriers to colorectal cancer screening. Available data indicate that low screening rates are due to both physician and patient factors as well as the cost and effort of sigmoidoscopy. Research indicates that physician reluctance to recommend sigmoidoscopy is due to disagreement with the guidelines, cost to the patient, and inconvenience (McPhee, Richard & Solkwitz, 1986, Sandler, Holland, Brooks, Konrad & Guild, 1989). Sigmoidoscopy is time consuming and is perceived as embarrassing and painful for patients. Physicians report patient lack of interest and fear of a cancer diagnosis (Resnicow, Schorow, Bloom, & Massad, 1989). However, one study that examined patient attitudes and compliance with sigmoidoscopy screening found that although patients reported high anxiety about the test, 75 percent complied with a recommendation from their physician to have the test and found the procedure to be less embarrassing and less painful than expected (39).

Patient compliance issues are thought to center on discomfort, embarrassment, and for sigmoidoscopy, cost. Yet public education about cancer screening can dramatically increase screening rates, as experience with both Pap smears and mammography have demonstrated. The American Cancer Society mounted a large scale colorectal cancer public awareness campaign from 1983 to 1986; during this time the percentage of asymptomatic individuals who ever had a fecal occult blood test rose from 28 percent to 39 percent (American Cancer Society, 1986). Among patients asked to return fecal occult blood test cards, compliance rates have been reported as high as 51 to 88 percent (Thompson, Michnick, Gray, Friedlander & Gibson, 1986). Compliance was found to be highest in programs where primary care physicians recommended the test as part of a regular annual exam or among attendees at community education programs sponsored by the American Cancer Society; lowest rates were in general practice settings (Winawer, Andrews, Flehinger, et al., 1980; Elwood, Erikson & Lieberman, 1978).

Research indicates that the most important motivator for undergoing screening is a recommendation by a primary care physician (Thompson, Michnick, Gray, Friedlander & Gibson, 1986; McCarthy & Moskowitz, 1993). Though most physicians agree with screening guidelines for early detection of cancer, many do not follow through in their practices. A survey in 1989 found that 67 percent of primary care physicians agree with the American Cancer Society guidelines for screening mammography, but the rates of recommendation to patients, and of patient compliance, appear to be much lower (American Cancer Society, 1990).

Since approximately 85 percent of all adults visit a health care provider at least once every two years, a major increase in screening could be predicted if health care providers recommended screening regularly to all age and risk appropriate patients.

## Increasing adherence

Health care provider strategies need to be used along with public education interventions to increase adherence with screening recommendations. Health care providers should be aware of which screening procedures are effective and how to perform them. They may consider recommendations issued by experts in their own

specialty or by nationally recognized panels (Belcher, Berg & Inui, 1988). It takes time and effort for recent information to be diffused and accepted. Several types of intervention strategies have been used successfully to promote screening activities among physicians. These include continuing education, office based systems (practice aids), organizational recommendations, peer comparison and feedback, and patient education materials. In one study that investigated how to improve rates of performance for seven cancer screening tests, a reminder system was found to be more effective than reviewing provider charts and giving feedback, although both procedures resulted in significant improvement over usual procedures (McPhee, Bird, Jenkins & Fordham, 1989). In another study of colorectal cancer screening, retrospective feedback of compliance rates by individual physicians, compared with those of their peers, improved adherence rates (Winickoff, Coltin, Morgan, Buxbaum & Barnett, 1984). Also, training programs can result in significantly improved cancer screening activity (Weisman, Celentano, Teitelbaum & Klassen, 1989; Hogness, Englestad, Linck & Schorr, 1992).

A final barrier to significantly improved rates of screening is lack of access to trained providers. It takes time to provide a thorough explanation that is required for compliance with fecal occult blood testing, while the effort necessary to implement sigmoidoscopy screening is considerable (Ransohoff & Lang, 1993).

It now seems that sigmoidoscopy is an effective means for detecting cancers early enough to reduce mortality. Given the evidence from the case-control study as well as the biological rationale for screening, a case can be made for screening with sigmoidoscopy every 5 to 10 years, beginning at age 50 (Ransohoff & Lang, 1993; Selby, 1993; Atkin, Cuzick, Northover & Whynes, 1993). The current challenge is not to develop appropriate guidelines or recommendations for sigmoidoscopy screening (because it has been advocated for over a decade) but to implement screening. If screening is actually implemented, other important issues will need to be addressed that may have enormous long term implications for cost and effort. These questions include who will perform the exams, and what is the appropriate follow up if an abnormality is detected (Ransohoff & Lang, 1993, Ransohoff, Lang & Kuo, 1991; Bond, 1993).

## Review of Intervention Studies

The literature on community based interventions to increase public awareness and promote secondary prevention for colorectal cancer is sparse. Further, most published studies represent cross sectional surveys rather than randomized controlled trials. The following section highlights interventions that promoted preventive screening by fecal occult blood testing; primary prevention initiatives focused on dietary change are also cited. Some studies are generalizable to the overall population in Connecticut communities, while others target subgroups to account for specific risk factors for colorectal cancer (which include increasing age, family history, and high fat/ low fiber diet). A list of intervention studies for colorectal cancer was obtained through MEDLINE by combining the MeSH term colorectal neoplasm, with the additional search terms community intervention, early detection, study, trial, and randomized. This resulted in selection of 32 articles. Each article was evaluated and included in this review if it

reported the methods and results of a study conducted in the United States since 1975 (Parsa, Wang, Schulman & Germana, 2000).

## **Direct Mailing**

Direct mailing interventions consisted of interventions that encouraged colorectal screening by sending letters and fecal occult blood testing kits to residents within the study region. Investigators found that the response rate to such interventions was consistently higher when additional interpersonal contact (i.e. a phone reminder or group education session) was incorporated into the intervention.

Myers and colleagues (1991) found that adding an instruction call after the fecal occult blood testing kits were mailed led to a significantly higher return rate than that of the other treatments, whereas enclosing an educational booklet with the kit did not improve the response rate at all. Further, a reminder call alone significantly improved the return rate compared to that of simply mailing the kit. The investigators note significantly higher rates of adherence in older individuals and females, and attribute non-adherence to participants' attitudes that the test was inconvenient.

Elwood et al. (1978) noted the highest response rates in a group that received AARP education sessions before receiving the fecal occult blood testing kits, followed by a group that was provided with personal house visits before receiving the kits. The reported cost per kit returned was \$ 0.83 for the education session and \$ 0.45 for the personal visits. By contrast, treatment groups that were mailed test kits without advanced education had much lower return rates, which increased the program cost to between \$2.84 and \$3.76 per return. Return rates were higher in older individuals (75-77 years) and for individuals who received return postage with their mailing, and did not differ significantly by sex or level of education. Return rates did not depend on whether the program was identified with the American Cancer Society or with American Association for Retired Persons.

Gordon et al. (1987) reported a statistically significant improvement in response rate when fecal occult blood testing kits were available at community health centers rather than obtainable by mail. The combined cost of the programs was \$16,765 in direct costs (kits, follow up exams, physician fees) and \$26,110 in indirect costs (volunteer staff, lab technicians, clerical support, promotion/publicity, postage and printing), leading to an allocation of \$9.12 per participant. The authors stressed the need to educate physicians as well as the public about proper screening procedures as the diagnostic work ups performed on the participants with positive fecal occult blood testing results were highly variable.

### Media Promotion

The success of media promotion programs appears to improve with the amount of time for which segments are aired, the use of multiple types of media, and the inclusion of educational segments about the value of the test.

The two week TV promotion developed by McGarrity et al. (1989) stressed that the early stages of colorectal cancer may not manifest noticeable symptoms but could still be detected clinically. Interviews with individuals who had been diagnosed with colorectal cancer as a result of screening were also broadcast. Fifty thousand dollars was spent for salaries, mailing and advertising; this cost was shared with the pharmacy chain that distributed the kits. A total of 57, 000 test kits were picked up and 29, 619 (53%) were returned; 3.9% (1, 165) of the tests were positive. Ninety three percent of persons with a positive result sought follow up screening. Out of detailed follow up on 744 persons, 58 cases of colorectal cancer were diagnosed at further evaluation out of which 80% were early stage. The authors note that the diagnostic tests employed on follow up screening were often insufficient (sigmoidoscopy only). A follow up of participants by Slusser et al. (1996) found that more cases were diagnosed at early stage and survived for five years than SEER data would predict. Survival rates were not improved for individuals older than 75 years, however.

Additional studies have also noted the insufficiency or variability of diagnostic work up following media advertised screening campaigns, and recommended that the public and professional be better educated about appropriate clinical procedures (Johnson et al., 1987). Winchester et al. (1980) hypothesized that the quality of work ups following the promotion of fecal occult blood testing screening on five news spots could be improved by strengthening the educational component of the intervention among both the public and professionals. Their subsequent intervention (1983) increased the quality of the news' segment content and included newspaper ads. The impact of the additional education on the general public was assessed by a questionnaire, which found that 61% after the intervention compared to 38% prior to the intervention believed that only some cancer cases were fatal; 72% versus 49% believed that a positive test did not necessarily indicate cancer; and the proportion who were aware of treatments other than colostomy increased three fold. As a result, the return rate was substantially higher than in the first intervention (43% versus 26%). Of the positive cases who did not schedule a physician visit on their own, a 15 minute telephone counseling session motivated 90% to make an appointment subsequently. Still, only 11% of positive cases were determined to have received appropriate examinations, suggesting a role for physician oriented education campaigns.

Winchester et al. (1980) also noted a significantly higher return rate among individuals who paid for their test kits compared to those who received complementary kits. This finding has been confirmed by Bloch et al. (1990), who sold kits to the community for \$1.00 each, refunded as a coupon to the affiliated pharmacy chain when the kit was returned. Their TV promotions combined brief publicity messages prior to kit availability with interviews of physicians, epidemiologists, cured patients, and advanced stage patients who had not undergone preventive screening. The investigators stated objective was to inform individuals over age 40 about the principles and methods of early detection and current treatment options. A noteworthy component of their study design was the use of high school and college students in addition to a volunteer staff to provide inexpensive administrative support.

Some studies have found that conducting mass media campaigns that address the entire population are overly ambitious. Cole et al. (1990) attribute their low return rate (37%) to targeting too large of a geographic region for their campaign. They recommend targeting specific regions or subpopulations for future mass screening efforts. It is important to realize that different types of media interventions may be more or less effective when the focus of the screening campaign if narrowed. For example, Mettlin et al. (1980) targeted their newspaper and radio advertisement promoting fecal occult blood testing and digital rectal exams to individuals aged 60 and older. They discovered that 30% learned of the program through their senior citizens program, 25% through the newspaper, 21% by word of mouth, and 16% from television and radio.

## Hospital based cancer interventions

Colorectal cancer screening was promoted through a hospital based intervention in one study. Richardson (1977) reported a return rate of 85% among the individuals who went to a community hospital or nursing home to pick up a fecal occult blood testing kit. A unique feature of the program was the use of non-medical American Cancer Society staff to analyze the fecal occult blood testing kits, as a measure of reducing program cost; physicians were consulted in planning the intervention and in diagnostic follow up.

## *Summary*

Given our understanding of the natural history and biological features of colorectal cancers and the recent studies providing evidence that screening reduced mortality, the challenge is to encourage increased screening rates above the current low utilization. The importance of provider acceptance and recommendation of a new screening procedure is demonstrated by the rapid increase in utilization of another screening procedure, mammography. The successful implementation of this procedure shows us that providers, as opposed to patients, are the first targets for education. For now, realistic short term screening targets should be set while more ambitious long term goals are considered. These goals must include not only increasing screening recommendations but also assuring that sufficient numbers of providers able to perform screening exist. Public awareness of the importance of screening and its financial coverage as well as continued surveillance of those screened must be addressed.

### **Conclusions**

The vision of the Connecticut Cancer Consortium is that, by working together, those involved in cancer-related issues can provide a framework for surveillance and research activities directed toward improving the health of Connecticut citizens. The Consortium has identified that initial efforts toward cancer control should be directed toward primary and secondary prevention of three cancer sites; lung, breast, and colorectal.

During this phase of cancer plan development, three priority cancer sites were addressed by the Connecticut Cancer Consortium: lung, breast, and colorectal. These cancer sites were chosen because they are among the most common cancers that affect the residents of Connecticut and scientifically based cancer prevention and/or early detection interventions exist. Subgroup committees were formed for each of the cancer sites in order to identify effective prevention and early detection interventions and identify important goals for each cancer site that should be addressed in the next phase of the plan. It is hoped that this document will provide fertile ground for collaboration regarding surveillance and research activities among the various members of the Consortium.

Although Connecticut tends to fare better than other states in the United States regarding cancer risk and screening behaviors, much work remains in order to reduce the burden of cancer within the state. It is important to recognize that disparities exist among various age, racial and ethnic groups in Connecticut regarding cancer risk and screening behaviors. For example, smoking is higher among youth and adults ages 18 to 34 as compared to those over age 35. In addition, smoking is higher among black and Hispanic racial/ ethnic groups. Breast cancer screening rates are lower among Hispanic women. Similarly, colorectal cancer screening is less for non-whites as compared to whites. These groups should be targeted for cancer control interventions.

The Consortium has identified goals, objectives, interventions, and evaluation criteria for each cancer site. Because resources are limited, priorities regarding each cancer site are identified so that efforts can be directed toward these goals initially. The priorities below were established based on the health priorities set forth by the Connecticut Department of Public Health Assessment (1998), Healthy People 2010 (Retrievable Online), and data from the Connecticut Department of Public Health, Behavioral Risk Factor Surveillance Survey and Youth Risk Behavior Survey describing the behavioral risk factors of Connecticut residents (Connecticut Department of Public Health, 2000) (see Table 17).

Table 17: Comparison of Various Cancer Prevention Goals and Current Status of **Connecticut Residents** 

Cancer Site	Connecticut DPH Priorities	Healthy People (HP) 2010 (2)	Connecticut Rates according to BRFSS and YRSS* (3)
Breast	Improvement in rates of breast cancer screening and follow up	Increase the proportion of women age 50 and over to 70% who received a mammogram within the past 2 years	Mammography ever screening rates: White: 82.4% Black: 75% Hispanic: 65% Income less than 25K: 75% Mammography ACS guidelines 40 and over (51%) HP guidelines 50 and over (68%)
Colorectal	Improvement in rates of colorectal cancer screening and follow up	Increase the proportion of adults age 50 and older to 50% who receive a fecal occult blood test with the preceding two years and who have ever received a sigmoidoscopy	Adults who have met ACS guidelines: 13.2% Adults who have met HP guidelines: FOBT past yr 24% FOBT ever: Whites: 39.9% Blacks: 20.8% Hispanic: 22.8% Sigmoidoscopy ever 45% Whites: 27% Non-whites: 47%
Lung (Adult)	Prevention and cessation of tobacco use	Reduce the proportion of adults (18 and older) who use tobacco products to 13% by 2010	Current adult smoking: 21.7% White: 20.7% Black: 26.7% Hispanic: 31.2% Unemployed: 45%
Lung (Youth*)	Prevention and cessation of tobacco use	Reduce the proportion of youth who use tobacco products in grades 9 through 12 to 21% by 2010	Current student smoking: 35.2% Grade 12 students 45%

<sup>\*</sup> Youth data is obtained from YRSS and adult data is obtained from BRFSS. Data set information is explained in Appendix 2.

<sup>1=</sup> State of Connecticut, Department of Public Health (1999).
2= Healthy People 2010 (Retrievable Online).
3= Connecticut Department of Public Health (2000).

Lung cancer is the major cause of cancer death in both men and women in the state of Connecticut. The most important factor to decrease the burden of lung cancer is to prevent the initiation of smoking and also to promote smoking cessation among those who smoke. While the percentage of smoking adults has declined over the past ten years, smoking among youth is on the rise. Almost all smokers take up the habit before they are twenty. Youth smoking in Connecticut is unacceptably high and efforts toward prevention of smoking and smoking cessation in this group should be targeted as a priority. Breast cancer is the most common cancer in Connecticut women and the second leading cause of cancer death. Although the proportion of Connecticut women having ever had a mammogram and clinical breast examination is high, rates for ongoing screening are much lower. Therefore, efforts directed toward increasing the proportion of women who obtain repeat screening should be targeted as a priority. Finally, colorectal cancer is the third most commonly diagnosed cancer in Connecticut and while detection and treatment of early stage cancers reduces mortality it is underutilized. Colorectal cancer screening has not received much attention. Because colorectal cancer screening has the potential to dramatically decrease mortality, increased attention should be directed toward improving screening among Connecticut residents. It is hoped that these priorities will help shape future directions for surveillance and research goals.

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## Appendix 1

## Sources of Information Used for Connecticut Cancer Plan

Page	Source
Page 6	Illinois Cancer Plan, 1999, (p.1-2)
Page 7	Draft Connecticut Cancer Plan
Pages 9-12	Healthy People 2010 (p.3-3 to 3-6), Connecticut
_	Department of Public Health, 1999.
Pages 12-19	State of Connecticut Department of Public Health, 1999,
	Connecticut Health Assessment (p.9)
Page 19-20	Draft Connecticut Cancer Plan and New England Task
_	Force on Prevention and Health Promotion, 1998, (A-1 to
	A-3)
Pages 20-21	Texas Cancer Plan, 1998, (14-17)
Page 22-23	North Carolina Cancer Plan, 1996, (II-3)
Pages 29-30	Florida Cancer Plan, 1997
Page 30	North Carolina Cancer Plan, 1996, and Connecticut Health
	Assessment, 1999
Pages 35	Florida Cancer Plan, 1997
Pages 36	Connecticut Department of Public Health, 1999
Pages 45-46	State of Connecticut Department of Public Health, 1999,
	Connecticut Health Assessment
Pages 48-51	Parsa, Wang, Schulman & Germana, 2000
Pages 53	North Carolina Cancer Plan, 1996
Pages 61- 62	State of Connecticut Department of Public Health, 1999,
	Connecticut Health Assessment
Pages 63-68	North Carolina Cancer Plan, 1996
Pages 69-70	State of Connecticut Department of Public Health, 1998
Pages 70-71	Connecticut Department of Public Health, 2000
Pages 71-74	Parsa, Wang, Schulman & Germana, 2000
Pages 74	Florida Cancer Plan, 1997
Pages 79- 81	State of Connecticut Department of Public Health, 1999,
	Connecticut Health Assessment
Pages 81-83	North Carolina Cancer Plan, 1996
Pages 84	Connecticut Department of Public Health, 2000
Pages 86-89	Parsa, Wang, Schulman & Germana, 2000

## Appendix 2

## **Data Set Information**

The BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS\*) collects data from non-institutionalized adults aged 18 and older through monthly random digit dialed telephone surveys. Data from the 1,838 Connecticut residents surveyed in 1996 were combined with data from the 2,250 residents surveyed in 1997, to yield a total sample of 4, 088. Raw data were adjusted for the probability of selection based on the number of telephone lines and adults in the household, and were post-stratified to be representative of the Connecticut adult population by age and gender. The data for the two years were analyzed as if the survey had been a continuous two-year survey and were not further adjusted for the varying monthly sample sizes. BRFSS collects information on behavioral risk factors that are related to one or more of 10 leading causes of death. These factors include tobacco use, alcohol consumption, diet and health, weight, drug use, screening utilization, and health insurance status. **Current smoking** as used in this document was defined as persons who reported smoking at least 100 cigarettes in lifetime and they currently smoke some days or every day.

The YOUTH RISK BEHAVIOR SURVEY (YRBS\*) collects data from high school students and was conducted in the Spring of 1997 by the Connecticut Department of Education in collaboration with the Center for Disease Control and Prevention. A total of 1, 733 students in grades 9-12 were surveyed, with approximately equal numbers in each grade. A two stage cluster sample design was used to produce representative samples in each state. The YRBS monitors six categories of priority health risk behaviors, including tobacco use, alcohol and drug use, sexual behaviors, unhealthy dietary behaviors, and physical inactivity. **Current smoking** as used in this document was defined as students who smoked on 1 or more of the 30 days preceding the survey.

The SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS (SEER) PROGRAM is a major component of the Cancer Surveillance Research Program established by the National Cancer Institute. This Cancer Surveillance Program collects information on cancer incidence, mortality, and stage specific survival in the United States from 11 population-based cancer registries and 2 supplemental registries covering approximately 14% of the population. The 11 SEER registries are located in five states (Connecticut, Iowa, New Mexico, Utah, and Hawaii) and six metropolitan areas (Detroit, San Francisco/Oakland, Seattle/Puget Sound, San Jose/Monterey, Atlanta, and Los Angeles. The two supplemental registries include American Indians in Arizona, which are registered by the New Mexico SEER registry, and 10 rural, predominantly black counties in Georgia, which are registered by the Atlanta registry.

<sup>\* =</sup> Connecticut cancer behavioral risk factor data has been analyzed and published by the Connecticut Department of Public Health (2000). Therefore, the publication, Connecticut Behavioral Health Risks: Factors Related to Cancer, was used as the source of data for the cancer control plan. In addition, information related to cancer incidence and mortality among racial/ethnic minority groups was obtained from data published by the Connecticut Department of Public Health (1999) in Multicultural Health.