

THE CONNECTICUT CANCER PARTNERSHIP

Public and Private Partners Working Together to Achieve Cancer Control

CONNECTICUT COMPREHENSIVE CANCER CONTROL PLAN 2005-2008

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June, 2005

The *Connecticut Comprehensive Cancer Control Plan, 2005-2008* is the product of the knowledge commitment, and collaboration of more than 100 members of the Connecticut Cancer Partnership. The Partnership's Core Committee directed the entire planning process, defining and creating subcommittees and work groups, guiding assessment and evaluation, and growing the Partnership. The individuals named below were members of the Core Committee throughout or at any stage of the Plan's development.

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The Connecticut Cancer Partnership's Core Committee gratefully acknowledges the valuable contributions of many other individuals to the development of the Plan.

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Members of the Partnership's priority area planning committees dedicated countless hours to researching and assessing needs, developing goals and objectives, setting targets, and creating strategies for achieving objectives. Their names are listed at the beginning of the sections on Prevention, Early Detection, Treatment, Survivorship, and Palliative and Hospice Care.

Anita Ruff, Maine Comprehensive Cancer Control Coordinator, and Polly Hager, Michigan Public Health Institute Cancer Control Services Project provided formative advice that set us on solid track.

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1 THE CONNECTICUT CANCER PARTNERSHIP

THE CONNECTICUT CANCER PARTNERSHIP

OVERALL GOAL OF THE CONNECTICUT CANCER PARTNERSHIP

To reduce the burden of cancer (incidence, morbidity, mortality, and disability) and to improve the quality of life of people with cancer in Connecticut

INTRODUCTION

The face of cancer in Connecticut is changing. More people are adopting healthy practices that reduce their risk of developing cancer and help ensure that new cancers are detected early, when they are the most treatable. The overall rate of new cancer cases in Connecticut has stabilized, and the death rate has been decreasing, due in large part to earlier detection and improved treatments.

Still, each year about 18,000 new cases of cancer are diagnosed and 7,000 Connecticut residents die of cancer. Four types of cancer (lung, colorectal, breast, and prostate) account for more than half of both total new cancers and total cancer deaths in Connecticut, and many of these could be prevented by lifestyle modification (e.g., smoking cessation, changes in diet), or by early detection through screenings (e.g., colonoscopy/sigmoidoscopy, mammography) with timely follow-up and treatment.

The prominence of cancer in the health of Connecticut residents is not likely to change; indeed, as our population ages, numbers of new cancer cases and deaths likely will increase, as will the number of cancer survivors; some cancers have become largely curable, whereas others are now manageable chronic diseases, thanks to early diagnosis and more effective treatments. While it is not yet possible to eradicate cancer, strategies can be developed to prevent or delay the onset of many cancers and to reduce or eliminate the outcomes of the disease--suffering and death. Much work is still needed in all areas of the continuum of cancer care--prevention, early detection, treatment, survivorship, and palliative and hospice care.

In 1998 the U.S. Centers for Disease Control and Prevention (CDC) created a model program for Comprehensive Cancer Control, and began to fund planning for state programs. Comprehensive cancer control is aimed at delivering public health messages and services related to cancer more efficiently. It integrates and coordinates existing programs focused on specific cancer sites or risk factors with one another and with health education, health promotion, and outreach activities, to maximize use of available resources.

The Connecticut Cancer Partnership was created to develop a statewide comprehensive cancer program--to assess the burden of cancer, set priorities, and formulate and carry out a comprehensive cancer control plan for our state.

SELECTED HIGHLIGHTS OF CANCER CONTROL IN CONNECTICUT

Connecticut has some of the best resources in the nation for documenting cancer and its risk factors among state residents, along with a rich history of research, development and implementation of successful cancer prevention and control programs. Some highlights of the cancer control resources and achievements in Connecticut are noted below.

Resources

- The Connecticut Tumor Registry, located at the Connecticut Department of Public Health (DPH), is the oldest of its kind in the United States, and contains information on the incidence, vital status, and treatment of all cancers diagnosed in Connecticut since 1935. It is one of only five statewide registries included in the National Cancer Institute's acclaimed SEER (Surveillance, Epidemiology, and End Results) cancer surveillance program.
- The Connecticut Death Registry, part of the DPH Vital Records division, is the second oldest in the nation and has records of cancer deaths dating from 1848.
- The Connecticut Hospital Discharge and Billing Data Base, which is managed by the Office of Health Care Access and shared with DPH, contains records of cancer hospitalizations and charges since 1989.
- Three surveys conducted by DPH—the Connecticut Behavioral Risk Factor Surveillance System (BRFSS), Connecticut Youth Risk Behavior Surveillance (YRBS), and the Connecticut Youth Tobacco Survey (CYTS)—have collected information on cancer risk factors since 1988, 1995, and 2000, respectively. In 2005, the Connecticut YRBS and CYTS will be administered together as the CT School Health Survey.
- The Yale Cancer Center (YCC) at Yale University School of Medicine has been an NCI-designated Comprehensive Cancer Center since 1974.
- The Cancer Information Service (CIS) of New England (1-800-4-CANCER) has been funded by NCI since its opening in 1975.

Achievements

- DPH was one of five states funded in 1987 by the NCI Cancer Control Technical Development in Health Agencies Program, to provide critical baseline data for statewide comprehensive cancer prevention and control program planning.
- The Connecticut Susan G. Komen Foundation Race for the Cure funded low-cost breast screening to uninsured women in 1994. This was the predecessor to the Connecticut Breast and Cervical Cancer Early Detection program (CBCCED), which was first funded by the CDC in 1995. CBCCED has 18 contracted health care providers, more than 100 clinic-based satellite sites, and several community agencies committed to educating and referring women for program services.

- Since 1996, DPH and ACS have cooperated in a Primary Care Project, which enhances cancer screening in community practices.
- DPH received a 5-year IMPACT (Initiatives to Mobilize for the Prevention and Control of Tobacco) grant from the CDC in 1994, to support collaboration with partners on two statewide coalitions working against tobacco control.
- In 1999, DPH received a 5-year Cooperative Agreement from the CDC Comprehensive State-based Tobacco Use Prevention and Control Program to reduce initiation among youths, promote cessation among youths and adults, eliminate exposure to environmental tobacco smoke, and identify and eliminate disparities. Connecticut Youth Tobacco Surveys were conducted in 2000 and 2002.
- Since 2000, the Federal Public Health and Health Service Grant Program has funded skin cancer prevention and education in childcare settings.
- The WISEWOMAN cooperative agreement (Well-Integrated Screening and Evaluation for Women Across the Nation) uses CBCCED sites to deliver health screening for cardiovascular disease along with breast and cervical cancers.
- A Comprehensive Breast Cancer Needs Assessment was funded by DPH and conducted by the UCHC Department of Community Medicine. It inventoried resources and projects throughout Connecticut dedicated to reducing the impact of breast cancer on the population through basic research, public health surveillance, clinical and ancillary services, and public policy advocacy. It serves as a model assessment for other priority cancers selected for cancer plan development.
- The Connecticut Colorectal Cancer Workgroup was established with representatives from DPH, ACS, and the American College of Gastroenterology. It achieved passage of state legislation that mandated third party reimbursement for colonoscopy as a screening tool in the prevention of cancer.

HISTORY OF THE CONNECTICUT CANCER PARTNERSHIP

In May 2002, a Leadership Institute for New England state leaders in cancer control was held in Quincy, MA, sponsored by the CDC, ACS, and NCI. Additional representatives at the meeting included the American College of Surgeons, Commission on Cancer (ACoS, CoC), the Association of Chronic Disease Directors (ACDD), the Intercultural Cancer Council (ICC), the National Dialogue on Cancer (now called C-Change) and North American Association of Central Cancer Registries (NAACCR).

The Connecticut leaders represented the Connecticut Cancer Partnership's five founding members--state agencies and organizations that had collaborated in the past on cancer control: ACS, DPH, UCHC, YCC, and CSMS. The 2-day leadership institute featured a workshop on creating a "building blocks" framework for comprehensive planning. This framework is based on meaningful collaboration among a broad range of partners, using a public-health-oriented approach to service delivery and a long-range perspective. Partnerships capable of implementing a plan and evaluating the outcomes were recommended. Upon returning to Connecticut, the leadership group agreed to support DPH's application to the CDC for funding to begin the state's comprehensive cancer planning initiative.

In October, 2002, DPH was awarded a cooperative agreement from the CDC to begin cancer planning. The leadership group, renamed the Core Committee of the Connecticut Cancer Partnership (CCP), became responsible for directing the planning process, defining and creating subcommittees and work groups, guiding the assessment and evaluation processes, and expanding the Partnership, all in accordance with the CDC's *Guidance for Comprehensive Cancer Control Planning* and building blocks.

In March, 2003, the Core Committee held a statewide conference on comprehensive cancer planning to which potential partners were invited. More than 100 people attended, representing a racially, ethnically, and geographically diverse cross-section of stakeholders in cancer prevention and control from throughout Connecticut: state and local public health agencies, other programs funded by CDC and NCI (Table 1), academic institutions, volunteer organizations, community

Table 1
CDC- and NCI-Funded Connecticut Programs Involved in Planning

Program (Organization or Agency)

Connecticut Breast and Cervical Cancer Early Detection Program (DPH)

Cancer Information Service of New England (YCC)

Connecticut Tumor Registry (DPH)

Extended Food and Nutrition Education Program (UConn Extension Service)

5-A-Day Program (DPH)

Obesity Prevention and Control Program (DPH)

Tobacco control program (DPH)

Connecticut Department of Education

Yale-Griffin Hospital Prevention Research Unit

groups, faith-based organizations, hospitals, cancer centers, professional organizations (oncology nurses, physicians and social workers), insurers, health care providers, researchers, patient care services, cancer survivors, and consumers.

Conference speakers were Kevin Brady, CDC Acting Director of Cancer Prevention and Control; experts from two states that had already finished their state cancer plans (Anita Ruff, Maine Comprehensive Cancer Control Coordinator; and Polly Hager, Michigan Public Health Institute Cancer Control Services Project); DPH Deputy Commissioner Norma Gyle and DPH cancer program staff; and members of the Partnership's Core Committee. Later in the meeting, attendees broke into committees corresponding to priority areas of the comprehensive cancer plan (Prevention, Early Detection, Treatment, Survivorship, Palliative and Hospice Care), and began developing vision statements and goal statements.

After the conference, the committees met frequently from March to June, to refine their goals and formulate objectives and strategies for achieving them. They reviewed literature and data, looked at existing programs and identified gaps, and considered issues that cut across all priority areas: health disparities, advocacy, communications, research, data, surveillance, and evaluation. Previous Connecticut cancer plans that were reviewed included: Connecticut Cancer Control Plan 2001-2004; Connecticut Tobacco Use, Prevention, and Control Plan, 2002; Comprehensive Cancer Breast Cancer Needs Assessment, 2002; and NECON (New England Coalition for Health Promotion and Disease Prevention) Task Force on Prevention and Control of Cancer, 1998. The ACS 2015 planning documents and Healthy People 2010 (U.S. Department of Health and Human

Services), a national health promotion and disease prevention agenda, were key reference materials.

The goals, objectives, and strategies of each subcommittee were submitted to the Core Committee for review, and two additional subcommittees--one on Governance and another on Data, Surveillance, and Evaluation--were created. Goals and objectives were discussed, and prioritized during a second day-long Partnership conference held in June, 2003. The objectives were reviewed by the Data, Surveillance, and Evaluation Committee, and refined to make them SMART (specific, measurable, achievable, relevant, and time bound) to the greatest possible extent.

THE CONNECTICUT CANCER PARTNERSHIP TODAY

Today, the Connecticut Cancer Partnership is a broad, vital consortium of more than 100 public and private partners working to fight cancer and improve the quality of life of Connecticut's residents. It currently is governed by a 22-member Core Committee (slated to transition to an elected Board of Directors later this year), and has nine standing committees representing the five major priority areas (Prevention, Early Detection, Treatment, Survivorship, and Palliative and Hospice Care), along with committees on Advocacy, Communications, Governance, and Data, Surveillance, and Evaluation. *Ad hoc* committees and work groups are convened as needed. The progress of the Partnership to date in comprehensive cancer control planning, according to the CDC's "building blocks" model, is shown in Table 2.

An open organization, the Partnership seeks broad representation in its membership. There are two membership categories, organizational and individual. Any organization in Connecticut interested in any aspect of cancer prevention and control can become a member. The organization designates a representative to attend Partnership meetings. Any individual interested in working in cancer prevention and control also can join the Partnership.

The Connecticut Cancer Partnership welcomes new members. We invite you to join with us in this important effort. If you would like information about the Partnership and how you can became involved, or if you have questions, please let us know.

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NEXT STEPS

The Connecticut Comprehensive Cancer Control Plan, 2005-2008 is intended to be an agenda for cancer control and prevention in our state. Organizations throughout Connecticut can use it to earmark specific goals and objectives to incorporate into their own implementation activities. The next steps are outlined below.

- 1. Submit the Plan to the CDC with a request for implementation funding
- 2. Broaden the Partnership, particularly in terms of geographic diversity and to include more corporate partners
- 3. Move from planning subcommittee structure to action subcommittees, and restructuring present membership accordingly
- 4. Transition governance structure from a Core Committee to a Board of Directors
- 5. Begin first-year implementation activities

Table 2
Building Blocks for Comprehensive Cancer Planning: Connecticut's Progress to Date

Objective	Planning Activities	Outcomes	Planning Goal
Enhance Infrastructure	Assess infrastructure needs and capacity Gain buy-in from leadership of coordinating agency Gain buy-in from leadicated coordinator/ staff Identify/hire dedicated core planning group Create core planning group Create core planning group Goordinate and monitor to guide the coordinating agencies Coordinate and monitor to guide the planning process staff	Management and administrative structures and procedures developed. Planning products produced, disseminated and archived	
Mobilize Support (funding, resources, political will etc.)	Assess current level of support level of planning Sectors Secure funds and in-kind resources for planning level of support Sectors	Partnership develops priorities for allocation of existing resources Gaps in resources and level of support identified	
Utilize Data/Research	Build linkages to registry and other data agencies and sources Review data and research as the basis for plan objectives and strategies Review data and research as the basis for plan objectives and strategies Collect needed data if feasible &/or incorporate into Plan Collect needed data into Plan Collect needed da	Planning and research data reviewed for needs assessment and strategy development Data/research gaps identified	T H E
Build Partnerships	Identify, contact, and invite potential partners Prepare for first partnership and capacity Prepare for first partnership and the potential partners Prepare for first partnership meeting Prepare for first partnership meeting Prepare for first partnership meeting Prepare for goals, vision and decision-making process with partners Establish partnership leadership Prepare for first partnership meeting Prepare for first partnership meeting Prepare for first partnership partnership meeting Prepare for first partnership partnership meeting Prepare for first partnership meeting Prepare for first partnership meeting Prepare for first partnership meeting Prep	Original members remain committed as new members join Partnership and subcommittee meetings held and attended.	P L A
Assess/Address Cancer Burden	Organize partnership around areas of interest Determine critical partnership around areas of interest partnership around areas of interest Determine critical areas of burden and high-risk populations Determine critical areas of burden and high-risk populations Determine critical areas of burden and high-risk populations Determine critical areas of burden and objectives for plan Determine critical measurable goals and objectives for plan Determine critical measurable goals and objectives for plan Determine critical areas of burden and high-risk populations objectives for plan Determine critical areas of burden and strategies Determine critical areas of burden and objectives for plan Determine critical areas of burden and objectives for pla	Target areas for cancer prevention and control selected and prioritized.	
Conduct Evaluation	Identify resources and staff for evaluation evaluation Define planning evaluation Document the planning process Document the planning process Identify emerging challenges, solutions, and outcomes of the planning process Provide technical assistance & training on evaluation to partners Identify emerging challenges, solutions, and outcomes of the planning process Provide technical assistance & training on evaluation to partners Identify emerging challenges, solutions, and outcomes of the planning process Provide technical assistance & training on evaluation to partners Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify emerging challenges, solutions, and outcomes of the planning process Identify e	A strategy for assessing planning process, monitoring implementation, and measuring outcomes in place.	

[] = Completed [] = Ongoing

2 CONNECTICUT, ITS POPULATION, AND CANCER

CONNECTICUT, ITS POPULATION, AND CANCER

INTRODUCTION

Connecticut is the southernmost New England state, bordered by Massachusetts to the north, Long Island Sound to the south, Rhode Island to the east, and New York to the west. Much of Connecticut's population lives in the larger cities along the coastal plain and in the river valley of the Connecticut River, which bisects the state from north to south.

Connecticut is characterized by high social and economic contrast and racial and ethnic diversity. It is the third smallest in area, but fourth most densely populated state in the U.S.; about 88% of its population lives in urban areas. Whether in terms of health status, income, poverty, racial composition, or almost any other factor, statewide averages for Connecticut often are misleading. Striking disparities appear across town lines, among racial and ethnic groups, and between urban and rural populations. These differences have engendered the concept of "two Connecticuts," one for people who live in the wealthiest state in the nation, and the other for those living in some of the most severe and concentrated pockets of poverty in the U.S. Recently the notion of "five Connecticuts" based on disparate social and economic factors has been proposed. The overall health of Connecticut's people varies dramatically between its wealthiest and poorest communities.

Connecticut's population is changing, and the demographic changes are reflected in both numbers and patterns of cancer and evolving needs for health care and support services. Disparities in cancer in relation to incidence, mortality, and treatment were fundamental considerations in the development of the *Connecticut Comprehensive Cancer Control Plan*.

CONNECTICUT'S PEOPLE

The Aging of the Population

Connecticut's population is older, on average, compared to the U.S. population as a whole. Older adults are the fastest growing segment of our population. Between 1990 and 2000, the median age of Connecticut residents increased from 34.4 years to 37.4 years, or 2.1 years greater than the national median age.⁴ During the same period, the number of people 65 years of age and older grew by more than 24,000 (Table 3).

Shifts in Racial and Ethnic Composition

Cancer rates and patterns vary across demographic groups, including racial and ethnic groups. From 1990 to 2000, the number and proportion of white persons in Connecticut decreased, whereas minority populations increased, in some cases by 50% or more (Table 3). Connecticut's population is still predominately white (81.6%) and non-Hispanic (90.6%); however, the racial and ethnic composition is dramatically different in the state's largest cities. Non-whites account for 72% of the population in Hartford, 57% in New Haven, and 55% in Bridgeport, and Hispanics (of any race) represent 41%, 21%, and 32%, respectively, of the population in these three cities. Hispanics are now the largest minority group in Connecticut and the United States, with the trend expected to continue.

Table 3
Population Changes for Certain Groups
Connecticut, 1990 to 2000⁶

	1990		2000		Change from 1990 to 2000	
Population Group	Number	% of Total	Number	% of Total	Number	%
	3,287,116	100	3,405,565	100ai	118,449	3.6
Total Population (all races and ages) White	, ,	87.0	, ,	81.6	-, -	-2.8
African American ^a	2,859,353		2,780,355		-78,988	
	274,269	8.3	309,843	9.1	35,574	13.0
Asian American/Pacific Islander	50,698	1.5	83,679	2.5	32,981	65.1
American Indian/Alaskan Native	6,654	0.2	9,639	0.3	2,985	44.9
Hispanic/Latino (any race)	213,116	6.5	320,323	9.4	107,207	50.3
Older adults (65+ years of age)	445,907	13.6	470,183	13.8	24,276	5.4

Source: U.S. Census Bureau, 2000

Social and Economic Characteristics

Education Level

Compared to the American population as a whole, Connecticut residents have achieved higher levels of education (Table 4). In 2000, 84% of state residents 25 years of age and older were high school graduates or higher, 31% had completed a bachelor's degree or more, and less than 6% had less than a 9th grade education. In contrast, in the cities of Hartford and Bridgeport, only 61% and 65% of residents, respectively, were high school graduates, only about 12% had a bachelor's degree or higher, and 17% and 15%, respectively had less than a 9th grade education.

Table 4
Changes in Selected Social and Economic Characteristics
Connecticut, 1990 and 2000 and United States, 2000

	Connecticut		
Characteristic	1990 ⁷	2000 ⁸	U.S. (2000) ⁹
Less than 9th grade education (age 25+)	8.4%	5.8%	7.5%
High school graduates (age 25+)	79.2%	84.0%	80.4%
Bachelor's degree or higher	27.2%	31.4%	24.4%
Speak language other than English	15.2%	18.3%	17.9%
Do not speak English "very well"	6.0%	7.4%	8.1%
Per capita income ⁷	\$20,198	\$28,766	\$21,587
Persons living below poverty level 10	6.6%	7.6%	12.4%

Source: U.S. Census Bureau, 2000

Language Spoken at Home

In 2000, nearly one in five Connecticut residents over 5 years of age spoke a language other than English, and more than 7% did not speak English "very well" (Table 4). In Hartford and Bridgeport, more

a "African American" refers to African Americans and individuals who consider themselves Black.

than 40% of the population spoke a language other than English, and more than one in five of them spoke English less than "very well."

People with a poor ability to read, write and speak English often have a poor understanding of medical information and advice. As a result, they are more likely to engage in risky behaviors like smoking, they are less likely to access health services such as screenings for cancer, and they end up with poor health outcomes, compared to people with high English literacy.¹¹

Income and Poverty

Connecticut is the wealthiest state in the nation, but the gap between its rich and poor is growing. Between 1990 and 2000 the *per capita* income^a of Connecticut residents rose by 42.5% to \$28,766 (Table 7). This figure was more than double the income defined by the federal government as "poverty level" for a family of three (\$13,740).¹² During the same period, while the poverty rate declined nationally, the number of people living below the poverty level in Connecticut rose from 217,347 to 259,514--an increase of nearly 20%--representing 7.6% of the state's population ((Table 4)

Nowhere are disparities among Connecticut's 169 towns more evident than those for income and poverty. In 2000, *per capita* income ranged from \$15,000 in Hartford to nearly \$94,000 in New Canaan, and poverty rates ranged from 0.7% in Killingworth to 30.6% in Hartford. Hartford, the capital of the wealthiest state in the nation, had the second highest poverty rate of all U.S. cities. 14

Compared to Connecticut residents of white race, who had the highest *per capita* income of any racial or ethnic group (\$31,505), *per capita* income was 58% lower for Hispanics and 47% lower for African Americans. Connecticut poverty rates were 7% for whites, 28% for African Americans, and 32% for Hispanics in 2002-2003. 6

The U.S. Census Bureau may be undercounting actual poverty in Connecticut. The cost of living in our state is higher than the national average, so though an individual's or family's income may be above the national threshold for poverty, they might still be living in stressed financial conditions by Connecticut standards.¹⁷

Health Insurance

Connecticut has one of the lowest percentages in the U.S. of people lacking health insurance.¹⁸ In 2004, 5.8% of the Connecticut population had no health insurance at the time they were surveyed, and 9.4% said they had been uninsured at some time during the prior year. Twenty-one percent of Hispanics, 7% of African Americans, and 3% of whites were uninsured, and these disparities were found to be related to low income and lack of permanent, full-time employment.¹⁹

Compared to people with health insurance coverage, those without health insurance have more difficulty accessing personal health services such as cancer screenings, use less medical services, receive less outpatient and inpatient care, and, as a result, tend to have worse health.²⁰ They often seek care at a later or more advanced stage of disease, leading to higher death rates.²¹

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^a *Per capita* income is the average income for every man, woman, and child in a geographic area. It is computed by dividing the total income of all the area's people 15 years of age and over by the area's total population.

TRACKING CANCER AND ITS RISK FACTORS

Connecticut has some of the best resources in the nation for documenting cancer trends and risk factors among state residents. The Connecticut Tumor Registry, housed within the Department of Public Health (DPH), is the oldest of its kind in the U.S. and contains information on incidence, b mortality, and first course of treatment for all reported cancer cases diagnosed in Connecticut since 1935. The Registry has a national distinction in being one of only five statewide registries in the U.S. that are included in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. The registries were selected for their ability to manage a cancer reporting system and, as a whole, to provide a representative subset of the United States population.

The Death Registry, part of the DPH Vital Records section, is the second oldest in the nation and has records of cancer deaths in Connecticut since 1848. The Connecticut Hospital Discharge and Billing Data Base (managed by the Office of Health Care Access and shared with DPH) contains records on cancer hospitalizations and charges since 1989. Three surveys conducted by DPH—the Connecticut Behavioral Risk Factor Surveillance System, Connecticut Youth Risk Behavior Surveillance System, and Connecticut Youth Tobacco Survey--have collected information on cancer risk factors among state residents since as early as 1988. In 2005 the Youth Risk Behavior Survey and Youth Tobacco Survey will be administered together as the Connecticut School Health Survey.

THE BURDEN OF CANCER IN CONNECTICUT

New Cancer Cases

More than 18,000 new cases of invasive cancer were diagnosed in Connecticut in 2001.²² In 2001 our state had the sixth highest rate in the U.S. overall, the fourth highest rate for females, and the tenth highest rate for males.²³

The ten sites of invasive cancers most frequently diagnosed among Connecticut males and females in Connecticut in 2001 are shown in Table 5. Prostate, breast, lung, and colorectal cancers, together with melanoma of the skin, accounted for 60% of cancers. A substantial number of these cancers can be prevented by lifestyle changes (i.e., lung cancer and melanoma), or may be detected early through screening (i.e., breast, prostate, and colorectal cancers).

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^b Cancer incidence is the number of new cases diagnosed or reported. Throughout this plan, all reported incidence rates are age-standardized. All hospitals and private pathology laboratories in Connecticut are required by law to report cancer cases to the Connecticut Tumor Registry.

^c Mortality means deaths. Throughout this Plan, all reported death rates are age-adjusted.

Table 5
Ten Most Frequently Diagnosed Invasive^a Cancers in Males and Females
Connecticut, 2001²⁴

(Excludes in-situ cancers, except bladder cancer)

Males			Females			
Туре	Number	Percent	Туре	Number	Percent	
1. Prostate	2,895	31.0%	1. Breast	2,935	31.8%	
2. Lung	1,322	14.2%	2. Colorectal	1,126	12.2%	
3. Colorectal	1,066	11.4%	3. Lung	1,113	12.1%	
4. Bladder	673	7.2%	4. Uterus	553	6.0%	
5. Melanoma (skin)	425	4.6%	5. Non-Hodgkin's lymphoma	336	3.6%	
6. Non-Hodgkin's lymphoma	382	4.1%	6. Melanoma (skin)	333	3.6%	
7. Kidney	321	3.4%	7. Ovary	299	3.2%	
8. Leukemia	223	2.4%	8. Bladder	273	3.0%	
9. Oral cavity, pharynx	219	2.3%	9. Thyroid	245	2.7%	
10. Stomach	209	2.2%	10. Kidney	211	2.3%	
All other cancers	1,595	17.1%	All other cancers	1,796	19.5%	
TOTAL	9,330	100.0%	TOTAL	9,220	100.0%	

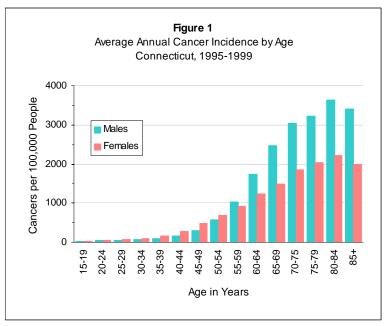
Source: Connecticut Tumor Registry, 2004

Age and Cancer Incidence

Most cancers tend to develop slowly and sometimes do not appear until decades after exposure to a carcinogen. Carcinogens are chemical, physical, or biological agents that can damage the genetic material in cells and can cause mutations. A number of mutations usually must occur for cancer to arise. The chances of developing cancer increase as a person gets older, because more mutations are likely to accumulate over time.

The odds of getting cancer are 1 in 71 for males and 1 in 51 for females from birth through age 39. But over the course of one's lifetime, the odds increase to about 1 in 2 for males and 1 in 3 for females.²⁶ In Connecticut in 2001, 59% of new cancer cases occurred in older adults (65 years of age and older),²⁷ and the median age at diagnosis was 68 years.²⁸ The distribution of new cancer cases by age is shown in Figure 1.

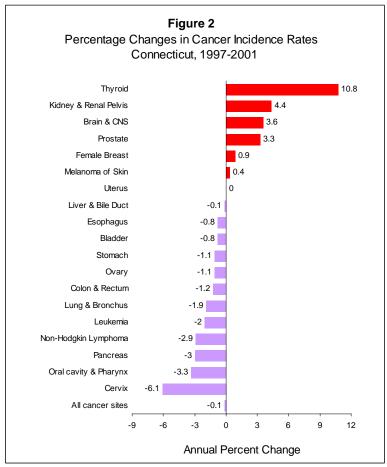
^a Invasive cancers are those that have penetrated into cells beyond the layer of tissue in which they developed, or have spread to distant parts of the body.



Source: Connecticut Tumor Registry, 2002

Trends in Cancer Incidence

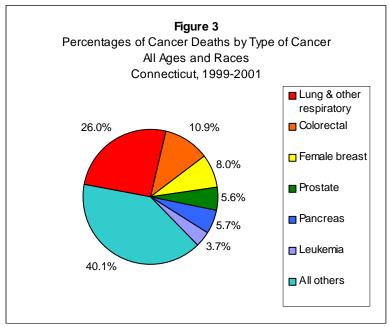
Changes in the rates of new cancers diagnosed among Connecticut residents from 1997 to 2001 are shown in Figure 2^{29} and are discussed later in this section under specific cancer sites.



Source: National Cancer Institute, 2004

Cancer Deaths

Cancer is the second leading cause of death in Connecticut, following heart disease. In 2001, more than 7,000 state residents died of cancer. Although Connecticut has one of the highest rates of new cancer cases in the U.S., in 2001 it had the 11th lowest death rate overall (eighth lowest for males and 25th lowest for females).³⁰ More than half of all cancer deaths in Connecticut are due to cancers of the lung, colon/rectum, female breast, and prostate (Figure 3).³¹



Source: Connecticut Department of Public Health, 2005.

The leading causes of cancer death in Connecticut are similar for different racial and ethnic groups, but vary between males and females (Table 6).

Table 6
Leading Causes of Cancer Death in Different Population Groups. 32
Connecticut, 1999-2001

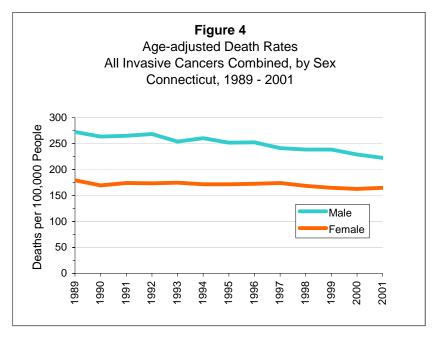
	Sex		Race/Ethnicity (Males and Females Combined)			
Rank	Males (All races)	Females (All races)	White, Non-Hispanic	African American Non-Hispanic	Hispanic	
1	Lung	Lung	Lung	Lung	Lung	
2	Prostate	Breast	Colorectal	Colorectal	Colorectal	
3	Colorectal	Colorectal	Female breast	Female breast	Female breast	
4	Leukemia	Pancreatic	Prostate	Prostate	Prostate	
5	Pancreatic	Ovarian	Leukemia	Pancreatic	Leukemia	

Source: Connecticut Department of Public Health, 2005.

From 1989-1991 and 1996-1998, age-adjusted death rates^d for cancer in Connecticut declined significantly for males and for whites, but not for other groups.³³ Death rates for all invasive cancers (1989-2001) by sex and race/ethnicity are shown in Figures 4 and 5.

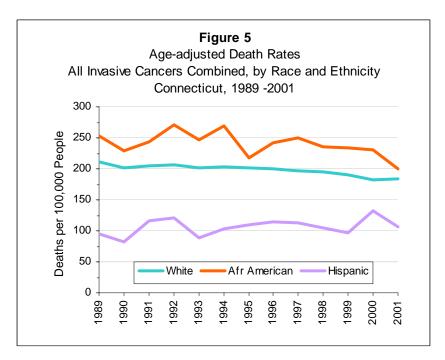
d Except for rates for specific age groups, overall death rates used in this Plan are age-adjusted to the U.S. 2000 standard population.

20



Source: Connecticut Department of Public Health, 2005

Note: Because of changes in cause-of-death coding in 1999, death rates for "all cancers" after 1998 are about 0.68% higher than if coded by earlier definitions and rules.

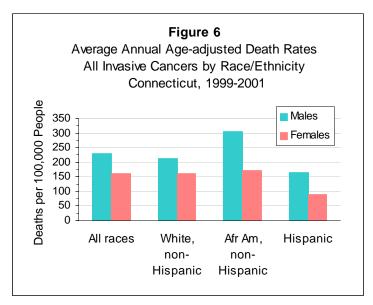


Source: Connecticut Department of Public Health, 2005

Note: Because of changes in cause-of-death coding in 1999, death rates for "all cancers" after 1998 are about 0.68% higher than if coded by earlier definitions and rules.

In 1999-2001, the Connecticut average annual age-adjusted death rate^e for all invasive cancers combined was 188.3 deaths per 100,000 people. Non-Hispanic African Americans had the highest death rates, whereas Hispanics had the lowest death rates (Figure 6).³⁴ The national target for the cancer death rate for all populations by 2010 is 159.9 deaths per 100,000 people.³⁵

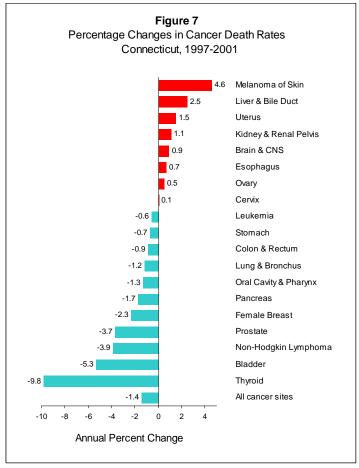
e Except for rates for specific age groups, overall death rates used in this Plan are age-adjusted to the U.S. 2000 standard population.



Source: Connecticut Department of Public Health, 2005

Trends in Cancer Deaths

The average annual percent changes in death rates from 1997-2001 for various types of cancer are shown in Figure 7³⁶ and are discussed under specific cancer types. The death rate for

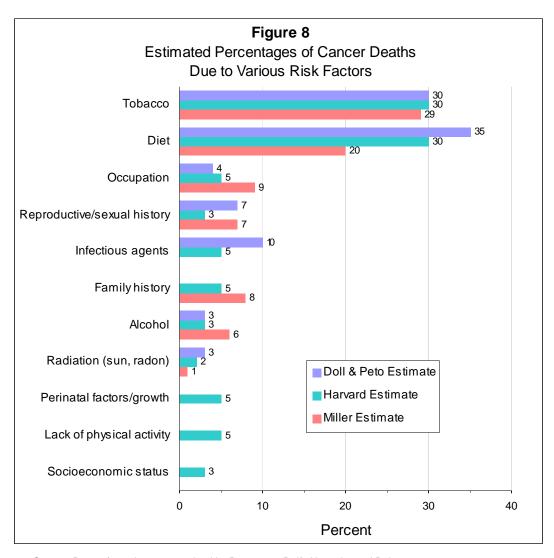


Source: State Cancer Profiles, 2004

all cancers combined (both sexes) declined by 1.4% per year during this period. Death rates for specific cancers, however, showed a wide range of increases and decreases. (See sections below on lung, female breast, colorectal, prostate, melanoma of skin, and ovarian cancers for discussions of specific death rates.)

Risk Factors for Cancer

It has been estimated that at least half of all cancer cases could be avoided or delayed if knowledge about causes and risk factors could be put into practice, but there is no general agreement about the proportion of cancers due to specific risks.³⁷ The contributions of various risk factors to cancer deaths have been estimated by different methods (Figure 8).³⁸ These estimates are helpful for identifying where cancer prevention activities should be focused. Some risk factors are modifiable (e.g., smoking, diet, and physical activity), whereas others (e.g., family history, reproductive history) cannot be altered. Some modifiable risk factors are discussed briefly below and in the *Prevention* chapter of this Plan.



Source: Drawn from data summarized by Brownson, Reif, Alavanja, and Bal, 1998

The prevalence of some key modifiable risk factors among Connecticut adults and adolescents is summarized in Table 7.

Table 7
Percentages of Connecticut Residents with Risks for Cancer

	Percentage of Persons at Risk*	
Risk Factor	Adults ³⁹	Students ⁴⁰
Current cigarette smoking (2003)	18.6%	22.5%
Eating less than 5 servings of fruits/vegetables a day (2003)	70.2%	78.4%
Physical activity:		
No leisure time physical activity (2003)	21.0%	N/A
No vigorous physical activity (2003)	69.4%	40.3%
No moderate physical activity (2003)	48.3%	73.9%
Body weight:		
Overweight (2003)	35.7%	N/A
Obese (2003)	19.1%	N/A
Heavy drinking (Adults, 2002; Students, 2003)	6.7%	27.2%
Did not use a condom during last intercourse (2003)	N/A	38.1%
Had sexual intercourse with 4 or more people in lifetime (2003)	N/A	13.7%
Never/almost never use condom during intercourse: (Adults, 1998; Students, 1999)	29.4%	54.7%
Males with multiple sex partners (1998)	23.6%	N/A
Females with multiple sex partners (1998)	41.0%	N/A

Sources: Behavioral Risk Factor Surveillance System and Youth Risk Behavior Survey (see references).

* Adults 18+ years of age; students in grades 9-12.

Tobacco

Nearly 90% of lung cancer deaths among men and 75-80% of deaths among women are related to cigarette smoking. In 1989 it was estimated that 1,970 cancer deaths in Connecticut each year (about 28% of cancer deaths) are associated with cigarette smoking; women lose about 16 years of expected life, and men lose about 13 years. In 2003, 18.6% of Connecticut adults reported they smoked every day or some days--about half the percentage that smoked in 1989 (Table 7). Younger adults (18-24 years of age) and those with lower incomes and education levels had the highest smoking rates (about twice the overall rate), and high school students were the most likely of all to smoke (22.5%).

Diet

In some studies, cancers of the stomach, esophagus, oral cavity, larynx, rectum, bladder, colon, cervix, and lung have been associated with low consumption of fruits and vegetables. High levels of fat intake, especially from red meat, have been associated with colorectal cancer. In 2003, seven out of ten Connecticut adults at eless than 5 servings of fruits and vegetables a day (Table 7). African Americans and Hispanics were less likely than whites to consume the recommended amount of servings, but the differences were not statistically significant. About 17% of Connecticut adults and 33.2% of students in grades 9-12 ate two or more servings of high-fat foods daily in 1996 and 1997, respectively (the most recent years for which data are available).

Alcohol

The combination of heavy alcohol consumption and tobacco smoke tends to increase the risk of cancers of the mouth, larynx, pharynx, and esophagus. Heavy alcohol consumption, alone, has been associated with cancers of the mouth, pharynx, larynx, esophagus, and liver. Alcohol consumption may also be associated with a modest increase in breast cancer. In 2002, 16.3% of Connecticut were at risk for heavy drinking (greater than 2 drinks per day for males and 1 drink per day for females), and in 2003, 27.2% of high school students reported drinking five or more drinks on one occasion (Table 7). Compared to other population groups, males and younger adults (18-24 years of age) were significantly more likely to report heavy alcohol consumption.

Physical Activity

Regular physical activity has been associated with reduced risk of colon cancer, and it may decrease the risk of breast and prostate cancers. ⁵² In 2003, 48.3% of Connecticut adults did not meet the recommendations for moderate physical activity, f and 69.4% did not meet the recommended guidelines for vigorous physical activity (Table 7). Students were the most active, and older adults (65+ years of age) were the least active. In 2001-2003, African Americans and Hispanics were significantly more likely than whites to report having no leisure time physical activity. ⁵⁴

Obesity

Obesity means having an abnormally high and unhealthy proportion of body fat. It is measured in terms of Body Mass Index (BMI). While obesity is a well established risk factor for diabetes, stroke, and cardiovascular disease, its relationship to cancer is less clear and is complex. Cancers of the colon, breast (postmenopausal), endometrium, kidney, and esophagus are associated with obesity, and in some studies links with other cancers also have been found. In Connecticut in 2003, more than half of Connecticut adults were overweight or obese, and about one in five was obese (Table 7). African Americans and Hispanics were significantly more likely than whites to be obese.

Infectious Agents

Viruses, bacteria, and parasites may account for up to 10% of total cancer deaths in the U.S. Infection with *Helicobacter pylori* (*H. pylori*) bacteria causes stomach ulcers and increases the risk of stomach cancer,⁵⁷ and infection with hepatitis B or hepatitis C viruses increases the risk of liver cancer.⁵⁸

Human papillomavirus (HPV) is a sexually transmitted agent that has been determined to cause almost all cervical cancers. ⁵⁹ It is less clear, however, what percentage of individuals with HPV infection go on to develop cervical cancer. In one study, about 60% of sexually active female college students were found to be infected with HPV at some time during the 3-year observation period. In this group, increased risk of infection was associated most strongly with number of lifetime sexual

^f Brisk walking, bicycling, vacuuming, gardening, or anything else that causes small increases in breathing or heart rate for 30 minutes or more per day 5 or more days a week.

^g Running, aerobics, heavy yard work, or anything else that causes large increases in breathing or heart rate or 20 minutes or more per day 3 or more days a week.

b Body Mass Index is calculated as a person's weight in pounds divided by height in inches squared multiplied by 703, or as weight in kilograms divided by height in meters squared. An online BMI calculator is available at the following Internet web site: http://www.cdc.gov/nccdphp/dnpa/bmi/calc-bmi.htm. Overweight = BMI 25.0 to 29.9. Obese = BMI ≥ 30.0.

partners of main regular partner, number of male sex partners in the past year, frequent alcohol consumption, African American race, and Hispanic ethnicity.⁶⁰

Condoms may prevent the transmission of HPV and other sexually transmitted infections. While there is no consistent evidence that condoms protect against HPV transmission, condom use is associated with lower rates of cervical cancer. In 1998, 29% of Connecticut adults with more than one sex partner--24% of males and 41% of females--reported they never or almost never used condoms. In 1999, more than half of high school students (61.2% of males and 48.5% of females) said they did not use a condom during their last sexual intercourse.

Radiation Exposure (Sunlight, Tanning Booth and Radon)

There is substantial evidence that exposure to ultraviolet radiation (UV) radiation, mainly from sunlight, is related to all types of skin cancer, including malignant melanoma of the skin.⁶⁴ UV exposure from sunlamps and tanning booths also increases risk of skin cancers.⁶⁵ In 2003, 34.4% of Connecticut adults reported they had been sunburned in the past year; of these people, 64.4% had two or more sunburns during that period.⁶⁶

Radon is a radioactive gas that arises naturally within soil and rock from the decay of radium. It can enter buildings through cracks in foundations, and accounts for about 10% of lung cancers. In 1986-1987, the only period for which data are available, 19% of Connecticut homes, or nearly one in five, had radon levels above the U.S. Environmental Protection Agency maximum exposure guideline; it was estimated that radon exposure may account for 280 of total lung cancer casesⁱ in Connecticut each year.⁶⁷

Social and Economic Factors

Several social and economic factors, including level of education, ability to speak English, income, and poverty are closely related to health status, including developing cancer. (See *Connecticut's People: Social and Economic Characteristics*, earlier in this chapter.) Many cancers, including cancers of the lung, stomach, and uterine cervix, are more common among poor and underserved groups. Low socioeconomic status (SES) is associated with increased smoking, alcoholism, poor nutrition, and reduced access to health care. Low SES is also associated with later diagnosis, reduced access to treatment opportunities, and reduced survival. In contrast, the risk of developing female breast cancer and melanoma of the skin is greater among persons with higher socioeconomic status (see below).

Prevention and Early Detection of Specific Cancers

The organization of the Connecticut Comprehensive Cancer Control Plan is based on the continuum of cancer care, from prevention through end-of-life, rather than on specific cancer sites. The cancers discussed below, however, figure importantly in planning for improvements in each of the priority areas, because they are preventable, effective screening methods are available, or more education about risk factors and early symptoms is needed.

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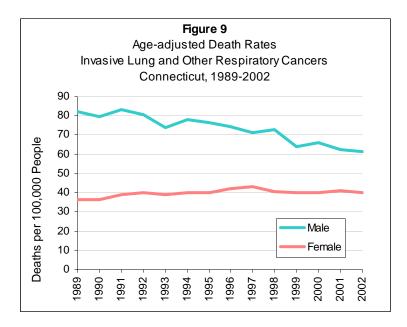
ⁱ In 2001 2,435 new cases of lung cancer were reported in Connecticut.

Lung Cancer

Lung cancer is one of the most preventable cancers. Nearly 90% of lung cancer deaths among men and 75-80% among women could be avoided if people never used tobacco products. In the past century, lung cancer has progressed from being a medical rarity to one of the most common forms of cancer. In 1914, for example, only 371 cases of lung cancer were reported in the entire U.S., whereas in 2002 it caused the deaths of five times that number of people in Connecticut alone.

Today, lung cancer, accounts for more than one in eight new cancer cases and more than one-fourth of all cancer deaths in Connecticut. It is the second most frequently diagnosed cancer and the leading cause of cancer deaths for both women and men. Incidence rates and mortality rates for lung cancer are lower in women than in men because of differences in smoking rates in the past; however, the gap between the sexes is narrowing. Between 1980-1984 and 1995-1999, the incidence rates for lung cancer in Connecticut fell by 11% for men but rose by nearly 50% for women. While death rates have been declining for men, they have been increasing for women (Figure 9), and in 1988, lung cancer overtook breast cancer as the leading cause of cancer deaths among Connecticut women and still holds that rank.

Disparities also exist in lung cancer incidence and death rates for different racial and ethnic groups. Among males, African Americans have the highest rates and Hispanics have the lowest rates.⁷⁴



Source: Connecticut Department of Public Health, 2005

Note: Because of changes in cause-of-death coding in 1999, death rates for lung cancer after 1998 are about 1.63% lower than if coded by earlier definitions and rules.

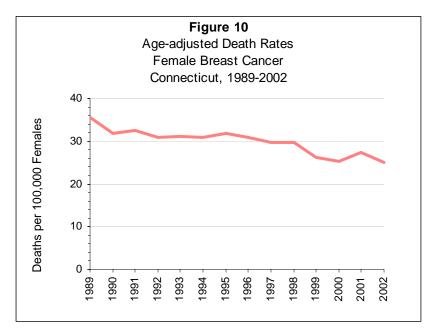
The survival of a person with cancer is strongly affected by the extent or anatomical "stage" of the disease at the time it is diagnosed. Generally, cancers that are detected early, before they have spread, are more treatable than advanced cancers, but there is no validated screening method for early detection of lung cancer among high-risk individuals. Based on 1995-2001 data from

U.S. cancer registries,⁷⁵ only 16% of lung cancers are diagnosed at "local" stages, when they are confined entirely to the lung and have not spread into nearby tissues or lymph nodes. The 5-year SEER relative survival rate for local stage lung cancer diagnosed in 1995-2001 was 49.4%. When diagnosed at the "distant" stage, when the cancer has metastasized, the 5-year relative survival rate was 2.1%.⁷⁶

Breast Cancer

Breast cancer is the most frequently diagnosed invasive cancer and the second leading cause of cancer death among women in Connecticut and the U.S. In 2001, Connecticut had the second highest incidence rate for invasive breast cancer in the nation.⁷⁷ While incidence rates for breast cancer have been rising, death rates have been decreasing. From 1980-1984 to 1995-1999, the age-standardized incidence rate for new cases of invasive female breast cancer in Connecticut rose by 27.5%, from 97.5 to 124.3 cases per 100,000 women,⁷⁸ partly associated with increased screening and detection.⁷⁹ There was an average annual increase of 0.9% per year from 1997 to 2001 (Figure 2).

From 1989 to 2000 the age-adjusted death rate for female breast cancer in Connecticut decreased by 30% (Figure 10). Breast cancer incidence rates tend to be higher for white females compared to African Americans or Hispanics, whereas death rates tend to be significantly higher for African Americans.⁸⁰



Source: Connecticut Department of Public Health, 2005

Note: Because of changes in cause-of-death coding in 1999, death rates for breast cancer after 1998 are about 0.56% higher than if coded by earlier definitions and rules.

Age is the greatest risk factor for female breast cancer; about 80% of new cases and nearly 90% of deaths occur in women 50 years of age and older. Other risk factors include a family history of breast cancer (especially in a mother or sister) or a previous breast cancer, carrying

certain genetic mutations, and reproductive and hormonal factors (early age at first menstrual period, no children, first pregnancy after 30 years of age, late age at menopause). Overweight, a sedentary lifestyle, alcohol consumption, and exposure to ionizing radiation during adolescence also might increase a woman's risk of developing breast cancer. Despite the long list of possible risk factors, few are strongly associated with the development of breast cancer, and together, they explain only about one-fourth of all breast cancers. ⁸²

Higher than expected incidence rates for female breast cancer were noted for several Connecticut towns during the time periods 1990-1994 and 1995-2000⁸³ Incidence rates for breast cancer tend to be associated with age at first birth, with risk increasing with increasing age.⁸⁴ Higher socioeconomic status is related to higher age at first birth, because women with higher incomes, educational attainment, and employment activity are more likely to delay childbearing.⁸⁵ In 2000, the average age of Connecticut women at first births--27.2 years--was the second highest in the U.S.⁸⁶

Regular professional screening (mammograms, clinical breast exams) may detect breast cancer at an earlier stage. In Connecticut, more than half of breast cancers are diagnosed at the local stage (Table 8). The 5-year relative survival rate (SEER) for breast cancer diagnosed in 1995-2001 was 88.2% overall--97.9% if found at local stages and 26.1% if found at the distant stage.⁸⁷

Table 8
Stage at Diagnosis for Selected Cancers⁸⁸
Connecticut, 1999

	Stage at Diagnosis*				
		Invasive			
Cancer Site	In situ	Local	Regional	Distant	Unknown
Breast (female)	20%	53%	21%	4%	3%
Colon-rectum	9%	38%	32%	14%	6%
Prostate	0%	90% (local/regional)		4%	5%
Melanoma of skin	42%	50% 4%		2%	3%

Source: SEER General Summary Staging System, Connecticut Tumor Registry, 2002

Invasive: Has penetrated beyond the layer of cells where it began.

Local: Invasive, but confined entirely within organ of origin.

Regional: Has spread by direct extension to adjacent organs or tissues, and/or to lymph nodes considered regional to the organ of origin, but no further spread has occurred.

Distant: Has spread beyond adjacent organs or tissues and/or to tissues or lymph nodes remote from the primary tumor.

The American Cancer Society recommends yearly mammograms starting at age 40; clinical breast exams about every 3 years for women in their 20's and 30's and every year for women 40 and older; and optional breast self exams for women 20 and older. The U.S. Preventive Services Task Force (USPSTF) recommends screening mammography, with or without clinical breast examination, every 1-2 years for women aged 40 and older. In 2002, 82.4% of Connecticut women 40 years of age and over reported they had a mammogram in the past 2

^{*} In situ: Confined to the layer of cells where it began; not invasive.

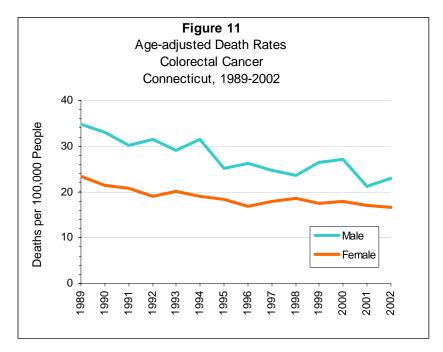
years, 72.3% reported they had a mammogram in the past year, and 74.8% said they had a clinical breast exam in the prior year. 91

Colorectal Cancer

In Connecticut, colorectal cancer (cancers of the colon and rectum) is the third most frequently diagnosed cancer in men and the second most common cancer in women (Table 5). In 2001, the incidence rate in Connecticut for white males was 1.3 times greater than for African American males; among females, it was 1.1 times greater for African Americans than for whites. Between 1980-1984 and 1995-1999, the age-standardized incidence rate for colorectal cancer among males declined by nearly 20%. The decrease for females was somewhat lower. From 1997 to 2001 the incidence rate for both sexes declined an average of 1.2% per year (Figure 2). 92

The incidence of colorectal cancer increases sharply with age; nationally, 50% of patients are diagnosed at 72 years of age and older. In 1999, 38% of colorectal cancers were diagnosed at local stages in Connecticut (Table 8). The 5-year relative survival rate (SEER) for colorectal cancer diagnosed in 1995-2001 was 64.1% overall, 90.4% when diagnosed at local stages and 9.7% when diagnosed at the distant stage.

Colorectal cancer was the third leading cause of cancer death among both men women and accounted for 10% of cancer deaths in Connecticut in 2002. Death rates for colorectal cancer are higher for men than for women (Figure 11), but have been declining for both sexes (Figures 7 and 11), which may reflect advances in screening and detection and improved treatments.



Source: Connecticut Department of Public Health, 2005

Note: Because of changes in cause-of-death coding in 1999, death rates for colorectal cancer after 1998 are about 0.07% lower than if coded by earlier definitions and rules.

Risk factors for colorectal cancer include a family history of colorectal cancer, a diet high in animal fat and low in fiber, physical inactivity and obesity, smoking, heavy alcohol consumption,

and a history of inflammatory bowel disease.⁹⁷ There is some evidence that the risk of developing colorectal cancer can be reduced by eating less animal fat and red meat, and more fruits, vegetables, fiber, and low-fat dairy products, regular aspirin use, taking folic acid and calcium supplements, and regular physical activity.⁹⁸

The American Cancer Society recommends screening for colorectal cancer beginning at age 50 with one of the following schedules: a yearly fecal occult blood test (FOBT) or fecal immunochemical test (FIT); flexible sigmoidoscopy every 5 years; annual FOBT or FIT, with flexible sigmoidoscopy every 5 years (preferred to either test alone); a double-contrast barium enema every 5 years; or a colonoscopy every 10 years. The USPSTF strongly recommends that clinicians screen men and women 50 years of age and older for colorectal cancer but does not recommend a specific method or schedule. In Connecticut in 2003, 27.2 % of Connecticut residents over 50 years of age reported they had a blood stool test in the last year, and 49.0% reported having a sigmoidoscopy or colonoscopy in the last 5 years.

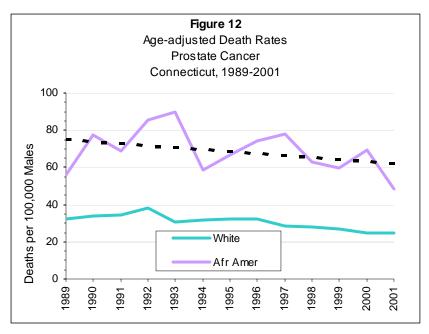
Prostate Cancer

Prostate cancer is the most frequently diagnosed cancer among males in Connecticut and the U.S. In 2001, nearly 3,000 cases were diagnosed in Connecticut, representing just under one-third of total new cancers (Table 5); the incidence rate for African American males was 1.4 times greater than that for white males. From 1980-1984 to 1995-1999, the average annual incidence rate for prostate cancer in Connecticut doubled. Some of this increase is likely due to increased screening using the PSA (prostate specific antigen) test. From 1997 to 2001, the age-adjusted incidence rate rose an average of 3.3% per year (Figure 2). Significantly more cases of prostate cancer than expected have been found in several towns in Fairfield County and in the city of Hartford and many of its surrounding towns.

Risk of prostate cancer rises sharply after age 50. In 2001, 63% of new cases in Connecticut were found in men 65 years of age and over. In 1999 in Connecticut, 90% of prostate cancers were diagnosed at the local and regional stages (Table 8). The 5-year relative survival rate (SEER) for prostate cancer diagnosed in 1995-2001 was greater than 95% when diagnosed at the local/regional stages and 33.5% when diagnosed at the distant stage.

In 2002, prostate cancer was the second leading cause of cancer deaths among Connecticut men, accounting for 12.2% of total cancer deaths. The death rate for African American males in Connecticut consistently has been about twice that of white males. Annual prostate cancer death rates from 1989-2001 for white males compared to African American males are shown in Figure 12. From 1997 to 2001 the overall age-adjusted death rate for prostate cancer fell by an average of about 4% per year (Figure 7).

Little is known about the risk factors for prostate cancer, but it is thought that hormonal and nutritional factors are related to risk. A family history of prostate cancer is also associated with increased risk. Some studies suggest that a diet rich in selenium, vitamin E, and lycopene (e.g., tomato sauce, tomatoes, pink grapefruit, watermelon) may protect against prostate cancer, whereas a diet high in animal fat and saturated fat may increase risk.¹¹¹



Source: Connecticut Department of Public Health, 2005

Note: Because of changes in cause-of-death coding in 1999, death rates for prostate cancer after 1998 are about 1.34% higher than if coded by earlier definitions and rules.

Dotted line shows linear trend for African Americans.

There is no general agreement about the value of screening for prostate cancer. The ACS recommends offering annual prostate specific antigen (PSA) blood tests and digital rectal examinations (DRE) to men age 50 and over, and at younger ages for African Americans and other men at high risk for developing prostate cancer. The USPSTF, however, currently does not recommend for or against routine screening for either test. In Connecticut in 2002, 43.4% of men 40 years of age and older reported they had a PSA test in the past 12 months, and 52.0% said they had a DRE in the last year.

Melanoma

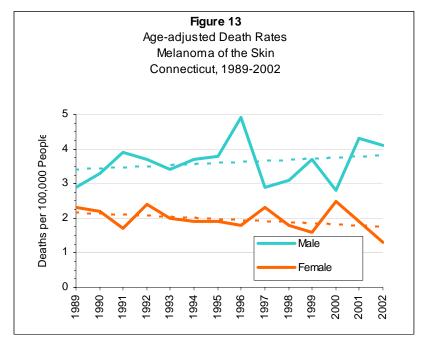
Melanoma of the skin accounts for 700-800 new cases of cancer each year in Connecticut. It is the fifth most commonly diagnosed cancer in men and the sixth most common in women (Table 5). The average annual incidence rate for melanoma of the skin among Connecticut males doubled between 1980-1984 and 1995-1999. From 1997 to 2001 the incidence rate rose an average of 0.4% per year (Figure 2). Higher than expected numbers of skin melanomas have been found for certain Connecticut towns on the ocean shoreline and near lakes, suggesting excess exposure to the sun. 117

Melanoma of the skin is a disease that affects people of white race almost exclusively; only about 2% of new cases in the U.S. are found in people of color. In Connecticut in 1999, 50% of melanomas were diagnosed at the local stage (Table 8). The 5-year relative survival rate (SEER) for melanomas diagnosed in 1995-2001 was 91.6% overall, 98.3% when diagnosed at local stages, and 16.0% when diagnosed at the distant stage.

Age-adjusted death rates and linear trends in rates for melanoma of the skin among Connecticut males and females are shown in Figure 13. The death rates tend to be higher for males than for females. From 1997 to 2001, the overall age-adjusted death rate for melanoma of the skin increased by an average of 4.6% each year, which was the steepest increase among the selected cancers studied (Figure 7). 120

Certain risk factors are linked strongly with melanoma of the skin. Risk is greatest for fair-skinned people who freckle or sunburn easily, and for those with a family history of melanoma. People who have multiple moles or large moles have an increased risk. Excessive exposure to UV radiation from the sun or from tanning lamps and beds, and a history of severe sunburns, especially during childhood, also increase risk. Protection from sun exposure and avoidance of artificial sources of UV radiation may help to prevent melanoma. In 2003, 34.4% of Connecticut adults reported they had a sunburn in the past year, and of this group, 64.5% reported two or more burns. ¹²¹

Neither the ACS nor the USPSTF currently has specific screening recommendations for the early detection of melanoma of the skin.



Source: Connecticut Department of Public Health, 2005

Note: Because of changes in cause-of-death coding in 1999, death rates for melanoma of the skin after 1998 are about 3.2% lower than if coded by earlier definitions and rules. Dotted lines show linear trends for males and females.

Ovarian Cancer

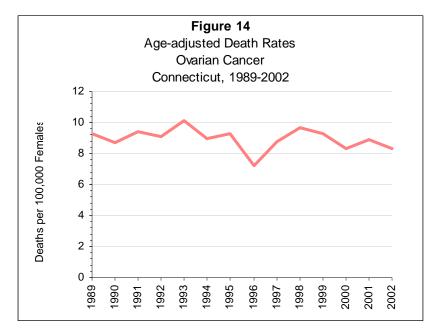
Ovarian cancer is the seventh most frequently diagnosed cancer among Connecticut women and accounts for about 300 new cancers annually (Table 5). The age-standardized incidence rate for ovarian cancer in Connecticut rose by 4.9% between 1980-1984 and 1995-1999, ¹²² and from 1997 to 2001 it declined by an average of 1.1% per year (Figure 2). Nationally, the incidence rate for ovarian cancer is about one-third lower for African American females than for whites. ¹²³

When detected at localized stages, the 5-year relative survival rate (SEER) for ovarian cancer is 93.6%; however, the early stages of ovarian cancer have no specific symptoms, so in 1995-2001, only 19% were diagnosed at local stages. The majority of ovarian tumors (68.1% in 1995-2001), are detected at the distant stage, when the 5-year relative survival rate is about 29%. 124

In Connecticut, ovarian cancer is the fifth leading cause of cancer death among females and the fourth leading cause of cancer death among white females. Age-adjusted death rates for ovarian cancer in Connecticut have fluctuated between about 8 and 10 deaths per 100,000 females from 1989-2002 (Figure 14), and from 1997-2001 rates declined by about 0.5% annually (Figure 7).

The risk factors for ovarian cancer are not well understood. Although several risk factors (e.g., having no children) may increase the likelihood that a woman will develop ovarian cancer, most women who develop the disease have no known risk factors, and only a small proportion of women with risk factors ever develop the disease. The risk of developing ovarian cancer increases with age, and in Connecticut in 2001, 56% of diagnosed ovarian cancers were found in women 60 years of age and over. The risk of developing ovarian cancers were found in the second s

Transvaginal sonography and the CA-125 blood test often are used to screen for ovarian cancer in women considered to be at high risk, but it is not known whether these tests are helpful. Because of the low prevalence of ovarian cancer and the invasive nature of diagnostic testing after positive screening, the USPSTF recommends against routine screening for it. 130



Source: Connecticut Department of Public Health, 2005

Note: Because of changes in cause-of-death coding in 1999, death rates for ovarian cancer after 1998 are about 0.46% lower than if coded by earlier definitions and rules.

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3 PREVENTING CANCER BEFORE IT STARTS

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Lawrence & Memorial Hospital

New London

Eric Triffin

West Haven Health Department

West Haven

Thomas Wegrzyn

Chesprocott Health District

Cheshire

PREVENTING CANCER BEFORE IT STARTS

VISION

All Connecticut residents will be engaged in the support and practice of individual and community risk reduction behaviors and activities to reduce cancer incidence

The Prevention Committee studied data on the risk factors for the most common types of cancer, determined the critical areas of burden and of high-risk populations, and assessed gaps in present programming to determine prevention goals and objectives for the Connecticut Comprehensive Cancer Control Plan.

GOAL

Reduce cancer risk through promoting healthy lifestyles and risk reduction behaviors among children and adults

WHY THIS GOAL IS IMPORTANT

- **1. Tobacco.** About 5,000 Connecticut residents die each year from smoking related illnesses, about 2,000 of which are cancers.¹
- Nutrition and physical activity. Higher consumption of fruits and vegetables and regular
 physical activity may lower risk of developing some cancers. Obesity is associated with
 increased risk for many cancers.
- Environmental exposures, especially sun. Exposure to ultra-violet radiation from the sun and artificial tanning devices is associated with an increase in both melanoma of the skin and the more common non-melanoma skin cancers.
- **4. Excessive alcohol use.** Excessive consumption of alcoholic drinks is associated with oral, laryngeal, pharyngeal, liver, and esophageal, cancers and possibly other cancers.
- 5. **Unprotected sex.** Human papillomavirus (HPV), which is transmitted by sexual contact, is an established cause of cervical cancer in women.

TOBACCO

About a third of all cancer deaths have been attributed to tobacco use. Although smoking rates have declined in recent years in Connecticut, an estimated 500,000 adults (18.6%) still smoke every day or some days.² In addition to adult smokers, more than 60,000 middle and high school students currently smoke.³ This number does not include high school dropouts, who are known to have higher smoking rates compared to students their ages who remain in school. More than 70% of middle and high school smokers think they could quit smoking now if they wanted to, but only half of current smokers in middle school and two-thirds of those in high school want to quit, and more than 60% were unable to remain off cigarettes for at least 30 days during their last quit attempt.

Every year, 48,000 Connecticut students reach the age of 11, which is the current average age of smoking initiation among eighth graders who are smoking. If this trend continues, 56,000 Connecticut youth will eventually die prematurely from smoking.⁴

The CDC's Community Guidelines⁵ identified four interventions for which the evidence is strongest for reducing tobacco use:

- 1. Increasing the unit price for tobacco.
- 2. Smoking bans and restrictions.
- 3. Media campaigns with interventions.
- 4. Comprehensive cessation programs.⁶

Connecticut's tobacco tax and smoking bans are among the nation's most effective and meet the Guidelines, but Connecticut lacks the comprehensive tobacco cessation services and media campaigns that can be expected to dramatically reduce our state's tobacco use. For example, from 2002 to 2003 New York City experienced the most significant one-year drop in tobacco use ever recorded. New York City credited its 11 % reduction to increasing its cigarette tax, its smoke free air act, and its cessation and public education programs. These are the four critical elements identified by the CDC Guidelines. Connecticut has done the first two. By adding the last two we can expect to see significant reductions in smoking, preventing thousands of tobacco-related deaths and saving millions of health dollars.

In 1999 in Connecticut, the economic cost of smoking was \$2.14 billion, or about \$3,732 per adult^a smoker. Adult smoking-attributable medical expenditures totaled \$1.27 billion or 9% of total expenditures for health care, and lost productivity attributable to smoking among adults cost \$859 million.⁸ For lung cancer, alone, Connecticut inpatient hospital charges in 2001 were \$44.4 million, or more than \$21,000 per hospitalization.⁹

Connecticut's tobacco tax of \$1.51 now ranks sixth in the country, and an increase of 74 cents has been proposed. Although it is among the highest in the nation, it is in line with our neighboring states, and has much room to grow. Rhode Island currently leads the nation with \$2.46, the cigarette tax in Massachusetts is \$1.51, New York has a \$1.50 tax, with an additional New York City tax of \$1.50, and New Jersey's tax is \$2.40.

The Connecticut Tobacco Use Prevention and Control Plan, produced in 2002 by the Connecticut Department of Public Health and Department of Mental Health and Addiction Services with funding from the State Legislature, is a plan that is comprehensive, sustainable, evidence-based, and data-driven. Its recommendations closely following CDC's Best Practices for Comprehensive Tobacco Control Programs call for comprehensive state and local action directed at social and environmental changes. It includes examples of some unique and effective programs, such as regional coalitions, and it addresses the important target population groups whose smoking rates are the highest. The Connecticut Cancer Partnership is committed to supporting the goals and objectives of this plan and advocating for funding its implementation.

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^a In 1999 there were an estimated 572,053 smokers 18+ years of age in Connecticut. (2001 Behavioral Risk Factor Surveillance System, Connecticut data.)

PREVENTION OBJECTIVE 1:

Decrease the proportion of adults (\geq 18 years) and youths (high school and middle school students) who currently use tobacco, paying special attention to populations experiencing tobacco-related disparities

Baseline

Adults: 18.6% (BRFSS, 2003)

High school: 22.5% (30-day prevalence, CYTS 2002) Middle school: 5.9% (30-day prevalence, CYTS 2002)

Targets

Adults: 17.5% (BRFSS)

High school: 20.0% (30-day prevalence, CYTS) Middle school: 5.0 % (30-day prevalence, CYTS)

Strategies

- 1. Support creating statewide smoking cessation program that meets Public Health Service and National Action Plan guidelines, including evidence-based counseling, pharmacotherapy, and a marketing campaign. These interventions should be available at no charge to the Medicaid and uninsured population
- 2. Advocate for an increase in the state tobacco tax sufficient to fund the state cancer and tobacco plans
- 3. Help initiate a statewide tobacco education media campaign like those shown to be effective in other states such as Florida and California
- 4. Support implementation of "Connecticut Tobacco Use Prevention and Control Plan," through advocating a combination of federal, state, and local funding
- 5. Advocate for implementation of local tobacco prevention and control plans.
- 6. Advocate for "Coordinated School Health Councils" throughout the state
- 7. Develop a forum for pharmaceutical, managed care, and industry (employers) to discuss pilot smoking cessation programs for employees that include pharmacotherapy products
- 8. Secure funding for Quitline services to continue in the state
- 9. Increase Smoke-Free College and University programs; identify effective programs and provide a forum and communications link (Partnership web site) for sharing effective programs

How Results Will Be Evaluated

- 1. Reduced adult and youth tobacco use
- 2. Increase in state tobacco tax
- 3. Initiation of statewide tobacco cessation program
- 4. Funding allocated to support implementation of state tobacco use prevention and control plan
- 5. Funding allocated to support implementation of local plans
- 6. Coordinated School Health Councils established throughout the state
- 7. Forum conducted, policy change language developed; pilot programs identified
- 8. Funding achieved for Quitline to 2007
- 9. Smoke Free College and University programs increased; resource list of effective programs and website material produced

NUTRITION, PHYSICAL ACTIVITY, AND OBESITY

Poor nutrition, the lack of physical activity, and obesity are interacting risk factors for several types of cancer. Current patterns of overweight and obesity in the United States could account for an estimated 14% of all deaths from cancer in men and 20% of those in women. In both men and women, body-mass index is significantly associated with higher rates of death due to cancer of the esophagus, colon and rectum, liver, gallbladder, pancreas, and kidney; the same is true for death due to non-Hodgkin's lymphoma and multiple myeloma. Significant trends of increasing risk with higher body-mass-index values have been observed for death from cancers of the stomach and prostate in men and for death from cancers of the breast, uterus, cervix, and ovary in women. (Overweight is defined as having a body mass index (BMI) of 25 to 29.9, and obesity as a BMI of 30 or greater. Low intake of fruits and vegetables may be associated with an increased risk of several cancers, including colon, laryngeal, oral, and lung. Physical activity is related to both colon and breast cancers; the relationship to other cancers is still being investigated.

During the past decade Americans have been using the *Nutrition Facts* labels to choose healthier packaged foods. Unfortunately, working people increasingly eat meals outside the home where virtually no nutrition information is readily available. Research shows that while the *Nutrition Facts* label has led producers to reduce the amount harmful fat, sugar, salt, and calories in packaged food, the lack of labeling in restaurants has contributed to the steadily higher fat, sugar, salt, and calories observed in restaurant fare. When restaurant menus contain nutritional information, sales of more healthful foods increase. To help people make healthier food choices, the Prevention Committee supports legislation to require large chain restaurants to put simple nutrition information, such as calories and the amount of fat, sugar, and salt, on their menu boards or menus.

It is clear that advocacy and policy change, along with community mobilization, need to be included in our program. Several resources, itemized below, are already being used to develop a coordinated program for Connecticut.

- 1. CDC's *Active Community Environment Initiative*, promoting walking, bicycling and the development of accessible recreation facilitates
- 2. Connecticut Department of Public Health's Obesity Program
- 3. NECON's (New England Coalition of Health Promotion and Disease Prevention) *Plan for Prevention and Control of Overweight and Obesity in New England*
- 4. AHRQ's (Agency for Healthcare Research and Quality) *Put Prevention into Practice* program, with resources for clinicians, patients, and office systems to increase the delivery of preventive services in primary care settings
- 5. The new *Dietary Guidelines for Americans 2005* developed by the U.S. Departments of Agriculture and Health and Human Services

Data concerning nutrition, overweight/obesity, and physical activity are being used to guide program development in Connecticut. Some of the pertinent data are highlighted below. ¹³

- 1. Although 60% of New England women and 40% of men believe that eating fruits and vegetables 'very likely' reduces cancer risks, less than one-third of Connecticut adults reported eating five or more fruits and vegetables daily.
- 2. Although 52% of women and 39% of men rated getting regular physical activity as 'very likely' to reduce one's risk of cancer, 68% of Connecticut adults reported mostly sitting or standing while at work and 21% reported they engage in no leisure time physical activity or exercise.

- 3. Compared to white non-Hispanics, African American non-Hispanics were 58% more likely and Hispanics were twice as likely to report having no leisure time physical activity (19%, 30%, and 39%, respectively).
- 4. Although 49% of women and 38% of men rated maintaining a healthy weight as 'very likely' to reduce one's risk of cancer, the proportion of overweight or obese adults in Connecticut has increased progressively during the past decade, and reached its highest levels of about 67% for men and about 44% for women in 2003.
- 5. The percentages of overweight or obese adults by race and ethnicity were: white, non-Hispanic, 54%; African American non-Hispanic, 70%; and Hispanic, 63%.

PREVENTION OBJECTIVE 2

Increase the proportion of adults (\geq 18 years) and youths (< 18 years) who make healthy food choices, including increasing consumption of fruits and vegetables to meet current HHS and USDA Dietary Guidelines for Americans

Baseline

Adults: 29.8%, consume at least 5 daily servings of fruits and vegetables (BRFSS 2003) High school students: 21.6%, consume at least 5 daily servings (CT School Health Survey 2003)

Targets

Adults: 35.0% meet current Dietary Guidelines for Americans^b (BRFSS)

Youth: 40.0% meet current Dietary Guidelines for Americans (CT School Health Survey)

Strategies

1. Advocate for nutrition labeling in chain restaurants

- 2. Advocate for changes in policies and curriculum to better support healthier eating and education about nutrition in schools
- 3. Advocate for a program of Coordinated School Health Councils
- 4. In conjunction with CDC's National Partnership 5-to-9-A-Day plan, develop a coordinated effort to increase consumption of fruits and vegetables to meet current Dietary Guidelines for Americans
- 5. Develop and implement a campaign targeted to community physicians for discussion with their patients to promote fruits and vegetables as well as guidelines related to calories, fats, and carbohydrates
- 6. Identify partners in food business and industry that can help make changes
- 7. Review existing data regarding barriers and motivating factors for healthy nutrition for all age and ethnic groups; identify best practices for implementation
- 8. Advocate for intervention research

How Results Will Be Evaluated

- 1. Restaurant labeling law introduced and supported by state leaders
- 2. New policies and curriculum instituted
- 3. Coordinated School Health Councils established
- 4. Partnership on 5-to 9-A-Day and coordinated effort developed
- 5. Campaign for pediatricians developed and implemented
- 6. New food industry partners committed to helping
- 7. Best practices identified and integrated into program

Dietary Guidelines for Americans, Fruit and Vegetable Intake: To meet nutrient adequacy recommendation, a range of 5-13 servings of fruits and vegetables each day is recommended for daily energy intakes of 1,200-3,200 calories. For a 2,000 calorie daily energy intake, 9 servings (4 ½ cups) are recommended.

PREVENTION OBJECTIVE 3

Decrease the proportion of adults (\geq 18 years) and high school students who engage in no leisure time physical activity or exercise

Baseline

Adults: 21.0% (BRFSS 2003)

High school students: 9.7% (CT School Health Survey, 2003)

Targets

Adults: 17.0% (BRFSS) High school: N/A

Strategies

- 1. Advocate for changes in policies and curriculum to better support and increase amount of physical activity for all students
- 2. Advocate for tax breaks for physical activity programs such as building walking trails
- 3. Develop and implement a campaign targeted to community physicians to encourage discussing need for physical activity with patients
- 4. Identify partners for long term strategies (DPH Obesity Program, CVD Program)
- 5. Review existing data regarding barriers and motivating factors for physical activity for all age and ethnic groups; identify best practices for implementation
- 6. Review materials to identify additional advocacy strategies for implementation
- 7. Advocate for intervention research in this area

How Results Will Be Evaluated

- 1. New policies and changes in school programs and curricula
- 2. Laws regarding physical activity tax breaks passed
- 3. Program for use with pediatricians developed and implemented
- 4. Partners identified and recruited; pooled resources and knowledge available
- 5. Report with findings and recommendations on how to impact change; best practices identified
- 6. Advocacy strategies identified and implemented
- 7. Funding for research achieved

PREVENTION OBJECTIVE 4

Reduce the percentage of overweight and obese adults (≥ 18 years) and children

Baseline

Overweight adults: men 45.7%, women 25.9%, (BRFSS 2003) Obese adults: men 19.9%, women 18.3%, (BRFSS 2003) High school students: 11.6% (CT School Health Survey, 2003)

Targets

Overweight adults: men 40.0%, women 20.0% (BRFSS) Obese adults: men 15.0%, women 15.0% (BRFSS) High school: 6.0% (CT School Health Survey))

Strategies

1. Advocate for nutrition labeling in chain restaurants

- 2. Advocate for changes in school food programs and curriculum
- 3. Develop plan to coordinate with ongoing programs and to involve new collaborating partners
- 4. Advocate for research to find effective intervention strategies
- 5. Advocate for Connecticut to participate in YRBS questions on this topic

How Results Will Be Evaluated

- 1. Restaurant labeling law introduced and supported by state leaders
- 2. Changes made in school food programs and in curriculum
- 3. New partners involved; plan developed
- 4. New research results on interventions

ENVIRONMENTAL EXPOSURES

The issues surrounding environmental exposures as risk factors for cancer are complex. Hundreds of chemicals, drugs, and other substances are known, probable, or possible human carcinogens, ¹⁴ though most people are unlikely to be exposed to them, and some naturally occurring substances in the environment (e.g., radon) are known to increase the risk of developing cancer. Exposure to ultraviolet (UV) radiation from sunlight and from artificial tanning lamps can damage DNA, the critical genetic material in cells. Damage of DNA in skin cells can sometimes lead to skin cancer.

There are two primary forms of skin cancer: non-melanoma and melanoma. Non-melanoma, the most common form, occurs in either basal or squamous skin cells that are located at the base of the outer layer of the skin, and rarely results in death. Compared to non-melanoma skin cancer, melanoma skin cancers are much less common, develop from the cells that produce skin color, and can be fatal. Higher rates of skin cancer occur in certain affluent communities and ocean shoreline towns of Connecticut, and are believed to be related, at least in part, to differences in recreational sun exposure. Sun-protective behaviors can lead to substantial reductions in sun exposure, thereby reducing the risk of developing either melanoma and non-melanoma skin cancer.

Most occupations in the United States do not present a risk for getting cancers. However, in some industries exposure to a range of carcinogens can present a hazard to workers over time. Protection from cancer risk in the workplace is essential and involves a combination of aggressive, scientifically based regulations, worker education and surveillance.

Some programs that evaluate and regulate environmental toxins and exposures already exist. The Radon Program at the Connecticut Department of Public Health provides educational outreach activities to the general public, and free testing devices are part of its outreach efforts. The Toxic Hazards Assessment Program at DPH evaluates and quantifies health risks from exposures to environmental contaminants, and attempts to decrease these risks by working with the Department of Environmental Protection (DEP) and informing the public and health care professionals about environmental hazards. DEP is the state regulatory agency that reviews and investigates environmental issues and identifies exposure problems. The Environmental Public Health Tracking Program is developing a comprehensive system for linking and reporting environmental, human exposure, and health effects data. The DPH Environmental Epidemiology group is working on a plan to add questions about perception of environment-related risks to the BRFSS survey.

PREVENTION OBJECTIVE 5

Increase the public's awareness of cancer-related environmental exposures and protective measures

Baseline

Not available

Strategies

- 1. Establish baseline and targets
- 2. Identify methods and develop program to increase knowledge and understanding of environmental exposures to cancer, especially radon, pesticides, and home use products
- 3. Improve partnership with federal, state and local governments, business and communities to reduce known exposures and to identify environmental risk factors
- 4. Identify new partners to support efforts

How Results Will Be Evaluated

- 1. Baseline established
- 2. Methods identified and implemented
- 3. Partnership improved
- 4. New partners identified and added to effort

PREVENTION OBJECTIVE 6

Increase the practice of sun protection behaviors, especially among youth Increase awareness of risk of overexposure to ultraviolet light in tanning booths

Baseline

Not available

Strategies

- 1. Establish baseline and targets.
- 2. Develop and implement a pilot program for elementary school children and their parents to educate them about the harms from UV exposure, especially to children, and to reduce the children's lifetime risk of skin cancer
- 3. Advocate for policies such as trees in schoolyards, the wearing of protective clothing and wraparound sunglasses with UV absorption factor
- 4. Develop and implement a campaign for pediatricians to inform parents about caring for the skin of babies and young children
- 5. Develop program to develop baseline information including questions in BRFSS
- 6. Review best practice education and policy models about UV light in tanning booths and develop implementation strategies

How Results Will Be Evaluated

- 1. Baseline established
- 2. Pilot program implemented
- 3. Policy changes made
- 4. Campaign for pediatricians developed and implemented
- 5. Questions added to BRFSS; baseline developed
- 6. Tanning booths program developed

ALCOHOL USE

Excessive alcohol intake is related to several forms of cancer. Alcohol use increases the risk of developing esophageal, mouth, and throat cancers. The combination of smoking and drinking alcohol magnifies this risk. Alcohol is also a significant risk factor for liver cancer and may be associated with a modest increase in breast cancer. Although moderate alcohol consumption may decrease the risk of heart disease and stroke, ¹⁶ the benefits and risks of alcohol consumption should be weighed carefully by individuals and viewed in the context of other risk factors. The American Cancer Society's recommendation (for those who drink) is to limit intake to two drinks per day for men and one per day for women.

PREVENTION OBJECTIVE 7

Reduce the percentage of adults and adolescents who engage in excessive drinking, which is defined as greater than 2 drinks per day for males and 1 drink per day for females

Baseline

Males: 7.2% (BRFSS 2003) Females: 6.3% (BRFSS 2003)

Adolescents: 27.2% (YRBS 2003-- 5 or more drinks on 1 or more occasions in the last month)

Targets

Males: 3.0% (BRFSS) Females: 3.0% (BRFSS)

Strategies

- 1. Partner with groups such as MAAD and mental health organizations to help support effort
- 2. Create program targeting physicians to help support discussion with patients regarding risks associated with alcohol use and cancer
- 3. Develop forum, through Partnership's web site and other means, to share effective programs

How Results Will Be Evaluated

- 1. Partnerships with groups organized
- 2. Program for physicians created
- 3. Communications forums established

MULTIPLE SEX PARTNERS AND UNPROTECTED SEX

Human papillomavirus (HPV), a sexually transmitted disease, is thought to be necessary for the development of cervical cancer. In many cases, risk for contracting the virus can be reduced by decreasing potential exposure to the virus, such as by limiting the number of lifetime sexual partners, avoiding partners who have had multiple sexual partners, and by women delaying their first sexual experience until they are older.

While there is no consistent evidence that condoms protect against HPV transmission, condom use is associated with lower rates of cervical cancer. The use of condoms should not be substituted, however, for routine screenings with Pap smears to detect and prevent cervical cancer (see Section 4, *Increasing Early Detection*). In Connecticut in 1998, the only year for which data are available, 89% of adults 18 years of age and older (86% of males and 93% of females) reported they had only one sex partner in the past year. Of this group, only 16% said they used condoms every time they had sexual intercourse. Among adults who had multiple sex partners (the higher risk group), 39% (46% of males and 27% of females) said they used a condom every time.¹⁷

PREVENTION OBJECTIVE 8

Increase to 50% the proportion of adults 18-64 years of age who always use condoms if sexually active with more than one sex partner

Baseline

Females: 26.5% (BRFSS 1998) Males: 46.0% (BRFSS 1998)

Target

Females: 50.0% (BRFSS) Males: 50.0% (BRFSS)

Strategies

- 1. Advocate for implementation of education and control plans
- 2. Advocate for Coordinated School Health Councils throughout the state

How Results Will Be Evaluated

- 1. Implement education and control plans
- 2. Funding allocated to support implementation of plan

PREVENTION OBJECTIVE 9

Increase to 95% the proportion of high school students who abstain from sexual intercourse or use condoms if sexually active

Baseline Data

82.6% (54.2% have never had sexual intercourse; 28.4% sexually active, use condoms) (YRBS, 2003)

Target

95% (YRBS)

Strategies

- 1. Advocate for implementation of education and control plans
- 2. Advocate for Coordinated School Health Councils throughout the state

How Results Will Be Evaluated

- 1. Funding allocated to support implementation of plan
- 2. Coordinated School Health Councils established throughout state

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PREVENTION TIMETABLE

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
Reduce cancer risk through promotion of healthy lifestyles and risk reduction behavior							
TOBACCO	Decrease adult and youth smoking prevalence	Support creating statewide smoking cessation programs					
		Advocate for increase in state tobacco tax to pay for state cancer and tobacco plans					
		Help initiate statewide tobacco education media campaign					
		Advocate for and support implementation of CT Tobacco use and Prevention and Control Plan					
		Advocate for implementation of local tobacco plans					
		Advocate for Coordinated School Health Councils					
		Develop forum for smoking cessation programs					
		8. Secure funding for Quitline					
		Increase Smoke-Free College and University programs and provide forum and communications link					
NUTRITION	Increase fruit and vegetable consumption	Advocate for nutrition labeling in chain restaurants					
		Advocate for school policy and curricula changes					

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
NUTRITION	Increase fruit and vegetable consumption	Advocate for Coordinated School Councils					
		Develop coordinated 5-to-9-A- Day program					
		Develop/implement community physician campaign					
		Identify business/industry partners					
		Review data on barriers and identify best practices					
		Advocate for intervention research					
	3. Increase physical activity	Advocate for school policy and curricula changes					
		2. Advocate for tax changes					
		3. Develop/implement community physician campaign					
		4. Identify new partners					
		5. Identify best practices					
		6. Add new advocacy strategies					
		Advocate for intervention research					
	Reduce overweight and obesity	Advocate for nutrition labeling in chain restaurants					
		Advocate for changes in school food programs and curriculum					
		Develop plan to coordinate w/ existing programs and involve new partners					
		Advocate for intervention research					
		Advocate for YRBS questions on overweight/obesity					

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
ENVIRONMENTAL EXPOSURES	Increase public awareness of cancer-related	Establish baseline					
	environmental exposures and protective measures	Identify methods and develop awareness program					
		3. Improve partnerships					
		4. Identify new partners					
	6. Increase practice of sun	Establish baseline and targets					
	protection behaviors and awareness of UV	Develop/implement pilot program					
	overexposure	Advocate for sun protection policies					
		Develop/implement pediatrician campaign					
		5. Develop BRFSS questions					
		6. Review education and policies for UV light in tanning booths					
ALCOHOL USE	Reduce excessive alcohol consumption among adults and adolescents	Improve partnership					
		2. Create physician program					
		3. Communications forums					
MULTIPLE SEX PARTNERS	Increase percent of adults who always use a condom if they have multiple sex partners	Advocate for implementation of education and control plans					
		Advocate for Coordinated School Health Councils					
	9. Increase proportion of high school students who abstain from sexual intercourse or use condoms	Advocate for implementation of education and control plans					
		Advocate for Coordinated School Health Councils					

4 INCREASING EARLY DETECTION

Early Detection Committee

Co-Chairs:

Laurie Bridger, MD Medical Director

Fairhaven Community Health Center

New Haven

Linda Mowad, RN Project Director

Cancer Information Service

Yale Cancer Center

New Haven

Past Co-Chair:

Christine Parker, MPH Health Program Supervisor CT Department of Public Health

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Members:

Judith Barr, ScD

Director of Education & Health Service

Evaluation Qualidigm Middletown

Bobbie Beck Case Manager Saint Francis Hospital

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Lawrence & Memorial Hospital

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CT Pathology Laboratories, Inc.

Willimantic

Anne Elwell

Director of Medicare Quality Improvement

Qualidigm Middletown

Donna Goss

Tumor Registrars Association of CT

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INCREASING EARLY DETECTION

VISION

Cancer will be detected as early as possible, using quality, accessible, affordable, comprehensive, evidence-based cancer screening methods.

Screening tests that detect cancers early can save lives, because cancers that are detected at early stages are often highly curable. For specific cancers, early detection also can reduce the time and severity of treatment, improve quality of life, and significantly improve survival. For some sites, screening can prevent the cancer from occurring, as when precancerous polyps are detected and removed during colonoscopy procedures used to screen for colorectal cancer.

EVIDENCE-BASED SCREENING TESTS

The Early Detection Committee reviewed data and literature regarding early detection of the major cancers. There presently are recommended, evidence-based screening tests for three major cancers: breast, cervical, and colorectal. Screening procedures also exist for cancers for which early detection could effect outcomes, but the evidence does not yet support widespread screening. Examples of these cancers include: lung, prostate, ovarian, uterine, skin, and oral cancers.

SCREENING RECOMMENDATIONS

Screening recommendations for early detection are strongest for three cancers--breast, cervix, and colon. Regular mammography and clinical breast exams are recommended for women over the age of 40. Cervical cancer deaths have decreased significantly during the past 40 years, in large part due to the Pap test. Screening for colorectal cancer not only can detects it early, but also can prevent it. Screening rates vary in Connecticut between males and females and by race (Table 1). Screening utilization also varies among other ethnic groups in the state.

Despite the existence of proven tests for these three cancers, their use is below the Healthy People 2010 objectives, especially in some ethnic and minority groups and among low-income persons.

Table 1
Screening Rates for Selected Cancers
Connecticut, 2000, 2001

		Percent Screened		
Cancer Site (Screening Test)	Population Group	Females	Males	
Female Breast (Mammogram in last 2 years)	White, 40+ years of age Afr Am, 40+ years of age	84.6% (2000) 84.2% (2000)	-	
Colon/rectum (Fecal occult blood test in last 2 years)	White, 50+ years of age Afr Am, 50+ years of age	38.4% (2001) 39.0% (2001)	36.7% (2001) 29.5% (2001)	
Colon/rectum (Sigmoidoscopy or colonoscopy in last 2 years)	White, 50+ years of age Afr Am, 50+ years of age	51.4% (2001) 47.6% (2001)	58.0% (2001) 39.2% (2001)	
Prostate (Prostate specific antigen test in last year)	White, 50+ years of age Afr Am, 50+ years of age	-	58.5% (2001) 64.4% (2001)	

Source: Weir, Thun, Hankey, et al. 2004. 2

The Committee also considered screenings that are not yet recommended, such as for lung, ovarian, and prostate cancers. For most of these, like lung and prostate cancer, the evidence is insufficient to recommend for or against screening, even for individuals at high risk. For some cancers, such as ovarian, the risk of potential harm has been found to outweigh the potential benefit, leading experts to recommend against screening. The Committee decided to weigh the burden of these cancers in Connecticut against the potential benefits and harms of screening, and to develop strategies that best fit the state for early detection of these cancers.

CANCER TRENDS IN CONNECTICUT

Connecticut has one of the highest incidence rates of invasive cancers in the United States. In 2001, Connecticut ranked fourth in the nation for new cancers among females and eleventh for new cancers among males.³ Data from the Connecticut Tumor Registry show that breast, prostate, lung, and colorectal cancers are the most frequently diagnosed cancers in Connecticut. Because cancer incidence is related to age (about six out of ten new cancers are diagnosed in persons 65 years of age and older), the number of new cancers diagnosed each year is growing, reflecting the aging of our state's population. The incidence of some leading cancers is higher in African Americans than in whites.

Cancer in Men

The incidence of prostate cancer has increased, and it is now the leading cancer found in Connecticut men. This is most likely due to the increased use of the prostate specific antigen (PSA) screening test. New cases of lung cancer are decreasing among Connecticut males, consistent with the trends in the rest of the country. However, more males, regardless of race, are dying from lung cancer than from prostate cancer.

Cancer in Women

Connecticut has the second highest rate of new breast cancer cases in the nation, most likely due to an aggressive screening program. Medicare data show an improvement in the use of screening mammography in all groups of women over 65 years of age. White females have a higher incidence of breast cancer than women of color, but the breast cancer death rate is higher for African American women. Early screening has reduced the incidence of invasive cervical cancer dramatically, particularly from 1995-2000, and in 2002 there were only 35 cervical cancer deaths in Connecticut. Ovarian cancer is the fifth leading cause of cancer death among Connecticut women and the fourth leading cause among white females. It is usually diagnosed in an advanced stage, due to a lack of reliable screening tests and a lack of knowledge about early signs by women and their physicians.

CANCERS ADDRESSED IN THE PLAN

The Early Detection Committee determined that breast, cervical, colorectal, lung, ovarian, prostate, oral, and skin cancers would be addressed in the Connecticut Comprehensive Cancer Control Plan. Accordingly, early detection goals and objectives focus on three areas:

- 1. Increasing the use of evidence-based cancer screening for colorectal, breast, and cervical cancers.
- 2. Eliminating racial and ethnic disparities by increasing access to screening.
- 3. Identifying and promoting the use of evidence-based strategies to educate and detect lung, ovarian, prostate, skin, and oral cancers for which proven early detection tests do not yet exist.

EXISTING PROGRAMS

Several well-established programs in Connecticut are active partners in the Connecticut Cancer Partnership. Among them is one of our state's strongest programs, the CT Breast and Cervical Cancer Early Detection Program (CBCCEDP) funded by the Centers for Disease Control and Prevention (funding for 2003-2004, \$1.6 million), with supplemental State funding of \$1.6 million in 2003-2004 for expanding the populations served. The Partnership has included this program and other existing programs within its strategies and will help to support and maintain it.

Since 2001 in Connecticut, individual and group health insurance policies have been required to cover colorectal cancer screening, including an annual fecal occult blood test, a colonoscopy, flexible sigmoidoscopy, or radiologic imaging.

Several major cities in Connecticut, including Waterbury, Stamford, Norwalk, and Danbury, have organized Mayors' Crusades Against Cancer (an American Cancer Society community mobilization initiative). Many of this program's screening and early detection priorities are addressed in this Plan. This program is being expanded, under the leadership of the American Cancer Society, and will be supported by the Plan.

GOAL 1

Promote, improve, and optimize the appropriate use of high-quality breast, colorectal, and cervical cancer screening and follow-up services

WHY THIS GOAL IS IMPORTANT

- 1. Breast cancer is the most commonly diagnosed cancer among women in Connecticut, which has the second highest incidence rate of breast cancer and the 12th highest breast cancer death rate in the nation.
- 2. Colorectal cancer is the fourth most common cancer diagnosed and the second leading cause of cancer death in Connecticut.
- 3. If all women who are over 18 years of age or who are sexually active had a Pap test on a regular basis, the survival rate for cervical cancer would be over 90%.
- 4. Breast, colorectal, and cervical cancers have evidence-based screening techniques available for both broad and high risk populations, with high risk populations identified.

EARLY DETECTION OBJECTIVE 1-1

Increase to 85% the percentage of women age 40 and over who have had a mammogram in the past two years

Baseline

82.4% (BRFSS, 2002)

Strategies

- 1. Maintain and promote current Breast and Cervical Cancer Early Detection Program (CBCCEDP) goals and objectives
- 2. Increase awareness of breast cancer risk factors and the benefits of early detection
- 3. Implement strategies to reduce economic barriers to access breast cancer screening

How Results Will Be Evaluated

- 1. Results from CBCCEDP program
- 2. Amount of provider and consumer education developed and placed
- 3. Screening among disadvantaged population

EARLY DETECTION OBJECTIVE 1-2

Increase the proportion of patients who receive timely and appropriate follow-up after receiving abnormal breast cancer screening results

Baseline

Not available

Strategies

- 1. Establish baseline
- 2. Develop and implement plan and mechanism to increase follow-up

How Results Will Be Evaluated

- 1. Baseline established
- 2. Plan and mechanisms developed and implemented

EARLY DETECTION OBJECTIVE 1-3

Increase to 90% the percentage of women who have had a Pap test within the past year

Baseline

73.4% (BRFSS, 2002)

Strategies

- 1. Maintain and promote goals and objectives of CBCCEDP program
- 2. Identify specific populations underutilizing cervical cancer screening for targeted educational activities
- 3. Develop and implement plan to reach targeted audiences

How Results Will Be Evaluated

- 1. Goals and objectives of CBCCEDP program maintained and promoted
- 2. Specific audiences identified for targeted educational activities
- 3. Plan to reach audience developed and implemented

EARLY DETECTION OBJECTIVE 1-4

Increase the proportion of patients who receive timely and appropriate follow-up on receiving abnormal Pap test screening results

Baseline

Not available

Strategies

- 1. Establish baseline
- 2. Increase follow-up, such as reminder and tracking systems

How Results Will Be Evaluated

- 1. Baseline established
- 2. Measure increased follow-up

EARLY DETECTION OBJECTIVE 1-5

Increase to 65% the percentage of adults 50 and over who have had a sigmoidoscopy or colonoscopy within the past five years

Baseline

49.0% 2002 (BRFSS)

Strategies

- 1. Conduct survey of screening facilities
- 2. Determine best practices
- 3. Conduct intervention
- 4. Evaluate results
- 5. Report findings

How Results Will Be Evaluated

- 1. Survey completed
- 2. Best practices determined
- 3. Intervention conducted
- 4. Increased usage of screening
- 5. Findings reported

EARLY DETECTION OBJECTIVE 1-6

Increase to 63% the proportion of adults 50 and over who have had a fecal occult blood test within the past year

Baseline

54.4%, 2002 (BRFSS) Note: The BRFSS reports "home" tests only.

Strategies

- 1. Conduct consumer education to increase use of fecal occult blood test
- 2. Reduce barriers to access colorectal cancer screening and follow-up.

How Results Will Be Evaluated

- 1. Awareness increased
- 2. Screening by disadvantaged adults increased

EARLY DETECTION OBJECTIVE 1-7

Increase the proportion of patients who receive timely and appropriate follow-up on receiving abnormal colon screening results

Baseline

Not available

Strategies

- 1. Establish baseline
- 2. Develop and implement plan and mechanism to increase follow-up, such as reminder and tracking systems

How Results Will Be Evaluated

- 1. Baseline established
- 2. Plan developed and implemented to increase follow-up

GOAL 2

Eliminate or decrease racial, ethnic, and socioeconomic disparities in access to and utilization of cancer screening

WHY THIS GOAL IS IMPORTANT

- There are glaring disparities in rates of new cancer cases and deaths from cancer among different socioeconomic groups, insured and uninsured populations, and certain racial and ethnic groups. These disparities can often be traced to under-use of screening services.
- 2. People with health insurance are more likely than the uninsured to receive appropriate preventive care, such as cancer screening tests.⁴
- 3. Screening rates for several cancers, but especially colorectal cancer, are particularly low among minority and low-income populations.⁴

EARLY DETECTION OBJECTIVE 2-1

Increase screening utilization among underserved minority groups (Developmental)

Baseline

Not available

Strategies

- 1. Establish baselines
- 2. Identify additional racial and ethnic communities and partners for cancer prevention and screening education and outreach initiatives
- 3. Research and/or develop evidence-based, multicultural education and outreach materials and programs for targeted communities
- 4. Working with targeted communities, pilot-test community programs
- 5. Develop plan to conduct and evaluate program effectiveness
- 6. Develop plan for wider implementation

How Results Will Be Evaluated

- 1. Baseline established
- 2. Number of additional partners identified
- 3. Number of evidence-based multicultural screening programs identified
- 4. Pilot test completed
- 5. Evaluation of effectiveness conducted
- 6. Plan in place to for wider implementation

EARLY DETECTION OBJECTIVE 2-2

Increase enrollment of underserved populations in cancer screening trials

Baseline

Not available

Strategies

- 1. Establish baseline.
- 2. Work with clinical trials programs in the state to increase enrollment of underserved populations in cancer screening trials.

How Results Will Be Evaluated

- 1. Baseline established.
- 2. Measure enrollment of underserved populations in cancer screening trials.

GOAL 3

Identify and promote evidence-based strategies for education and early detection of cancers without proven early detection tests

WHY THIS GOAL IS IMPORTANT

- 1. Although high risk populations for lung, ovarian, and skin cancers have been identified, evidence to date does not support the use of currently available screening tests.^a
- 2. High-risk populations for prostate cancer have been identified and there are screening tests for prostate cancer (PSA or DRE), but the evidence is insufficient to recommend for or against their use in routine screening.
- 3. Lung cancer is the leading cause of cancer deaths in Connecticut. Skin cancer had the state's largest increase in cancer death rates from 1997-2001. Prostate cancer is the second leading cause of cancer deaths among Connecticut men. Ovarian cancer is the fifth leading cause of cancer deaths among Connecticut women.
- 4. Connecticut-based health institutions are national leaders in advancing knowledge of the above four cancers and seek to reduce their burden as part of their mission.

^a For lung cancer: low dose computerized tomography, chest x-ray, or sputum cytology. For ovarian cancer: CA-125 blood test or transvaginal sonography. For skin cancer: total;-body skin examination.

EARLY DETECTION OBJECTIVE 3-1

Seek and develop strategies to reduce morbidity and mortality for cancers with high incidence or mortality rates for which effective screening tests are not yet available, including lung, ovarian, and prostate cancers

Baseline

Not available

Strategies

- 1. Establish baselines.
- 2. Identify evidence-based education and screening methods.
- 3. Develop pilot programs to educate and to detect cancers with high state mortality rates, but without proven screening tests, including lung, ovarian, and prostate cancer.
- 4. Investigate evidence-based strategies to promote education about and participation in clinical trials for cancer screening.

How Results Will Be Evaluated

- 1. Baseline established
- 2. Number of evidence-based education and screening modalities identified
- 3. Pilot programs initiated for lung, ovarian, and prostate cancers
- 4. Increase in public awareness
- 5. Number of evidence-based strategies identified and put in place
- 6. Number of evidence-based screening clinical trials strategies

EARLY DETECTION OBJECTIVE 3-2

Increase awareness of lung, ovarian, prostate, skin, and oral cancers, for which there are no widely accepted, evidence-based, screening modalities, through education about risk factors and symptoms

Baseline

Not available

Strategies

- 1. Establish baseline
- 2. Promote education for healthcare providers about these cancers and their associated risk factors
- 3. Increase public and professional awareness regarding current developments in cancer genetics
- 4. Disseminate guidelines from the National Comprehensive Cancer Network (NCCN) to primary care providers about timely referral of patients at risk for ovarian cancer to a gynecologic oncologist
- 5. Promote medical student training sessions regarding best detection practices
- 6. Promote and conduct outreach education activities to increase consumer awareness of risk reduction factors associated with these cancers

How Results Will Be Evaluated

- 1. Baseline established
- 2. Percentage increase in educational sessions for healthcare providers.
- 3. Percentage increase in medical student training sessions
- 4. Number of programs identified and promoted
- 5. Number of outreach education activities conducted
- 6. NCCN guidelines disseminated to primary audiences

EARLY DETECTION OBJECTIVE 3-3

Increase public awareness of risk factors and early signs of skin cancer with emphasis on malignant melanoma

Baseline

Not available

Strategies

- 1. Establish baseline
- 2. Develop school-based program to increase awareness and effect behavior of school aged youth
- 3. Publicize risk factors and early signs of skin cancer, especially malignant melanoma
- 4. Publicize ACS Sun Safe Communities

How Results Will Be Evaluated

- 1. Baseline established
- 2. School-based program implemented
- 3. Public awareness increased
- 4. Number of communities implementing ACS Sun Safe Communities initiative

REFERENCES

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¹ U.S. Preventive Services Task Force. *Guide to Clinical Preventive Services, 3rd Edition.* (Periodic Updates)

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³ U.S. Cancer Statistics Working Group. 2004. *United States Cancer Statistics: 2001 Incidence and Mortality*. Atlanta, GA: Department of Health and Human Services and National Cancer Institute.

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EARLY DETECTION TIMETABLE

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
Promote, improve and optimize use of breast, colorectal and cervical screening and follow-up	1-1. Increase percentage of women 40+ who have had mammogram in past year to 85%	Maintain, expand and promote current CBCCEDP goals and objectives					
		2. Increase awareness					
		Implement plan to reduce economic barriers to screening					
	1-2. Increase proportion of patients who receive timely follow-up after an abnormal breast screening	1. Establish baseline					
		2. Increase follow-up					
	1-3. Increase percentage of women with Pap test in two years to 90%	Maintain, expand and promote CBCCEDP program					
	-	2. Identify target populations					
		3. Develop/implement plan					
	1-4. Increase proportion of patients with timely follow-up after receiving abnormal Pap test results	Establish baseline					
		Implement plan to increase follow-up					

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
Promote, improve and optimize use of breast,		Conduct survey of detection facilities					
colorectal and cervical	had sigmoidoscopy or	2. Determine best practices					
screening and follow- up	colonoscopy to 65%	3. Conduct intervention					
		4. Evaluate results					
		5. Report findings					
	1-6. Increase percentage of adults 50+ with FOBT to 63%	Educate consumers about FOBT					
		Reduce barriers to screening and follow-up					
	1-7. Increase awareness of skin cancer risk and early signs	Establish baseline					
		Develop/implement plan and mechanisms					
		3. Increase awareness					
2. Eliminate or decrease	utilization among underserved	Establish baseline					
racial, ethnic, and		2. Identify additional partners					
socioeconomic disparities to access to and utilization of cancer screening		Research and develop programs and materials					
		4. Pilot test programs					
		Develop program evaluation plan					
		Develop plan for wider implementation					

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
3. Identify and promote	3-1. Seek and develop	1. Establish baseline					
evidence-based	strategies to reduce	2. Identify methods					
strategies for early detection of cancers	morbidity and mortality of cancers lacking	3. Pilot projects					
without proven early detection tests	effective early detection tests	Promote awareness of clinical trials					
	3-2. Increase awareness of	1. Establish baseline					
	ovarian, prostate, skin and oral cancers	Promote education for healthcare providers					
		Publicize cancer genetics awareness					
		Disseminate NCCN guidelines for ovarian cancer referral					
		Promote medical student training					
		Promote and conduct outreach education					
	3-3. Increase awareness of risk factors and early signs of skin cancer	1. Establish baseline					
		Develop school-based program					
		Publicize risk factors and early signs of skin cancer					
		Publicize ACS Sun Safe Communities					

5 ASSURING QUALITY TREATMENT FOR ALL PATIENTS

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ASSURING QUALITY TREATMENT FOR ALL PATIENTS

VISION

All Connecticut residents will have equal access to high-quality, evidence-based cancer care

As a result of new treatments, many people with cancer are being cured of their disease or are living longer with a good quality of life. Cancer is still a difficult disease to treat, however, requiring complex therapy, often with one or more modalities. It is important that both health care providers and their patients have access to the latest treatment information, so they can better understand treatment choices. Patients need to be assured that services are geographically and financially available, that the treatment they receive is evidence-based and of high quality.

Connecticut's cancer treatment services are relatively well distributed throughout the state. Acute care hospitals, cancer centers, freestanding oncology centers, and physician offices along with appropriate support services are accessible to most Connecticut residents. Several aspects of offering high quality, evidence-based cancer care still need to be addressed, however, to ensure accessibility to all Connecticut residents.

The Treatment Committee of the Connecticut Cancer Partnership believes that cancer treatment outcomes will be improved by identifying barriers and promoting the following in the Connecticut Comprehensive Cancer Control Plan:

- Standards of care
- Participation in clinical trials when appropriate
- A Statewide Clinical Trials Network
- Equal access to treatment resources
- Quality of life support systems
- Education services for patients and the general public
- Education services for health care professionals
- Accreditation of hospitals by the American College of Surgeons Commission on Cancer

STANDARDS OF CARE

Guidelines for cancer treatment and care have been formulated and published by several national organizations, such as the National Comprehensive Cancer Network (NCCN). These guidelines, when used, help health care professionals to offer standardized care to their patients. Coupled with up-to-date treatment information, treatment guidelines are essential for providing quality care. Although such guidelines are available, many oncology providers, patients, and their families and friends either are not aware of the available information or do not know where and how to find it. Providing treatment information and guidelines that are consumer friendly and making information on related subjects available to multiple audiences is a goal of the Treatment Committee.

Studies conducted by the Connecticut Tumor Registry, alone or with SEER (the National Cancer Institute's Surveillance Epidemiology, and End Results program), a can be used to monitor outcomes in quality standards. The Committee will review data from two SEER Patterns of Care (POC) studies that include Connecticut-specific data regarding use of state-of-the-art care. POC studies provide valuable information on cancer treatments that are documented in hospital records. The goal of the SEER POC studies are to: 1) evaluate the diffusion of state-of-the-art cancer therapy into community practice, 2) disseminate findings in scientific journals and through professional meetings, and 3) work with professional organizations to develop educational opportunities to increase the use of state-of-the-art cancer therapy and quality of care in community practice.

The SEER POC studies show that there is room for improvement in care in Connecticut. In a study of breast cancer, use of guideline therapy for node positive women was 66% in Connecticut versus 70-75% in the United States.¹ With colorectal cancer, 49% of Connecticut patients received standard adjuvant treatment compared to 57% in the United States.² The Prostate Cancer Outcomes Study (PCOS), which includes Connecticut data, has detailed information about how prostate cancer is treated in the U.S. (and Connecticut) and the various effects of these treatments on men's functioning and overall quality of life. Results from PCOS also have been used to assess racial differences in stage of diagnosis and treatment to help explain the significantly higher death rates from prostate cancer among African American men in the United States.³

CLINICAL TRIALS

Access to clinical trials is considered another indicator or quality of care. Many advances in cancer treatment have been a result of clinical trials. Despite efforts by the National Cancer Institute and national patient advocacy groups, the proportion of adult cancer patients who participate in clinical trials continues to be low. There are many barriers to participation, such as unwillingness of physicians to enroll patients, refusal of eligible patients to participate, misunderstanding of the nature and reasons for the trials, and social, cultural and economic issues, especially for minority patients.

A recent poll conducted by Harris Interactive⁴ showed that 32% of adults would be very willing to participate in a clinical cancer trial if asked to do so. Another 38% said they would seriously consider participation if asked. Seventy-five percent of respondents thought clinical trials were associated with "high-quality clinical care."

Access to clinical trials is important in offering quality treatment to Connecticut patients. Patients should be informed about new therapies being studied, to gain a better understanding of the relative advantages and drawbacks of treatment alternatives and conventional therapies. Increased physician awareness and commitment to enrolling patients is needed. Important objectives of this Plan are to ensure access to all clinical trials open in Connecticut, help promote the value of clinical trial participation, and assure that all oncology physicians have access to participation.

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The SEER program of the National Cancer Institute is the most authoritative source of information on cancer incidence and survival in the U.S. It currently collects and publishes cancer incidence and survival data from 11 population-based cancer registries and three supplemental registries, representing about 14% of the U.S. population.

The clinical trial infrastructure in Connecticut also needs to be improved, to stimulate and translate cancer research. More needs to be done to accelerate new therapeutic strategies and to make "cutting edge" cancer therapies available to all Connecticut residents. Three types of clinical trials are generally available in the state: NCI-sponsored trials, drug-company-sponsored trials, and investigator-initiated clinical trials. The latter type is where Connecticut scientists most need assistance to develop the novel, significant therapies that will eventually cure most cancers. To do so, a system is needed to ensure that investigator-initiated trials sponsored by the state's cancer scientists accrue the patients necessary to enable them to advance cancer treatment and care.

The Treatment Committee proposes establishing a new statewide clinical trials network to support Connecticut investigator-initiated clinical trials. The network will establish needed central research and administrative infrastructure, and it would add data managers and research nurses--the infantry of clinical trials--across Connecticut. This would enable cancer doctors in every area of the state to access promising new therapies. The network would serve as a model for other states to develop similar networks.

EQUAL ACCESS TO TREATMENT

The extent of barriers and gaps in equal access to treatment services has not been clearly defined in Connecticut. Barriers include the complexity and fragmentation of the health care system, lack of available providers and services, including support services, lack of cultural competence or cultural sensitivity among health care providers, geographic isolation, childcare, transportation, finances, lack of personal resources and a personal support system, and social and cultural barriers such as language, individual perceptions and values, racial, ethnic, or gender discrimination.

Lack of knowledge is also a barrier to access. Before they can receive appropriate treatment, patients must be aware of the availability of treatment services. Education is an important component of treatment and can be helpful to patients and their families in making decisions about cancer treatment options, support services, and other aspects of care. It is also important to document what services are being provided geographically, and to determine service patterns and whether finances are influencing treatment choices.

This Plan calls for an assessment of the extent of gaps and barriers to cancer treatment services in Connecticut. After the needs have been identified, strategies will be developed to address them. A resource guide will be developed for multimedia use to help patients, families, and providers identify where services are available. In addition, all activities will take into consideration the diverse cultural, literacy, and access needs of Connecticut's population groups. Educational and informational resources will be appropriately developed, implemented, and marketed to ensure cultural appropriateness.

SUPPORT SYSTEM FOR QUALITY-OF-LIFE

Cancer diagnosis and treatment can alter quality of life dramatically by creating psychosocial and emotional needs in addition to physical needs and treatment-related adverse effects. Many

cancer patients experience pain or other symptoms during their treatment phase, which require management by experts. Not all patients have access to adequate pain control methodologies or to adequate symptom management during treatment. Furthermore, information on evidence-based complementary medicine for cancer patients is not readily available. This Plan addresses the need to identify barriers to patient access to symptom and pain management, develop strategies to overcome the barriers, and promote existing pain and symptom management standards and resources. It also addresses the identification of existing resources for evidence-based complementary and alternative treatment information.

EDUCATION OF HEALTH PROFESSIONALS

Numerous educational opportunities for health care professionals regarding cancer management issues occur in Connecticut each year. However, there is no central source for this information, for use either in planning activities or in promoting them. The Plan calls for the development of a central web-based resource that cancer clinicians can access easily to learn about educational activities in a comprehensive way.

ACCREDITATION: AMERICAN COLLEGE OF SURGEONS COMMISSION ON CANCER

To receive accreditation, hospitals must achieve American College of Surgeons (ACoS) standards for access to multidisciplinary consultation and treatment, ongoing quality assessment that monitors treatment effectiveness and outcomes, and the availability of modern technology. Currently, 21 of Connecticut's 31 acute care hospitals (68%) have ACoS-approved cancer programs. Several strategies are outlined to increase the percentage of accredited hospitals to 90%.

GOAL

Ensure that Connecticut residents will have equal access to high quality, evidence-based cancer care

WHY THIS GOAL IS IMPORTANT

- 1. There is no single readily available place to access treatment guidelines and information.
- 2. Only 67% of acute care hospitals in Connecticut are ACoS accredited.
- 3. Only about 5% of adult patients participate in cancer clinical trials.
- There are barriers, both for patients and providers, to participate and enroll in cancer clinical trials.
- 5. Barriers exist in assuring equal access to treatment.
- Support systems and standards for pain and symptom control are not accessible to all patients and families.

TREATMENT OBJECTIVE 1

Increase the proportion of cancer care providers and cancer patients with access to treatment information and evidence-based quality standards of care, taking into consideration cultural, literacy, and access needs (Developmental)

Baseline

Not available

Strategies

- 1. Develop and promote a Connecticut Cancer Partnership web site as a vehicle for information dissemination throughout the state
- 2. Encourage use of 800 numbers as information lines
- 3. Encourage use of grand rounds as a way of providing professional education
- 4. Develop content on treatment information and guidelines. Identify appropriate viable web sites as link sources (e.g., NCI, ACS), taking into account needs of diverse populations
- 5. Develop mechanism for all organizations that sponsor educational activities for cancer care professionals to relay information to central data base
- 6. Develop and implement marketing plan, including measurement tools
- 7. Conduct surveys of available non-web based resources for the public (telephone lines, written information, etc.), taking in account needs of diverse populations
- 8. Develop, implement and market patient educational resources to diverse populations

How Results Will Be Evaluated

- 1. Web site developed; funding assured
- 2. Number of calls received
- 3. Number of physicians attending grand rounds sessions
- 4. Number and type of web sites; appropriate cancer guidelines availability
- 5. Number and mechanisms in place for organizations to list professional education; use of mechanisms
- 6. Marketing plan developed; measurement tools developed
- 7. Surveys completed; gaps identified; agreements made with other organizations for links; and web site use tracked
- 8. Cancer treatment public information materials available which meet needs of all Connecticut residents

TREATMENT OBJECTIVE 2

Increase the proportion of cancer care providers and cancer patients with access to comprehensive information on clinical treatment trials (Developmental)

Baseline

Not available

Strategies

- 1. Identify all health care providers who are involved with cancer care
- 2. List all open Connecticut clinical trials in Connecticut hospitals, cancer centers and oncology offices on the CCP web site and provide link to NCI's PDQ information
- 3. Develop system for updating information
- 4. Review available patient education materials on clinical trials (what trial is, how to discuss with physician, how to access availability for specific diagnosis) for cultural sensitivity and literacy appropriateness; if needed, develop culturally and literacy appropriate materials
- 5. Promote available literature

How Results Will Be Evaluated

- 1. Health care providers identified
- 2. Web materials developed; number of hits to pages
- 3. System for updating developed
- 4. Patient materials reviewed and if needed new materials developed
- 5. Marketing plan developed

TREATMENT OBJECTIVE 3

Build a statewide clinical trials network supporting investigator-initiated trials and removing barriers, to allow more clinicians to enroll patients easily into clinical trials

Baseline

Not available

Strategies

- 1. Help establish a statewide clinical trials network to support state investigator-initiated trials and remove barriers for community oncologists to enroll patients in clinical trials
- 2. Support adding research nurses and data managers to enable community oncologists to easily add patients to state clinical trials
- 3. Establish an alliance among the state, university, and in-state pharmaceutical private sector to develop prevention and therapeutic trials that will contribute to a better understanding of the biology of cancer, provide access to novel therapeutics to patients in Connecticut, and strengthen the proposed trials network
- 4. Create inventory of private practice oncologists and clinicians with an oncology subspecialty who presently participate in clinical trials; assess number and location of non-participating physicians interested in forming a linkage to data collection and analysis resources
- 5. Collaborate with other local, regional and statewide organizations to decrease barriers for small private practices to participate in clinical trials
- 6. Facilitate multidisciplinary research programs in specific cancer areas

How Results Will Be Evaluated

- 1. Statewide clinical trials network created
- 2. Research nurses and data managers added to remove barriers for community oncologists to enroll patients in state clinical trials
- 3. Alliance formed
- 4. Inventory built; linkages formed
- 5. Collaboration strategies developed and put into effect; number of private practice physicians participating
- 6. Multidisciplinary research programs facilitated

TREATMENT OBJECTIVE 4

Reduce the proportion of cancer patients who experience difficulty or delays in accessing treatment or who do not receive needed treatment (Developmental)

Baseline

Not available

Strategies

- 1. Conduct literature search on gaps and barriers to treatment. Conduct focus groups to determine if Connecticut barriers and gaps differ
- 2. Form Subcommittee to address issues such as cost of treatment and ancillary needs and to develop strategies to lessen and/or eliminate barriers and gaps
- 3. Develop cancer treatment resource guide to assist patients, families and clinicians in identifying financial, cultural, and support services
- 4. Utilize data from development of guide to enhance systems for comprehensive cancer care
- 5. Conduct a study, in collaboration with appropriate organizations and agencies, of cancer treatment modalities currently being used and the resulting treatment outcomes, based on data from the Connecticut Tumor-Registry

- 1. Literature search and focus groups conducted; barriers and gaps identified
- 2. Subcommittee formed; strategies developed
- 3. Resource guide developed; number of hits on web site; number of laws passed to close gaps
- 4. System for comprehensive care developed for patients in need of special services
- 5. Tumor Registry study conducted

TREATMENT OBJECTIVE 5

Increase the proportion of cancer patients and their families who have access to support systems, including psychosocial support and evidence-based complementary medicine (Developmental)

Baseline

Not available

Strategies

- 1. Establish baseline
- 2. Assess available support services within the state
- 3. Determine data base(s) containing evidenced-based complementary/alternative medicine information for cancer patients and families

How Results Will Be Evaluated

- 1. Baseline established.
- 2. List of support services and gaps
- 3. List of databases that will be linked on the web site for complementary/alternative medical information

TREATMENT OBJECTIVE 6

Increase the proportion of cancer patients who have access to pain and symptom management during treatment (Developmental)

Baseline

Not available

Strategies

- 1. Identify barriers to accessing pain and symptom management during treatment, by conducting literature searches, focus groups and surveys of patients, families and health professionals
- 2. Build through the Partnership a coalition of health care providers to develop strategies to assist patients in overcoming barriers to quality pain and symptom management
- 3. Identify and offer professional education opportunities focused on pain management and quality of life issues
- 4. List and promote national symptom and pain management standards on CCP web site

- 1. Barriers to accessing pain and symptom management during treatment identified
- 2. Collaboration among health care professionals developed and strategies identified
- 3. Professional education opportunities identified and offered
- 4. Material listed on CCP web site

TREATMENT OBJECTIVE 7

Increase to 28 the number of Connecticut acute care hospitals that are accredited by the American College of Surgeons (ACoS)

Baseline

24 of Connecticut's 31 acute care hospitals are accredited sites (2005)

Target

28 of Connecticut's 31 acute care hospitals are accredited sites

Strategies

- 1. Develop mechanisms to identify barriers and benefits to Connecticut hospitals in ACoS accreditation
- 2. Determine strategies to overcome barriers and highlight benefits and implement program
- 3. Develop and implement a professional education plan regarding all aspects of ACoS accreditation for professionals

How Results Will Be Evaluated

- 1. Survey developed and conducted; barriers identified; marketing plan developed
- 2. Educational plan developed and implemented
- 3. 28 acute care hospitals with ACoS accreditation

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TREATMENT TIMETABLE

Goal Objective		Strategy	2005	2006	2007	2008	On- going
Ensure equal access to high quality, evidence-based	Increase treatment information and evidence-based standards of care	Develop and promote Connecticut Cancer Partnership web site					
cancer care		2. Encourage 800 number use					
		Encourage grand rounds for education					
		4. Content development					
		5. Database for organizations					
		Develop and implement marketing plan					
		7. Surveys of other resources					
		8. Materials for other populations.					
	Increase access to clinical trials information	Identify health care providers					
		2. Web site listings					
		System for updating info					
		Review/develop culturally sensitive patient materials					
		5. Promote available literature					
	Build statewide clinical trials network	Help establish clinical trials network					
		Support adding nurses and data managers					
		3. Establish alliance					
		Build inventory, assess interest					
		5. Collaborate w/ other agencies					
		6. Facilitate research programs					

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
	Reduce difficulty and delays in obtaining treatment	Conduct literature search, focus groups on barriers and gaps					
	3	Create subcommittee to address issues, strategies					
		3. Develop resource guide					
		4. Utilize data from guide					
		Conduct study on treatment modalities and outcomes					
	5. Increase access to support	Establish baseline					
		2. Assess support services					
		3. Complementary databases					
	6. Increase access to pain	Identify barriers					
	and symptom management	2. Collaborative partnership					
		Educate health care professionals					
		Promote symptom and pain management standards					
	7. Increase to 28 the number of ACoS accredited hospitals	Identify barriers to and benefits of accreditation					
		Overcome barriers, and highlight benefits					
		Develop/implement education plan on accreditation					

6 EMPOWERING SURVIVORS AND THEIR FAMILIES

Survivorship Committee

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EMPOWERING SURVIVORS AND THEIR FAMILIES

VISION

Working together to assure a positive quality of life for Connecticut cancer survivors and their families

INTRODUCTION

Completing cancer treatment is a challenge for many cancer patients and their families. Although they are relieved to have ended this phase, they are leaving the health care team with whom they have long been associated and have many concerns about what their next steps should be. "Those who have lived through treatment talk about the first few months as a time of change. It is not so much 'getting back to normal' as it is finding out what is normal for... now." 1

Cancer patients and their families need to be empowered to make effective choices not only during treatment but also after it has been completed. With the passage of time, the needs and problems of people who have had cancer change, with some requiring few services while others find it difficult to continue without support and many resources to help them.

In 2004, the Centers for Disease Control and Prevention in partnership with the Lance Armstrong Foundation produced a national action plan for the public health community to address cancer survivorship.² Some of its key objectives are to increase awareness of cancer survivorship and its impact, train health care professionals to improve delivery of services and increase awareness of issues faced by cancer survivors, and ensure that all cancer survivors have adequate access to post-treatment follow-up services. The Connecticut Cancer Partnership's Committee on Survivorship studied many survivorship issues and independently formulated goals and objectives for Connecticut that interface well with those of the national action plan.

RISING NUMBER OF SURVIVORS

Improvements in early detection and treatment together with successful prevention efforts have ensured that more people in the United States live with cancer than die from the disease. The 5-year relative survival rate for all invasive cancers combined rose significantly from about 50% for those who were diagnosed in the mid-1970s to 65% for those diagnosed in 1995-2001.³ In the U.S., the number of persons living with cancer rose from 3.0 million (1.5% of the population) in 1971 to 9.8 million (3.5%) in 2001, and it is estimated to reach 11.3 million by the year 2015.⁴

While some cancer survivors are free of the disease, others continue to struggle with active cancers, and many are affected by long-term and late side effects. According to a recent study, cancer survivors have worse health, more lost work days, and a poorer quality life, compared to people who have never had cancer. Even long-term cancer survivors (11 or more years after diagnosis) had substantially more health problems than others.⁵

The growing number of persons living with cancer presents challenges to public health practitioners--to understand and address the needs of cancer survivors and to develop programs that promote their health and well being.

THE AGING OF THE POPULATION.

Not only are more people surviving cancer, but also elderly populations in the U.S. and Connecticut are growing. The number of Americans 65 and over grew by 3.75 million from 1990-2000, and the number of elderly in Connecticut increased by more than 24,000.⁶ In 2000 Connecticut ranked tenth among states having the highest percent of elderly (13.8%).⁷ Cancer occurs more frequently with age, and the number of people over 65 years with cancer is expected to double within the next 30 years to 6 million.⁸

For many older Americans, cancer and other health problems combine with the aging process to make the tasks of daily living harder to accomplish. As the Connecticut population ages, increased efforts will likely be needed to plan for the optimal health of older persons, many of whom will become cancer survivors. (See Section 2, *Connecticut, Its Population, and Cancer* for a detailed discussion of our state's demographics in relation to cancer.)

INCREASING DIVERSITY OF THE POPULATION

The population of the United States and Connecticut is also becoming more racially and ethnically diverse. Whereas whites made up almost 75% of the population in 2000, the U.S. Census Bureau estimates that by 2050, Hispanics will account for almost 25% of the population and African Americans, Asian Americans, and Native Americans will combine to total almost 25% of the population. ¹⁰

These and other minority population groups will face more barriers in overcoming the long-term residual side effects of treatment because of cultural and language differences; these differences may also affect outcomes. In Connecticut, African Americans have the highest cancer death rate. They are more likely than persons of any other racial or ethnic group to develop cancer, and are about 33% more likely to die of cancer than persons of white race. (See Section 2, *Connecticut, Its Population, and Cancer*, for a detailed discussion of diversity in relation to cancer in Connecticut.)

GROWING NUMBER OF HOME CAREGIVERS

Cancer affects not only the person with the disease but also family members, friends, and caregivers. The number of families and friends who have had to assume responsibilities for caring for cancer patients continues to increase. Home caregivers are usually untrained and unprepared to assume their new, complex role. Because caregivers are likely to be older persons, they often have their own health problems that limit the support they can provide. Reduced income, economic stress, limited or diminishing social support networks, loss of loved ones, and changing living arrangements can all interfere with the ability to cope with the residual effects of treatment.

Although family caregivers think that information is critical to helping them cope with their responsibilities, they have difficulty obtaining information about what to expect and what to do, and they feel they receive inadequate education from health care professionals. Also, while support for patients is abundant, caregiver support is lacking.¹¹ These concerns are central to Connecticut's goals and objectives for survivorship.

GOAL

To ensure a high quality of life and care for all Connecticut residents living with cancer and for their families

WHY THIS GOAL IS IMPORTANT

- 1. The number of cancer survivors is growing rapidly; it will increase from 9.6 million today to an estimated 11.3 million in 2015.
- Although the majority of survivors successfully adapt to gradual physical and psychological recovery during the first year after treatment ends, about 20-25% report depressive symptoms.
- 3. Some survivors struggle with persistent and late physical effects of treatment for many years, if not throughout their lifetimes.
- 4. The few national guidelines for follow-up that do exist are not well known or used by the average practitioner.
- 5. There is often a lack of continuity of care for survivors across and within specialty care practice.
- 6. Resources for supportive interventions are limited in ambulatory care settings, where most survivors have received their treatment and care.
- 7. No one--neither patients and their families nor the health care professionals--knows who is responsible for what.
- 8. No one knows the scope of existing services or if the services meet the needs.

SURVIVORSHIP OBJECTIVE 1

Increase the proportion of cancer survivors and cancer care providers who access and utilize survivor support services (Developmental)

Baseline

Not available

Strategies

- 1. Develop baseline
- 2. Identify organizations currently providing survivorship services in state
- 3. Identify criteria for deciding how to assess the quality of each service organization prior to including it in the centralized information data base
- 4. Develop and maintain centralized information clearinghouse of survivorship services and survivor organizations that will be housed on the Connecticut Cancer Partnership's web site
- 5. Create alternative communications vehicles to assist those unable to utilize web-based information, such as 800 numbers, public libraries, VNAs, and area agencies on aging
- 6. Develop a decision-making tool for use by survivors when selecting an organization that will best serve their needs

- 7. Promote the availability of services to survivors and health care providers, utilizing expertise of the Partnership's Communications Committee
- 8. Develop and implement a plan to improve access to information about services for underserved cancer survivor populations, including the elderly, children, minorities and the uninsured
- 9. Evaluate the impact and benefits of existing survivor services on the quality of life of Connecticut cancer survivors

How Results Will Be Evaluated

- 1. Baseline developed
- 2. Number of organizations identified
- 3. Criteria developed
- 4. Clearinghouse developed and published to Partnership web site; use of web site: number of hits, number of pages reviewed, type of user, on-line satisfaction survey results with organizations
- 5. Communications vehicles created
- 6. Decision-making tool developed
- 7. Promotion of services completed
- 8. Number of underserved survivors who access support services
- 9. Evaluation results

SURVIVORSHIP OBJECTIVE 2

Increase the proportion of cancer survivors who are knowledgeable about published guidelines for survivorship care (Developmental)

Baseline

Not available

Strategies

- 1. Identify current survivorship care guidelines and make them available to survivors
- 2. Define "high quality care" for cancer survivors
- 3. Identify barriers to quality cancer care and gaps in services
- 4. Utilize this information on barriers and gaps to promote public policy change
- 5. Survey survivors to determine the baseline number of survivors aware of guidelines for survivorship care
- 6. Determine future survey needs

- 1. Current guidelines identified
- 2. Definition established for "high quality care"
- 3. Barriers and gaps identified
- 4. Number of public policy changes made
- 5. Baseline survivor survey completed; number of survivors aware of guidelines identified
- 6. Increased awareness and use of services by survivors

SURVIVORSHIP OBJECTIVE 3

Increase the proportion of health care providers who are knowledgeable about evidence-based survivorship care (Developmental)

Baseline

Not available

Strategies

- 1. Identify national guidelines (evidence-based) for survivorship care
- 2. Conduct a survey of health care providers to determine the baseline number of providers aware of available guidelines for survivorship care
- 3. Educate health care professionals about existing research and survivorship studies/issues for cancer survivors
- 4. Advocate for increased funding that will expand survivorship research
- 5. Identify future survey needs

- 1. National guidelines identified
- 2. Survey completed; baseline determined
- 3. Educational activities conducted
- 4. Advocacy activities/increased funding
- 5. Increased number of providers providing evidence-based survivorship care

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SURVIVORSHIP TIMETABLE

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
Ensure high quality of life and care	f 1. Increase access and use of support services by	Develop baseline					
	survivors and providers	2. Identify organizations					
		3. Identify criteria for quality					
		Develop/maintain information clearinghouse					
		5. Other communications					
	7. Promotion plan 8. Access for underserving proportion of survivors knowledgeable about published guidelines giving evidence-based survivorship care and survivorship care 2. Increase proportion of survivors knowledgeable about published guidelines giving evidence-based survivorship care 2. Define 'high quality of the proportion of survivorship care and disseminate giving evidence-based survivorship care	6. Decision making tool					
		7. Promotion plan					
		8. Access for underserved					
		9. Evaluate impact/benefit					
		Identify national guidelines for survivorship care and disseminate					
		2. Define 'high quality care'					
		3. Identify barriers and gaps					
		Survey survivors to determine baseline					
		5. Determine future survey needs					

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
	Increase proportion of health care providers	Identify survivorship care guidelines					
	knowledgeable about survivorship care	Conduct survey of health care providers					
		3. Educate health professionals					
		Advocate for increased funding					
		5. Identify future survey needs					

7 HELP AT THE END OF LIFE

Palliative and Hospice Care Committee

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HELP AT THE END OF LIFE

VISION

All Connecticut residents will be informed of and have access to palliative and hospice care services

Few people are ready to make the hard choices that are needed at the end of life. However, palliative and hospice care--offering the best quality of life during the time that remains by taking care of the body, mind, and spirit--can ease the pain and make life better for those who are dying of cancer, and for their family and friends.

AVAILABILITY AND ACCESSIBILITY OF CARE

Many patients do not receive adequate palliative and hospice care services, even when the services are requested. This is the result of several factors. First, the kind, quality, and amount of palliative and hospice care received varies with the setting in which terminally ill patients reside (at home, long-term care facilities, assisted-living facilities, hospitals, or prisons). Second, health care professionals are often inadequately trained in palliative or end-of-life care. Third, there are often financial barriers. Medicare and some insurance plans cover hospice care, whereas palliative care is often covered indirectly, if at all. Finally cultural backgrounds, religious beliefs, and socioeconomic status can affect both the use and delivery of palliative and hospice care.

In 2002, Last Acts, the nation's largest coalition to improve care and caring near the end of life, issued the nation's first state-by-state report card on the availability and use of care at the end of life.¹ Connecticut's grades varied greatly, with residents who are terminally ill and dying found to be well served in some aspects but not in others (Table 1). It is the intent of the Committee on Palliative and Hospice Care to improve Connecticut's performance, using the same or similar criteria as those used by Last Acts.

Connecticut residents would like their health professionals to communicate better with patients and families about death and dying, provide referrals to hospice and palliative care more readily, offer more counseling to dying patients, and make spiritual support more available.² A need and an interest also exist to develop hospice programs in Connecticut's correctional facilities.³

Table 1
End-of-Life Care in Connecticut
Strengths and Challenges

	Strengths	Challenges				
•	The majority of hospitals offer pain management programs Policies regarding advance directives, such as living wills and medical powers of attorney, are	•	Policies on pain management do not do a good job of ensuring good pain control for the dying 41.5% of Connecticut nursing home residents with cancer report persistent severe pain			
•	strong Hospice care is geographically available	•	Hospice care is not widely used Only 21% of Connecticut's cancer patients die at home, even though most Americans say they prefer to die at home			

Source: Last Acts, 2002.1

PALLIATIVE AND HOSPICE CARE IN CONNECTICUT

Hospice care has a long history involving many partners in Connecticut. The first inpatient hospice in the United States was established in New Haven in 1974, inaugurating the national hospice movement. Three local organizations in the state, the Connecticut Cancer Pain Initiative, Qualidigm (the Quality Improvement Organization for Connecticut), and the Connecticut Chapter of the National Prison Hospice Association have issued recommendations about pain and/or end-of-life care in Connecticut and have begun improvement initiatives. The Connecticut Comprehensive Cancer Control Plan supports these organizations and their recommendations in its goals and objectives. These organizations have agreed to work collaboratively with the Connecticut Cancer Partnership on strategies to further their identified priorities and initiatives. The Connecticut Council for Hospice and Palliative Care, which represents most of the hospice programs in the state, is one of the major partners. The Coalition to Improve End-of-Life Care, funded by Robert Wood Johnson, has completed a study of residents' views of death and dying, among its projects.

Although the data from the *Last Acts* documents and other reports have been useful in establishing some goals and objectives, much information is still missing. Few data are available on the use of palliative and hospice services in Connecticut by underserved populations, such as racial and ethnic minority groups. Activities during the first two years of implementation of this plan will include a search for ways of collecting the additional information at a reasonable cost.

GOAL 1

To ensure that high quality palliative and hospice care services are available and accessible to all Connecticut residents

WHY THIS GOAL IS IMPORTANT

- 1. In 2000, only 0.23% of Connecticut's primary care and primary care subspecialty physicians were certified in palliative care. (Grade C--Last Acts Report, 2002¹)
- In 2000, only 0.48% of Connecticut's full time registered nurses were certified in palliative care. (Grade C--Last Acts¹)
- 3. Connecticut residents would like better communications with providers about death and dying, more prompt referrals to hospice and palliative care, better coordination of care, more counseling to dying patients, and more access to spiritual care.
- 4. Minorities, religious, and ethnic residents would like providers to have a better understanding of the cultural context (diet, language, and religion) of their patients.
- 5. Poor and medically underserved populations may have less access to palliative and hospice care services.
- 6. Minorities may be less informed about services due to language or cultural barriers.
- 7. Only 32.5% of Connecticut hospitals self-report palliative care programs. (Grade D--Last Acts¹)
- 8. 57.5% of hospitals self-report hospice programs. (Grade C--Last Acts¹)
- 9. Few hospice and palliative care services are available to long term care facilities and prisons.

Increase the number of health care professionals (physicians, nurses, social workers, and spiritual counselors) who are knowledgeable about palliative and hospice care (Developmental)

Baseline

Not available

Strategies

- 1. Identify organizations that offer palliative or hospice care education programs and facilitate collaboration to increase end-of-life-educational opportunities in Connecticut.
- 2. Investigate best practices to increase amount of palliative and hospice care included in curricula in medical, nursing, counseling and pastoral care schools in Connecticut
- 3. Work with health professional groups to develop continuing education programs
- 4. Develop mentoring programs
- 5. Write articles for and publish articles in state journals and professional newsletters; distribute appropriate national publications
- 6. Create a centralized database of information and resources for healthcare professionals
- 7. Disseminate information to providers on Medicare hospice benefits and end-of-life resources available in state
- 8. Work with health professional groups to provide interactive workshops on communicating with patients and families about end-of-life care, particularly for physicians
- 9. Work with health professional groups and faith communities to educate health care providers on cultural practices/preferences at end of life, including what choices religious traditions permit
- 10. Develop programs to educate hospital chaplains and community clergy on care of the dying

- 1. Organizations identified; number of collaborative programs initiated
- 2. Number of schools with curriculum content
- 3. Number of health professionals attending CEU programs
- 4. Increased numbers of mentors/mentoring programs
- 5. Number of articles published
- 6. Database developed
- 7. Amount of material disseminated
- 8. Number of workshops provided; attendance numbers, evaluation of learning
- 9. Program developed; numbers given
- 10. Number of clergy educated

Increase the number of health professionals who are board certified in palliative and hospice care

Baseline

18 certified physicians (2004--American Board of Hospice and Palliative Medicine)

65 certified nurses (2004--National Board for Certification of Hospice and Palliative Nurses)

Target

25 certified physicians (American Board of Hospice and Palliative Medicine)

95 certified nurses (National Board for Certification of Hospice and Palliative Nurses)

Strategies

- 1. Assess geographic distribution of Connecticut physicians and nurses board certified in palliative and hospice care
- 2. Develop and offer educational opportunities and incentives to becoming certified to physicians and nurses working in hospice and palliative care settings
- 3. Implement best practices to recruit more health care professionals into palliative and hospice care, targeting underserved areas

How Results Will Be Evaluated

- 1. Assessment completed, distribution baseline determined
- 2. Number of educational opportunities offered
- 3. Number of professionals recruited from underserved areas
- 4. Number of physicians and nurses board certified in palliative and hospice care

PALLIATIVE & HOSPICE CARE OBJECTIVE 1-3

Increase the number of health insurance programs that provide coverage for pain and palliative/hospice services (Developmental)

Baseline

Not available

Strategies

- 1. Assess current coverage offered by Medicare, Medicaid and private insurance companies; establish baseline
- 2. Develop and implement a program to educate third-party payers regarding compassionate, cost-effective palliative and hospice care
- 3. Work with stakeholder organizations to improve benefits for pain or palliative and hospice services as appropriate
- 4. Advocate for adoption of a Medicaid benefit for hospice and palliative care for Connecticut

- 1. Assessment completed; baseline set
- 2. Payer education program developed; number of payers educated
- 3. Amount of improvement in benefits
- 4. Medicaid hospice benefit added

Increase the proportion of facilities that self-report palliative care programs

Baseline

32.5% of hospitals self-report palliative care programs (2000--American Hospital Association annual survey)

Data not available for long term care (LTC) facilities

Target

50% of hospitals self-report palliative care programs (American Hospital Association annual survey)

Target for LTC to be determined

Strategies

- 1. Assess current status of palliative care services in long-term care facilities; establish baseline
- 2. Disseminate information on programs designed to help educate hospitals and long-term care facilities in integrating palliative care into clinical services

How Results Will Be Evaluated

- 1. Assessment completed; baseline established.
- 2. Program to educate hospitals and LTC facilities identified and disseminated
- 3. Increase in percentage of hospitals and long term care facilities self reporting palliative care program

PALLIATIVE & HOSPICE CARE OBJECTIVE 1-5

Increase the number of hospitals and long term care facilities that have contractual agreements with Medicare-certified hospice programs (Developmental)

Baseline

Not available

Strategies

- 1. Assess current status of hospital and long term care contracts with Medicare-certified hospice programs; establish baseline
- 2. Identify and implement best practices to facilitate identified non-affiliated entities to contract with Medicare-certified programs
- 3. Use best practices to create ongoing program

- 1. Assessment completed; baseline established.
- 2. Best practices identified
- 3. Increase in number of entities with contractual agreements with Medicare-certified hospice programs

Improve end-of-life care in Connecticut State correctional facilities

Baseline

2 Connecticut prisons with volunteers trained in palliative and hospice care¹

Target

Provide education on end-of-life care to prison staff and inmate hospice volunteers in Connecticut

Strategies

- 1. Support efforts of Connecticut Chapter of the National Prison Hospice Association and the Connecticut Prison Hospice Initiative to work in conjunction with the Connecticut Department of Correction's Hospice and Palliative Care Program to train prison staff at new staff orientation (Staff Academy) and annual staff trainings
- 2. Support efforts to train inmate hospice volunteers as needed

How Results Will Be Evaluated

- 1. Number of educational programs presented
- 2. Number of prison inmates trained as hospice volunteers
- 3. Number of prison staff trained on end-of-life care
- 4. Number of prison inmates who receive support services from hospice volunteers
- 5. Number of inmates who die with hospice support

PALLIATIVE & HOSPICE CARE OBJECTIVE 1-7

Assess patient and family satisfaction with palliative and hospice services (Developmental)

Baseline

Not available

Strategies

- 1. Obtain statewide and local annual survey data from National Hospice and Palliative Care Organization (NHPCO) to determine baseline
- 2. Develop strategies to increase survey participation by Medicare-certified hospice programs in Connecticut

- 1. Data obtained; baseline determined
- 2. Increase in number of hospices participating in NHPCO survey

Inmate hospice volunteers have been trained at two Connecticut prisons--49 at one facility and 35 at the other. Together, the two programs have serviced 25 inmates, of which 13 have died (*Brief History*, 2003, and personal communication from Connecticut Chapter of the National Prison Hospice Association, December, 2004).

Improve end-of-life care services in State Veterans Home (Developmental)

Baseline

Not available

Strategies

- 1. Partner with State Veterans Home administrators and staff to assess end-of-life needs
- 2. Develop educational and support plan to address Veteran residents' needs for palliative and hospice care services

How Results Will Be Evaluated

- 1. Needs identified
- 2. Plan developed

GOAL 2

Ensure that Connecticut residents have improved quality of life through effective management of pain and other symptoms

WHY THIS GOAL IS IMPORTANT

- 1. Connecticut earned a grade of D+ for the extent that state policies contain language that potentially enhances or impedes pain management⁴
- 62.5% of Connecticut hospitals self-report pain management programs (Grade B--Last Acts¹)
- 3. 38.1% of Connecticut nursing home residents have persistent pain (Grade C--Last Acts)
- 4. 41.5% of Connecticut nursing home residents with a cancer diagnosis have persistent severe pain⁵
- 43.6% of terminally ill Connecticut nursing home residents have persistent severe pain⁵
- 6. 53% of primary care physicians and 46% of specialists in Connecticut rated their own ability to treat patients' pain as no better than fair to poor⁶

PALLIATIVE & HOSPICE CARE OBJECTIVE 2-1

Increase legislation and public policy supporting pain, palliative, and hospice care services to achieve Grade C in strength of pain policies in Connecticut

Baseline

Grade D+ for strength of pain policies (2003--Pain and Policies Studies Group)

Target

Grade C for strength of pain policies (Pain and Policies Studies Group)

Strategies

1. Develop program to support goals of Connecticut Pain Initiatives recommendations from the March, 2003 Connecticut Pain Summit (see *Additional Resources* at end of this section)

How Results Will Be Evaluated

- 1. Program in place to support recommendations of Pain Summit
- 2. Grade C on PPSG report

PALLIATIVE & HOSPICE CARE OBJECTIVE 2-2

Decrease the prevalence of pain among Connecticut nursing home residents

Baseline

8.5% prevalence of pain among Connecticut nursing home residents (Centers for Medicare and Medicaid Services [CMMS], 2002)

Target

7.8% prevalence of pain among Connecticut nursing home residents. (CMMS, 2005)

Strategies

1. Implement program to support efforts of Qualidigm to improve quality of pain management in Connecticut nursing homes

How Results Will Be Evaluated

1. Quality improvement goals of Qualidigm achieved

PALLIATIVE & HOSPICE CARE OBJECTIVE 2-3

Demonstrate an increase in patient and family satisfaction with management of pain and symptoms (Developmental)

Baseline

Not available

Strategies

- 1. Monitor patient/family satisfaction with pain and symptom management through yearly surveys by Connecticut Council for Hospice and Palliative Care
- 2. Survey cancer survivors' pain experience through American Cancer Society Navigation program
- 3. Investigate and adopt best practices to support efforts of Connecticut health care organizations to comply with JCAHO pain standards of care
- 4. Review and disseminate data on compliance with JCAHO pain standards in Connecticut health care institutions

- 1. Increased patient/family satisfaction scores
- 2. Improved cancer survivor pain experience documented by ACS Navigation program
- 3. Improved compliance with JCAHO pain standards in health care institutions

GOAL 3

Ensure that Connecticut residents are more aware of, better prepared for, and more willing to seek palliative and hospice care

WHY THIS GOAL IS IMPORTANT

- 1. In 2000, only 19.4% of Connecticut residents died while on the Medicare hospice benefit (Grade D--Last Acts¹)
- 2. The median length of stay in hospice in Connecticut in 2001 was 21.5 days (Grade D--Last Acts¹)
- 3. 17.3% of Connecticut resident deaths (all causes) occurred at home in 2002 (Connecticut Department of Public Health, provisional death data)
- 4. 26.6% of cancer deaths among Connecticut residents occurred at home in 2002 (Connecticut Department of Public Health, provisional death data)
- 5. Connecticut residents want and need more information and open discussion about death and dying²

PALLIATIVE & HOSPICE CARE OBJECTIVE 3-1

Increase utilization of palliative and hospice care

Baseline

19.4% of deaths while on Medicare hospice benefit (2000--Dartmouth Atlas of Health Care Working Group)

21.5 days median length of hospice stay (2001--National Hospice and Palliative Care Organization)

26.6% cancer deaths at home (2002--Connecticut death data)

Targets

25% of all deaths while on Medicare hospice benefit (Medicare)

35 days median length of stay on hospice (NHPCO)

40% of cancer deaths at home. (Connecticut death data)

Strategies

- 1. Investigate and implement best practices to educate public on benefits and availability of palliative and hospice care
- 2. Adopt best practices to target education on hospice and palliative care to clergy and parish nurses, elderly service providers, minority populations/immigrant groups, corporations, community health centers, and schools
- 3. Sponsor public forums in communities, churches, and businesses on death planning
- 4. Working with religious leaders, develop and disseminate statements that educate members of religious communities on permitted choices at end of life
- 5. Support changes in Connecticut's advanced directive legislation to make procedures easier to understand and implement

How Results Will Be Evaluated

- 1. Increase in number of patients who die with hospice care; increase in number of cancer patients who die at home; increase in medium length of stay on hospice
- 2. Best practices identified and adopted; number of programs, and number of participants attending targeted educational programs
- 3. Number of programs and number of participants in public forums
- 4. Number of positive changes in legislation

PALLIATIVE & HOSPICE CARE OBJECTIVE 3-2

Increase the number of referrals to hospice and palliative care, especially among persons from minority and medically underserved populations (Developmental)

Baseline

Not available

Strategies

- 1. Obtain baseline data on annual number of referrals to hospice, including sub-analysis by demographic criteria
- 2. Conduct needs assessment to identify barriers to access for all residents, particularly minority/underserved populations; develop program to overcome barriers
- 3. Identify and establish priority partnerships (African-American, Hispanic and other minority church leaders, senior citizen groups and public health departments) to increase palliative and hospice care outreach to minority and underserved populations.
- 4. Advocate for adoption of Medicaid benefit for hospice and palliative care in Connecticut
- 5. Adopt and disseminate Local Medical Review Policy (LMRP) for hospice care

- 1. Assessment of hospice referral patterns completed; baseline established
- 2. Needs assessment conducted and barriers identified
- 3. Priority partnerships identified and established to reach minority and underserved populations
- 4. Medicaid hospice benefit adopted in Connecticut
- 5. LMRP adopted; number disseminated
- 6. Increase in number of referrals to hospice especially among minority and underserved populations

ADDITIONAL RESOURCES

1. Connecticut Pain Summit, Promoting Proper Use of Opioid Analgesics. Report and Recommendations, March 31, 2003.

See also: http://www.aacpi.wisc.edu/regulatory/CTrep.pdf

2. Nursing Home Quality Improvement Initiative

See also: http://cms.hhs.gov/quality/nhqi/

As part of the Nursing Home Quality Initiative (NHQI), launched by the Centers for Medicare and Medicaid Services (CMS) in November 2002, Qualidigm, the Quality Improvement Organization for Connecticut has been working collaboratively with stakeholders to decrease the pain experienced by nursing home residents.

The data on the prevalence of pain is derived from the Minimum Data Set (MDS) collected on all nursing home residents and is defined as moderate pain on a daily basis or severe pain within a seven-day period. Baseline data for CT, reported in November 2002, reveals the prevalence of pain among CT nursing home residents to be at 8.5%. The goal of this initiative is to decrease the prevalence of pain experienced by nursing home residents.

3. Brief history of the State of Connecticut Department of Correction Hospice and Palliative Care Program. See also http://www.npha.org/brochurect.htm

REFERENCES

¹ Last Acts. 2002. *Means to a Better End: A Report on Dying in America Today*. http://www.rwjf.org/news/special/meansReport.pdf

² McGraw SA, E. Dobihal, R. Baggish, and E.H. Bradly. 2002. How can we improve care at the end of life in Connecticut? Recommendations from focus groups. *Connecticut Medicine* 11:655-664.

³ Zimmermann, N., F.S. Wald, and A.S. Thompson. 1998. *Finding Common Ground for Hospice Care in Connecticut Prisons*. National Prison Hospice Association. http://www.npha.org/brochurect.htm

⁴ Pain and Policy Studies Group. 2003. *Achieving Balance in State Pain Policy: A Progress Report Card.* http://www.medsch.wisc.edu/painpolicy/2003_balance/

⁵ Brown University School of Medicine, Center for Gerontology and Health Care Research. 2005. Facts on Dying: Policy Relevant Data on Care at The End of Life. Connecticut State Profile. http://as800.chcr.brown.edu/dying/ctpspdata.htm

⁶ Patrick and Catherine Weldon Donaghue Medical Research Foundation and the American Society of Law, Medicine and Ethics. *Connecticut Statewide Management Study*. 12/2000 (Unpublished report.)

PALLIATIVE AND HOSPICE CARE TIMETABLE

Goal	Objective	Strategy		2006	2007	2008	On- going
Ensure high quality palliative and hospice services	1-1. Increase number of health professionals knowledgeable	Identify organizations offering end-of-life education; facilitate collaborations					
		Investigate best practices for curricula					
		Develop continuing education programs					
		4. Develop mentoring programs					
		5. Publish articles					
		Created centralized database for web site					
		7. Disseminate Medicate hospice benefits information					
		8. Provide interactive workshops					
		Communicate cultural practices					
		10. Educate clergy					
	1-2. Increase number of health professionals certified	Assess distribution of board certified physicians and nurses					
		Educational opportunities and incentives					
		3. Recruit for underserved area					

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
	1-3. Increase number of plans that provide coverage for	Assess current coverage; establish baseline					
	palliative and hospice	2. Educate third-party payers					
	services	Work with stakeholder organizations to improve benefits					
		Advocate Medicaid hospice benefit					
	1-4. Increase proportion of facilities that self-report	Assess current status and establish baseline					
	palliative care programs	Disseminate program information					
	1-5. Increase number of hospitals and long term care facilities with Medicare-certified program	Assess current status; establish baseline					
		Facilitate non-affiliates to contract					
		3. Create ongoing program					
	1-6. Increase number of	1. Support staff training programs					
	prisons offering palliative and hospice care	Support volunteer training					
	1-7. Increase patient/family satisfaction with	Obtain statewide surveys from NHPCO					
	pain/symptom management	2. Increase survey participation					
	1-8. Improve end-of-life care services in State Veterans Home	Assess needs and develop educational and support program					
Ensure quality of life through pain and symptom manage- ment	2-1. Increase legislation and public policy supporting pain, palliative and hospice care	Support goals and recommendations of Connecticut Pain Initiative					

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
Ensure quality of life through pain and symptom management	2-2. Decrease prevalence of pain among nursing home residents	Support Qualidigm quality improvement program					
	2-3. Increase patient and family satisfaction of	Monitor satisfaction through yearly surveys					
	symptom relief	Survey pain experiences through ACS Navigation program					
		3. Support efforts to meet JCAHO pain standards					
		Disseminate data on JCAHO compliance					
Ensure residents more aware, better prepared	3-1. Increase utilization	Educate public on benefits and availability					
and more willing to		2. Target education					
seek care		3. Sponsor public forums					
		Develop and disseminate materials on religious choices					
		5. Advance directive legislation changes					
	3-2. Increase number of referrals	Obtain data on number of referrals					
		Conduct needs assessment to identify barriers					
		3. Establish priority partners					
		Advocate for Medicaid hospice benefit					
		5. Adopt/disseminate LMPR					

8 CROSS-CUTTING ISSUES

ADVOCATING FOR QUALITY PROGRAMS AND ACCESS

ADDRESSING HEALTH DISPARITIES

COMMUNICATING ABOUT THE PLAN AND THE PARTNERSHIP

STIMULATING AND TRANSLATING RESEARCH

DATA, SURVEILLANCE AND EVALUATION

ADVOCATING FOR QUALITY PROGRAMS AND ACCESS

VISION

An active coordinated advocacy program and quality tracking system to address issues covered in the Connecticut Comprehensive Cancer Control Plan

Each day local, state, and national legislative decisions are made that influence the lives of cancer patients and survivors. Connecticut has a long tradition of organizations and agencies working together to enact legislation and to formulate and implement policies regarding cancer. Advocacy at all levels will be needed for successful implementation of the Connecticut Comprehensive Cancer Control Plan.

Advocacy strategies have been delineated in each area of the Plan (Table 1). The Advocacy Committee of the Connecticut Cancer Partnership will work to build a collaborative program, taking into account the needs of each of the other committees. It will promote beneficial laws, regulations, and policies, and will coordinate advocacy efforts needed for the Plan as a whole. Together with the Core Committee and the organizations most involved in advocacy in the state, it will help set priorities for the advocacy program.

OBJECTIVE 1

Develop internal structure and tracking instruments to coordinate advocacy efforts for the Connecticut Comprehensive Cancer Control Plan

Strategies

- 1. Support advocacy issues identified in the Plan (Table 1)
- 2. Build cancer advocacy capacity through recruitment of key decision-makers, such as legislators, insurers, lobbyists, pharmaceutical companies, corporations, state agencies, families, survivors
- 3. Identify, engage, and involve interested public/private companies and agencies to garner ongoing support for the Plan
- 4. Create programs to educate legislators and their staff about important issues in the Plan
- 5. Create tracking system and data base of persons and legislation, to monitor progress on advocacy
- 6. Create and publish a data base of enacted laws and policies related to cancer
- 7. Create an expanded grassroots effort, working with organizations already in the field

Table 1 Connecticut Comprehensive Cancer Control Plan Strategies from Each Priority Area Related to Advocacy

Prevention

- Advocate for increase in state tobacco tax sufficient to fund state cancer and tobacco plan implementation
- Advocate for statewide smoking cessation program that meets Public Health Service and National Action Plan guidelines, including evidence-based counseling, pharmacotherapy, and a marketing campaign. These interventions should be available at no charge to the Medicaid and uninsured population
- Advocate for and support implementation of the State Tobacco Use Prevention and Control Plan, including funding through federal, state, and local sources
- Advocate for and support implementation of local tobacco prevention and control plans
- √ Advocate for nutrition labeling in chain restaurants
- Advocate for changes in policies and curricula to better support healthier eating in schools and education about nutrition
- √ Advocate for program of coordinated school health councils
- √ Advocate for intervention research in nutrition, obesity and physical activity
- Advocate for changes in policies and curricula to better support and increase amount of physical activity for all students
- √ Advocate for tax breaks for physical activity programs such as building walking trails
- √ Advocate for Connecticut to participate in Youth Risk Behavior Surveillance questions on obesity
- ✓ Advocate for a pilot school-based program to educate children about the dangers of the sun
- Advocate for sun protection policies such as trees in schoolyards, the wearing of protective clothing and wrap-around sunglasses with UV absorption factor
- √ Support sound legislation that reduces the risk of exposure to UV light in tanning facilities.

Early Detection

- ✓ Advocate for breast, cervical, and colorectal screening the meets or exceeds American Cancer Society and U.S. Preventive Services Task Force guidelines
- √ Advocate for the Breast and Cervical Cancer Early Detection Program
- ✓ Develop and implement methods to reduce economic barriers to access breast cancer screening
- Advocate for pilot programs to improve meaningful early detection of cancers without proven screening tests, such as lung, ovarian, and prostate cancer.

Treatment

- Advocate for a Statewide Cancer Clinical Trials Network to bring state investigator-initiated trials to Connecticut's cancer patients
- ✓ Form statewide collaborative effort to address issues such as cost of treatment and ancillary needs and to develop methods of lessening and/or eliminating barriers and gaps in treatment

Survivorship

- ✓ Identify barriers to quality cancer care and gaps in survivorship services
- √ Utilizing information on barriers and gaps to promote public policy change
- √ Advocate for increased funding to expand survivorship research

Palliative and Hospice Care

- Support changes in Connecticut's advanced directive legislation to make procedures easier to understand and implement
- √ Advocate for adoption of Medicaid benefit for hospice and palliative care
- ✓ Advocate for legislation and public policy supporting pain, palliative, and hospice care services

ADDRESSING HEALTH DISPARITIES

VISION

Every person in Connecticut--regardless of age, gender, race, ethnicity, income, education, geographic location, disability, or sexual orientation--will have equal access to cancer resources and care

It is a troubling fact that certain population groups are more likely than others to develop cancer and less likely to survive it. As discussed in Section 2, *Connecticut, Its Population, and Cancer*, the burden of cancer is often greatest for low-income people from racial and ethnic minority groups.

DISPARITIES IN NEW CANCER CASES AND DEATHS

In the U.S.,^a African American males have the highest rate of new cancer cases overall (Table 2), and both males and females of African American race have the highest death rates (Table 3). American Indian males and African American females have the lowest cancer survival rates of any population group in the U.S.¹

Table 2
Cancer Incidence Rates, All Sites, by Racial and Ethnic Group
U.S. 1997-2001

	New Cases per 100,000 Persons		
Population Group	Males Females		
White	556.5	429.8	
African American	689.2	400.1	
Asian American/Pacific Islander	385.9	302.8	
American Indian/Alaska Native	263.2	222.5	
Hispanic/Latino	419.8 309.9		

Source: SEER Cancer Statistics Review, 1975-2001²

Even greater disparities exist for specific types of cancer. In the U.S., African American women are 15% less likely than whites to develop breast cancer, but they are 34% more likely to die from it. African American males are 62% more likely than white males to develop prostate cancer, and more than twice as likely to die from it. Asian Americans/Pacific Islanders have comparatively low incidence rates for the major cancer sites, but they have the highest incidence and death rates of all population groups for stomach and liver cancers; the incidence rate for liver

^a Connecticut statistics are available for Hispanics and African Americans, but numbers are too small to be reliable for other population groups.

b In Connecticut, compared to whites, African American women are 30% less likely to develop breast cancer and 15% more likely to die from it.

cancer in this group is nearly three times that of whites, and the death rate is 2.5 times greater. For cervical cancer, Hispanic women have the highest rate of new cases (nearly double that of whites), and African Americans and Hispanics have the highest death rates.³

Cancer Death Rates, All Sites, by Racial and Ethnic Group U.S., 1997-2001

	Deaths per 100,000 Persons		
Population Group	Males Females		
White	245.5	165.5	
African American	347.3	196.5	
Asian American/Pacific Islander	151.2	100.5	
American Indian/Alaska Native	167.0	113.4	
Hispanic/Latino	174.0 111.6		

Source: SEER Cancer Statistics Review, 1975-20014

Trends in cancer incidence and deaths also differ among population groups. While lung cancer incidence rates, for example, have been falling for males and females in all other population groups, from 1992-2002 rates rose an average of 0.5% per year among African American females. Similarly, the incidence rate for uterine cancer fell for whites but rose for African American, Asian American/Pacific Islander, and Hispanic women. During the same period, the colorectal cancer death rate increased for American Indians/Alaska Natives, while it decreased for other population groups.⁵

There is no simple explanation for these and other disparities. The reasons behind them are complex and may be related to lifestyle practices such as smoking and diet, and to socioeconomic factors like income, education, health insurance status, and level of access to primary and preventive care. Although population diversity is one of our greatest assets, it also presents myriad health challenges that need to be addressed. Creative interventions are needed to reach and serve higher risk populations.

DISPARITIES IN PREVALENCE OF RISK FACTORS FOR CANCER

Tobacco smoking, fruit and vegetable consumption, lack of exercise, overweight, and obesity all are established or suspected risk factors for many types of cancer. In the U.S., African Americans are more likely than whites or Hispanics to smoke. Compared to whites, African Americans and Hispanics are less likely to meet guidelines for physical activity or to eat five or more servings of fruits and vegetables daily.⁶ African Americans and Hispanics also have higher prevalence of overweight and obesity, compared to whites.⁷

BARRIERS TO HEALTH CARE ACCESS

There are numerous barriers to health care access for the prevention, early detection, and treatment of cancers among different population groups, and all barriers are potential contributors to disparities in cancer incidence and deaths. Many of these have been discussed in some detail

in Section 2 of this Plan (*Connecticut, Its Population, and Cancer*). Certain groups, especially the uninsured or underinsured, lower socioeconomic groups, and racial and ethnic minorities are particularly vulnerable and face unique barriers.

Health Insurance

Among Connecticut residents in 2004, 21% of Hispanics, 7% of African Americans, and 3% of whites were without health insurance. Although they represent less than 10% of Connecticut's population, Hispanics constituted 40% of its uninsured. It is well documented that the uninsured and Medicaid recipients are more likely to be diagnosed with cancer at a later stage, leading to poor outcomes compared to those with insurance.

Socioeconomic Status

Connecticut poverty rates in 2002-2003 were 7% for whites, 28% for African Americans, and 32% for Hispanics. Compared to white non-Hispanics, the *per capita* income of Hispanics was 59% lower and that of African Americans was 48% lower in 2000. Relative to those from higher social classes, people from lower social classes are less likely to receive cancer screenings, and their survival rates also are lower, even when they have health care coverage. Uncovered costs for transportation, child care, and medical supplies can drain resources and cut treatment time short. Compared to more advantaged patients, those from lower social classes also receive less adequate treatment and have more difficulty obtaining palliative and supportive care.

Race and Ethnicity (Language and Culture)

Race and ethnicity, in themselves, are not barriers to care or causes of disparities. On an individual level, however, race or ethnicity might affect access in terms of language, cultural attitudes and perceptions, poverty, or inadequate training and sensitivity among health care providers to understand and meet the needs of specific population groups.

The inability to speak and read English well is associated with lower use of health care services, such as screening services, and less compliance with recommended procedures.¹⁴ Problems result not only from the use of English by providers, but also from variation in educational opportunities for providers (in culturally competent communication) and for patients (in both general literacy and health literacy).

Sensitivity to cultural issues that make it difficult for some underserved populations to receive screening and treatment is important in planning cancer control programs. Social and cultural barriers to care have been identified at the level of the health care system (i.e., access to care, diversity in leadership/workforce), processes of care (i.e., receipt of appropriate screening and treatment), and the individual (provider-patient encounter) levels. Insufficient minority recruitment into the health professions, and a general lack of accessible interpreter services or appropriate health educational materials also contribute to the problem. Provider education on cross-cultural issues occurs rarely if at all.

DISPARITIES OBJECTIVE 1

Develop internal structure to coordinate cross-cutting efforts to increase access to health care and reduce health disparities

Strategies

- 1. Support remediation of access and health disparities issues identified in the Plan (Table 4)
- 2. Identify relevant geographic disparities in access for age-gender subgroups, and identify solutions to alleviate disparities and gaps in access to cancer-related care including populations with special needs
- 3. Identify cross-cutting strategies to increase cancer service access and resources for all populations through public education
- 4. Identify disparities in financial barriers to care for cancer patients and advocate for change
- 5. Advocate to ensure access to health insurance coverage for cancer patients and survivors so that their treatment and continuing care needs are met

Table 4 Connecticut Comprehensive Cancer Control Plan Strategies from Each Priority Area Regarding Health Disparities

Prevention

- ✓ Support access/disparities goals of Connecticut Tobacco Use, Prevention, and Control Plan
- Review existing data regarding barriers and motivating factors for healthy nutrition for all age and ethnic groups; identify best practices for implementation
- Review existing data regarding barriers and motivating factors for physical activity for all age, racial and ethnic groups; identify best practices for implementation

Early Detection

- ✓ Maintain and promote access/disparities goals in the current Breast and Cervical Cancer Early Detection Program (CBCCEDP) goals and objectives
- Develop and implement strategies to reduce economic barriers to access breast cancer screening
- ✓ Identify specific populations under-utilizing cervical cancer screening for targeted educational activities; develop/supplement Plan to reach targeted audiences

Treatment

- ✓ Increase access to treatment information and evidence-based quality standards of care by health care professionals and the public, taking into consideration cultural, literacy, and access needs
- Increase access to comprehensive clinical treatment trial information by cancer patients and cancer care providers
- Improve access to cancer treatment services, so that no cancer patient has financial or other barriers to treatment
- Ensure that all cancer patients have access to pain and symptom management during treatment

Survivorship

✓ Improve access to quality treatment and supportive care for underserved cancer survivor populations, including the elderly, children, minorities and the uninsured

(Table 4 continues)

Table 4 (Continued) Connecticut Comprehensive Cancer Control Plan Strategies from Each Priority Area Regarding Health Disparities

Palliative and Hospice Care

- Educate health care providers on cultural practices/preferences at end of life including what choices religious traditions permit
- Recruit more health care professionals into palliative and hospice care, targeting underserved areas
- ✓ Provide education on end of life care to CT prison staff and inmate hospice volunteers
- √ Address palliative and hospice care needs of veteran's in state Veteran's Hospital
- Target education on hospice and palliative care to clergy and parish nurses, elderly service providers, minority populations/immigrant groups, corporations, community health centers and schools
- ✓ Develop programs to overcome barriers to access for all residents, particularly minority/underserved populations
- Identify and establish priority partnerships to increase palliative and hospice care outreach to minority and underserved populations

COMMUNICATING ABOUT THE PLAN AND THE PARTNERSHIP

VISION

An active, coordinated communications program that will raise awareness about the Plan and the Partnership for a wide variety of audiences

A creative, well-organized communications program is essential to the success of the Connecticut Cancer Partnership and its Comprehensive Cancer Control Plan. If the strategies in the Plan are to be implemented successfully, many diverse audiences need to be reached with information. Audiences include patients, health professionals, present and new partners, policy makers, state leaders, public agencies and organizations, target populations, the public and the private sectors. A Communications Committee, made up of experts in the public relations and communications fields, is formulating a plan with goals and objectives for each of the audiences to be reached and messages that need to be communicated. The Committee will work collaboratively with other Partnership Committees to support their communications needs (Table 5) and will ensure that these needs are met in a structured, orderly manner.

Table 5 Connecticut Comprehensive Cancer Control Plan Strategies from Each Priority Area Regarding Communications

Prevention

- Support creating statewide tobacco cessation program that meets Public Health Service and National Action Plan guidelines, including evidence-based counseling, pharmacotherapy, and a marketing campaign
- Help initiate a statewide tobacco education media campaign like those shown to be effective in other states such as Florida and California
- ✓ In conjunction with the National Partnership 5-A-Day Plan, develop a coordinated effort to increase consumption of fruits and vegetables
- Develop and implement campaigns targeted to community physicians for discussion with their patients to promote fruits and vegetables, guidelines related to calories, fats, carbohydrates, the need for physical activity and risks associated with alcohol use and cancer
- Develop and implement a campaign for pediatricians to inform parents about caring for the skin of babies and young children

Early Detection

- Increase awareness of breast cancer risk factors and the benefits of early detection
- ✓ Develop and implement plan to reach specific audiences with targeted education messages on cervical screening
- Conduct consumer education to increase appropriate colorectal screening
- Increase public awareness of risk factors and early signs of skin cancer, especially malignant melanoma
- ✓ Increase public awareness of ACS Sun Safe Communities
- Research and/or develop evidence-based, multicultural education and outreach materials to increase screening utilization among racial and ethnic minority groups
- Promote and conduct outreach education activities to increase consumer awareness of risk reduction factors for ovarian, prostate, skin and oral cancers

Table 5 (Continued) Connecticut Comprehensive Cancer Control Plan Strategies from Each Priority Area Regarding Communications

Treatment

- Develop and promote a Connecticut Cancer Partnership web site as a vehicle for information dissemination throughout the state
- ✓ Develop content on treatment information and guidelines for web site
- Develop and implement a marketing plan, including measurement tools
- Develop, implement and market patient education resources on treatment information and standards of care to diverse populations
- Review available patient education materials on clinical trials for cultural sensitivity and literacy appropriateness and if needed develop new materials. Develop marketing plan for promotion of patient education materials
- Develop cancer treatment resource guide to assist patients, families and clinicians in identifying financial, cultural and support services
- Determine databases that carry evidence-based complementary/alternative medicine information for cancer patients and families
- Develop and implement a professional education plan regarding all aspects of ACoS accreditation for professionals

Survivorship

- Develop and maintain centralized information clearinghouse of survivorship services and survivor organizations to be house on the Connecticut Cancer Partnership web site
- Create alternative communications vehicles to assist those unable to access web-based information
- ✓ Promote availability of services to survivors and health care providers
- Develop and implement a plan to improve access to information about services for underserved cancer survivor populations
- ✓ Identify current survivorship care guidelines and disseminate availability to survivors
- Educate health care professionals about existing research and survivorship studies/issues for cancer survivors

Palliative and Hospice Care

- Create a centralized database of information and resources for healthcare professionals
- ✓ Develop and implement a program to educate third-party payers regarding compassionate, costeffective palliative and hospice care
- Disseminate information on programs designed to help hospitals and long-term care facilities integrate palliative care into clinical services
- Investigate and implement best practices to educate public on benefits and availability of palliative and hospice care
- Sponsor public forums in communities, churches, and businesses on death planning

COMMUNICATIONS OBJECTIVE 1

Develop a plan to communicate information about the Connecticut Comprehensive Cancer Control Plan and Connecticut Cancer Partnership

Strategies

- 1. Review communications work from other states
- 2. Develop communications goals and objectives
- 3. Determine primary and secondary audience(s) with priority, pertinent characteristics, and rationale
- 4. List activities for each defined audience/market
- 5. Propose channels to be used (mass media, exhibits, web site, newsletters, company publications, health professionals, community events, banners, etc.)
- 6. Identify materials to be developed or adapted
- 7. Develop messages; test on target audiences
- 8. Produce promotion/materials and distribution plan
- 9. Determine key tasks, time line and resources needed
- 10. Create evaluation plan (with Data, Surveillance and Evaluation Committee)

COMMUNICATIONS OBJECTIVE 2

Create plan for ongoing communications with members

Strategies

- 1. Develop PowerPoint presentation
- 2. Develop text for fact sheets on issues for use at regional meetings
- 3. Assist in developing format, stylebook and text for web site
- 4. Develop newsletter formats (e.g., e-news)

COMMUNICATIONS OBJECTIVE 3

Prepare campaign for release of Plan

Strategies

- 1. Create goals and objectives for campaign
- 2. Determine time and place of release
- 3. Develop plan for press conference
- 4. Determine speakers for press conference
- 5. Identify other persons to invite to press conference
- 6. Determine media invitees
- 7. Prepare materials for press kit news releases, photos, fact sheets on plan, lists of committees, etc.
- 8. Arrange logistics for day of press conference

COMMUNICATIONS OBJECTIVE 4

Identify and train Partners for a Speakers Bureau

Strategies

- 1. Develop goals and objectives
- 2. Create criteria for recruiting speakers
- 3. Generate training program for speakers
- 4. Write text for PowerPoint presentation
- 5. Write text for video
- 6. Identify persons to appear in video
- 7. Work with advertising agency, supervise creation of presentation and video
- 8. Develop system for booking speakers, scheduling them
- 9. Produce evaluation plan for speakers' bureau

COMMUNICATIONS OBJECTIVE 5

Produce community guides on specific subjects for target group use

Strategies

- 1. Develop goals and objectives for guide
- 2. Gather information
- 3. Develop text, graphics
- 4. Work with agency to supervise creation of layout, printing
- 5. Produce evaluation plan

COMMUNICATIONS OBJECTIVE 6

Develop and produce two portable exhibits

Strategies

- 1. Develop goals and objectives for each exhibit
- 2. Develop basic design, messages, text, and graphics for each exhibit
- 3. Supervise creation of exhibits
- 4. Develop system for scheduling, setting up, and taking down exhibits
- 5. Produce ancillary material for exhibits (brochures, fact sheets, etc.)
- 6. Produce evaluation plan

STIMULATING AND TRANSLATING RESEARCH

VISION

To perform cutting-edge cancer research in Connecticut and translate it into practice

Research is the engine that is changing our understanding of cancer. In discussing the implications of cancer research, Dr. Andrew Van Eschenbach, Director of the National Cancer Institute, noted, "While we have much more to learn about this complex disease, our increased understanding of cancer at the genetic, molecular, and cellular levels is opening up enormous opportunity to interrupt the initiation and progression of the disease. Over the course of the 20th century, the primary strategy for treating cancer was 'seek and destroy.' Now, in an effort to preserve healthy cells and improve outcomes, we are increasing efforts to 'target and control' cancer by modulating and altering the behavior of the disease.... We will strive to prevent cancer before it starts, identify cancers that do develop at the earliest stage, eliminate cancers through innovative treatment interventions, and biologically control those cancers that we cannot eliminate, so they become manageable, chronic diseases."

The following activities related to cancer research are key to the Connecticut Comprehensive Cancer Control Plan.

- Translate research discoveries into better methods of prevention, early detection, and treatment
- 2. Deliver these methods to all who could benefit from them
- 3. Increase partnering and resources among Connecticut's researchers
- 4. Support research projects in the Plan
- 5. Develop methods of identifying and funding additional priority projects
- 6. Increase participation in clinical trials

CONNECTICUT'S MAJOR RESEARCH INSTITUTIONS

Connecticut has long been a leader in many fields of cancer research, from basic laboratory work to clinical, prevention, and intervention studies. Considerable cancer research on various subjects is being conducted in Connecticut, with the majority of studies being carried out at Yale University and the University of Connecticut (Table 6). Research in prevention, early detection, behavior modification, communications, and policy development is not as widespread as is research into the biology, causes, and treatment of cancer. Several clinical trials, mostly in the treatment area, are available in the state's medical centers and hospitals (Table 7). In 2004, Connecticut institutions--mainly Yale University, University of Connecticut, and Connecticut Department of Public Health--received grants totaling more than \$28 million from the National Cancer Institute to support new and ongoing research projects. In addition, more than \$6 million of research was funded in Connecticut by the American Cancer Society--approximately \$1.5 million at the University of Connecticut and \$4.8 million at Yale.

Table 6
NCI-Funded Research in Connecticut
(NCI Research Portfolio, 2003)

	Number of Studies by Institution				
Type of Research	Yale	UConn	Wesleyan	O ther ^a	Total Studies
All Types	71	18	1	7	97 ^b
Biology	32	13	1	1	47
Causes/Etiology	29	6	-	-	35
Early Detection and Diagnosis	7	1	-	2	10
Treatment	13	3	-	3	19
Cancer Control, Survivorship, Outcomes	6	-	-	1	7
Scientific Model Systems	4	-	-	-	4

a Other = Ikonisys, Inc., June Biotechnologies, Inc., Real-Time Analyzers, Sibtech, Inc. Ultrasound Detection Systems LLC, Vion Pharmaceuticals

PREVENTION RESEARCH CENTERS.

The CDC is administrating a nationwide network of 28 Prevention Research Centers (PRCs) funded by the National Cancer Institute and associated with schools of public health, medicine, or osteopathy. The network comprises academic researchers, public health agencies, and community members that conduct applied research in disease prevention and control. These centers serve as a national resource for developing effective prevention strategies and applying those strategies at the community level. The Yale-Griffin Prevention Center in Derby, Connecticut is one of three PRCs in New England and-is the only hospital-based PRC in the network. A member of the Center's staff serves on the Connecticut Cancer Partnership's Core Committee.

b Research types total to more than 97 because NCI classified some research studies in multiple categories.

Table 7
Clinical Trials at Connecticut Medical Centers and Hospitals¹⁶

Research Entity	No. Programs
CALGB (Cancer and Leukemia Group B)	5
CDC prevention trials	1
Cancer communications trials	2
COG (Central Oncology Group)	1
ECOG (Eastern Cooperative Oncology Group)	8
EORTC (European)	1
GOG (Gynecologic Oncology Group)	
Industry and pharmaceutical companies	16
NASBP (National Surgical Adjuvant Breast and Bowel Project)	9
NSCLC Complementary	1
Institutional Nursing, Quality of Life	1
Nutrition	1
Pediatric and POG (Pediatric Oncology Group)	2
ROTG (Radiation Oncology Trials Group)	2
SELECT (Selenium and vitamin E Cancer Prevention Trial) (SWOG)	1
STAR Trial, co-STAR trial (Tamoxifen/Raloxifen) NSABP	16
SWOG (Southwest Oncology Group) treatment trials	4

Source: Connecticut Cancer Partnership Treatment Committee, 2003 Telephone Survey

GENETICS

Cancer is a genetic disease resulting from multiple molecular abnormalities that are inherited or acquired during life. Genetics research therefore can directly affect the prevention, prediction, diagnosis, and treatment of cancer. Genetics can provide insight into the biological basis of inheritance, and can be used to determine individual risk for certain types of cancer. Although the risk contributed by genetic factors in cancer is small when compared with lifestyle factors such as smoking and diet, lifetime risk for those with certain genetic mutations is high. In the areas of treatment and prevention, gene therapy--delivering therapeutic genetic material into a patient's cells to fight or help prevent cancer--is being studied in several clinical trials for major cancers.

Numerous ethical, legal, and social issues surround genetic testing, giving rise to a need for policy decisions concerning matters such as privacy of medical records, whether to take preventive measures to lessen risk, and the use of genetic information as a basis for discrimination in insurance and employment.

In recognition of the need to address the implications of genetics for public health, the Connecticut Department of Public Health, with funding from the U.S. Health Resources and Services Administration, collaboratively has drafted a long-range *Connecticut Genomics Action Plan*. Some objectives of the plan are to assess the adequacy of and identify areas of improvement to the current system of genetic screening, treatment, and services.

CANCER RESEARCH STRATEGIES

Each priority area of the Connecticut Comprehensive Cancer Control Plan contains objectives with implementation strategies involving research (Table 8). A framework is needed to achieve an integrated and collaborative program of cancer research in Connecticut, especially in the areas of intervention, policy, communications, and behavior change, and for coordinating the efforts needed to translate and disseminate the research findings.

Table 8 Connecticut Comprehensive Cancer Control Plan Strategies from Each Priority Area Related to Research

Prevention

- ✓ Advocate for intervention research in increasing physical activity
- √ Advocate for research to find effective intervention strategies in reducing obesity

Early Detection

- Research and/or develop evidence-based, culturally sensitive materials and programs for increasing screening rates in targeted communities
- ✓ Investigate science-based strategies to promote education about and participation in clinical trials for cancer screening

Treatment

- ✓ Build statewide clinical trials network supporting investigator-initiated trials and removing barriers, to allow more clinicians to enroll patients easily into clinical trials
- Conduct, in collaboration with appropriate organizations and agencies, a study of current cancer treatment modalities being used and resulting treatment outcomes, based on data from the Connecticut Tumor Registry
- Determine database(s) that carry evidenced-based complementary/alternative medicine information for cancer patients and families
- ✓ Facilitate multidisciplinary research programs in specific cancer areas

Survivorship

✓ Advocate for increased funding that will expand survivorship research

RESEARCH OBJECTIVE 1

Develop internal structure to coordinate cross-cutting research efforts for the Connecticut Comprehensive Cancer Control Plan

Strategies

- 1. Support research issues identified in the Plan (see Table 8)
- 2. Research cross-cutting solutions to allow greater funding for intervention, policy, communications and behavioral research
- 3. Develop a statewide intervention research alliance; develop further relationships with the Yale-Griffin Prevention Research Center and with the other funded NCI PRCs
- 4. Support the Connecticut Genomics Action Plan

DATA, SURVEILLANCE, AND EVALUATION

VISION

A coordinated system for reviewing data collection activities and evaluating progress

Connecticut has a well-established system of cancer surveillance. The *Connecticut General Statutes* require that all new cancer cases, inpatient hospitalizations for cancer, and deaths due to cancer are reported to the Connecticut Tumor Registry, Connecticut Office of Health Care Access, or the Connecticut Department of Public Health. The Tumor Registry is the oldest registry of reported cancers in the United States, with records dating back to 1935. It is a part of the National Cancer Institute's Surveillance, Epidemiology and Ends Results (SEER) Program, and, together with other SEER registries, collects data used to set priorities for preventing and treating cancer in the United States. Data are contributed to the Registry's data base by Connecticut hospitals and private pathology laboratories, and through reciprocal agreements with all surrounding states and several other states.

Data on cancer hospitalizations are maintained in the Hospital Discharge and Billing Data Base, which includes data beginning with 1991. Death data have been maintained in the Connecticut Death Registry, part of the DPH Vital Records section, since 1848. Information on risk factors for cancer are collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Surveillance survey, and the Connecticut Youth Tobacco Survey. Other types of cancer-related data are collected through specialized studies and programs such as the Connecticut Breast and Cervical Cancer Early Detection Program at DPH.

The Data, Surveillance, and Evaluation Committee of the Connecticut Cancer Partnership has been instrumental in guiding the Plan's development, by reviewing all objectives to ensure that as many as possible are SMART (specific, measurable, attainable, realistic, and time-phased). Following the model of *Healthy People 2010*, those objectives in the plan without adequate baseline data have been labeled 'developmental,' and strategies include developing methods of obtaining suitable data. Strategies involving data, surveillance and evaluation from the major priority areas of the Plan are summarized in Table 9. The Committee's objectives and strategies are discussed below.

GOAL

To ensure the continued availability of high quality cancer-related data, and support the collection and synthesis of data described in the Connecticut Comprehensive Cancer Plan that are not currently available

DATA, SURVEILLANCE, & EVALUATION OBJECTIVE 1

Increase the use and timely dissemination of available information to increase knowledge about cancer incidence, prevalence, stage at diagnosis, treatment, hospitalizations, deaths, and related behavioral and environmental risk factors in Connecticut (Developmental)

Strategies

- 1. Promote the Connecticut Tumor Registry (CTR) and the use of CTR data to professionals by holding workshops or/and presentations about the CTR
- 2. Disseminate information about the CTR to the public, including information on reporting requirements for cancer
- 3. Explore use of the DPH and Partnership web sites to publicize cancer incidence, prevalence, stage at diagnosis, hospitalization, and death data
- 4. Continue support for the following existing data bases and collection mechanisms:
 - Connecticut Tumor Registry (CTR)
 - Connecticut Death Registry
 - Hospital Discharge and Billing Data Base
 - Behavioral Risk Factor Surveillance System (BRFSS)
 - Youth Risk Behavior Surveillance (YRBS)
 - Connecticut Youth Tobacco Survey (CYTS)
 - Breast and Cervical Cancer Early Detection Program
- 5. Support the publication of data on the incidence, prevalence, stage at diagnosis, treatment, hospitalizations, deaths, and trends for cancer and related risk factors in Connecticut

DATA, SURVEILLANCE, & EVALUATION OBJECTIVE 2

Create a mechanism for the Data, Surveillance, and Evaluation Committee to assist other committees in developing data collection tools, implementing data collection, and analyzing data required for setting baselines and targets and for measuring progress on objectives

Strategies

- 1. Meet routinely with members of all Partnership committees
- 2. Design methods of setting baselines and targets
- 3. Develop methods for measuring progress on objectives

DATA, SURVEILLANCE, & EVALUATION OBJECTIVE 3

Evaluate the implementation of the Connecticut Cancer Plan

Strategies

- 1. Enhance the mechanism for evaluating the implementation of the Connecticut Cancer Plan
- 2. Conduct annual evaluations
- 3. Disseminate evaluation results to the Partnership

TABLE 9

Connecticut Comprehensive Cancer Control Plan Strategies from Each Priority Area Regarding Data, Surveillance, & Evaluation

Prevention

- ✓ Establish baseline for physical activity for high school students
- Establish baseline for cancer-related environmental exposures and protective measures

Early Detection

- Establish baseline for patients who do not receive timely and appropriate follow-up after receiving abnormal breast cancer screening results
- Establish baseline for patients who do not receive timely and appropriate follow-up after receiving abnormal Pap test results
- ✓ Establish baseline for patients who receive timely and appropriate follow-up after receiving abnormal colon screening results
- ✓ Establish baseline for public awareness of risk factors and early signs of skin cancer
- ✓ Establish baseline for screening utilization among racial and ethnic communities

Treatment

- ✓ Complete surveys of available non-web-based resources for public (e.g., telephone lines, written information), taking into account needs of diverse populations
- ✓ List all open Connecticut clinical trials in Connecticut hospitals, cancer centers, and oncology offices and provide link to NCI's PDQ information
- Create inventory of private practice oncologists and clinicians with an oncology subspecialty who presently participate in clinical trials; assess number and location of non-participating physicians interested in forming a linkage to data collection and analysis resources
- Conduct survey to determine number of private practice oncologists presently participating in clinical trials; assess number and location of non-participating physicians interested in forming a linkage to data collection and analysis resources
- ✓ Conduct literature search on barriers and gaps to treatment; conduct focus groups to determine if Connecticut barriers and gaps differ
- ✓ Conduct literature search, focus groups and surveys of patients, families and health professionals regarding barriers that hinder patients in accessing pain and symptom management during treatment
- Develop mechanisms to identify barriers and benefits to Connecticut hospitals for ACoS accreditation

Survivorship

- Establish baseline for number of survivors and providers who access and utilize survivor support services
- ✓ Identify criteria for deciding how to assess the quality of the service organization before including it in the centralized information database
- ✓ Survey survivors to determine the baseline number of survivors aware of guidelines for survivorship care
- Conduct a survey of health care providers to determine the baseline number of providers aware of available guidelines for survivorship care.

Palliative and Hospice Care

- Assess geographic distribution of CT physicians and nurses certified in palliative and hospice care
- ✓ Identify organizations that offer palliative or hospice care education programs and facilitate collaboration to increase end-of-life-educational opportunities in Connecticut.
- Assess current coverage for pain and palliative/hospice services offered by Medicare, Medicaid and private insurance companies; establish baseline
- Assess current status of palliative care services in long-term care facilities; establish baseline
- Assess current status of hospital and long term care contracts with Medicare-certified hospice programs; establish baseline
- ✓ Obtain statewide and local annual survey data from NHPCO to determine baseline; develop strategies to increase survey participation by Medicare-certified hospice programs in Connecticut
- ✓ Assess end-of-life needs, in partnership with Veteran's Home administrators and staff
- Monitor patient/family satisfaction with pain and symptom management through yearly surveys by CT Council for Hospice and Palliative Care
- ✓ Survey cancer survivors' pain experience through ACS Navigation program
- Review and disseminate data on compliance with JCAHO pain standards in CT health care institutions
- ✓ Obtain baseline data on annual number of referrals to hospice, including analysis by demographic criteria
- Conduct needs assessment to identify barriers to access to hospice and palliative care for all Connecticut residents, particularly minority/underserved populations

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¹⁴ Mandelblatt and Yabroff, op cit.

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DATA, SURVEILLANCE, AND EVALUATION TIMETABLE

Goal	Objective	Strategy	2005	2006	2007	2008	On- going
availability of high quality cancer-related data and support the collection and synthesis of data described in the Connecticut Comprehensive Cancer Plan that are not currently available 2. Create for the Survei Evalua Commother of the Conmother contents of the Conmother contents of the Conmother contents of the Cont	Increase use and timely dissemination of information about cancer and its risk factors	Promote the Connecticut Tumor Registry (CTR), hold workshops and presentations					
		Disseminate information about the CTR					
		Explore use of DPH and partnership web site for publicizing cancer information					
		Continue support for existing data bases and collection mechanisms					
		Support publication of data on cancer and its risk factors					
	2. Create a mechanism for the Data, Surveillance, and Evaluation Committee to assist other committees	Meet routinely with members of other Partnership committees					
		Design methods of setting baselines and targets					
		Develop methods for measuring progress					
	3. Evaluate the implementation of the Connecticut Comprehensive Cancer Plan	Enhance the mechanism for evaluating the Plan					
		2. Conduct annual evaluation					
		Disseminate evaluation results to the Partnership					

APPENDICES

Appendix 1 ACRONYMS USED IN THE PLAN

ACS American Cancer Society

ACDD Association of Chronic Disease Directors

ACoS American College of Surgeons

AHRQ Agency for Healthcare Research and Quality
BRFSS Behavioral Risk Factor Surveillance System

CBCCEDP Connecticut Breast and Cervical Cancer Early Detection Program

CDC Centers for Disease Control and Prevention
CIS Cancer Information Service (Yale University)
CMMS Centers for Medicare and Medicaid Services

CSMS Connecticut State Medical Society

CTR Connecticut Tumor Registry

CYTS Connecticut Youth Tobacco Survey

DPH Connecticut Department of Public Health

FOBT Fecal Occult Blood Test
HPV Human Papillomavirus

ICC International Cancer Council

JCAHO Joint Commission on Accreditation of Healthcare Organizations

LMRP Local Medical Review Policy

LTC Long Term Care

MADD Mothers Against Drunk Driving

NACCR North American Association of Central Cancer Registries

NCI National Cancer Institute

NCCN National Comprehensive Cancer Network

NDC National Dialogue on Cancer (now called C-Change)

NECON New England Coalition for Health Promotion and Disease Prevention

NHPCO National Hospice and Palliative Care Organization

NPHA National Prison Hospice Association

PPSG Pain and Policy Studies Group
PRC Prevention Research Center
PSA Prostate Specific Antigen

UCHC University of Connecticut Health Center

YCC Yale Cancer Center

YRBS Youth Risk Behavior Surveillance

WISEWOMAN Well-Integrated Screening and Evaluation for Women Across the Nation

Appendix 2 SUMMARY LIST OF GOALS AND OBJECTIVES

PREVENTING CANCER BEFORE IT STARTS

Goal

Reduce cancer risk through promoting healthy lifestyles and risk reduction behaviors among children and adults

Objectives

- Decrease the proportion of adults (≥ 18 years) and youths (high school and middle school students) who currently use tobacco, paying special attention to populations experiencing tobacco-related disparities
- 2 Increase the proportion of adults (≥ 18 years) and youths (< 18 years) who make healthy food choices, including increasing consumption of fruits and vegetables to meet current HHS and USDA Dietary Guidelines for Americans</p>
- 3 Decrease the proportion of adults (≥ 18 years) and high school students who engage in no leisure time physical activity or exercise
- 4 Reduce the percentage of overweight and obese adults (≥ 18 years) and children
- 5 Increase the public's awareness of cancer-related environmental exposures and protective measures
- 6 Increase the practice of sun protection behaviors, especially among youth Increase awareness of risk of overexposure to ultraviolet light in tanning booths
- 7 Reduce the percentage of adults and adolescents who engage in excessive drinking, which is defined as greater than 2 drinks per day for males and 1 drink per day for females
- 8 Increase to 50% the proportion of adults 18-64 years of age who always use condoms if sexually active with more than one sex partner
- 9 Increase to 95% the proportion of high school students who abstain from sexual intercourse or use condoms if sexually active

INCREASING EARLY DETECTION

Goal 1

Promote, improve, and optimize the appropriate use of high-quality breast, colorectal, and cervical cancer screening and follow-up services

Objectives

- 1-1 Increase the percentage of women aged 40 and over who have had a mammogram in the past two years to 85% by 2008
- 1-2 Increase the proportion of patients who receive timely and appropriate follow-up after receiving abnormal breast cancer screening results
- 1-3 Increase the percentage of women who have had a Pap test within the past year to 90% by 2008
- **1-4** Increase the proportion of patients who receive timely and appropriate follow-up on receiving abnormal Pap test screening results
- **1-5** Increase the percentage of adults 50 and over who have had a sigmoidoscopy or colonoscopy within the past five years to 65% by 2008
- **1-6** Increase the proportion of adults 50 and over who have had a fecal occult blood test within the past year to 63% by 2008
- 1-7 Increase the proportion of patients who receive timely and appropriate follow-up on receiving abnormal colon screening results

Goal 2

Eliminate or decrease racial, ethnic, and socioeconomic disparities in access to and utilization of cancer screening

Objectives

- 2-1 Increase screening utilization among underserved minority groups (Developmental)
- 2-2 Increase enrollment of underserved populations in cancer screening trials

Goal 3

Identify and promote evidence-based strategies for education and early detection of cancers without proven early detection tests

Objectives

- 3-1 Seek and develop strategies to reduce morbidity and mortality for cancers with high incidence or mortality rates for which effective screening tests are not yet available, including lung, ovarian, and prostate cancers
- **3-2** Increase awareness of lung, ovarian, prostate, skin, and oral cancers, for which there are no widely accepted, evidence-based, screening modalities, through education about risk factors and symptoms
- **3-3** Increase public awareness of risk factors and early signs of skin cancer, with emphasis on malignant melanoma

ASSURING QUALITY TREATMENT FOR ALL PATIENTS

Goal

Ensure that Connecticut residents will have equal access to high quality, evidence-based cancer care

Objectives

- 1 Increase the proportion of cancer care providers and cancer patients with access to treatment information and evidence-based quality standards of care, taking into consideration cultural, literacy, and access needs (Developmental)
- 2 Increase the proportion of cancer care providers and cancer patients with access to comprehensive information on clinical treatment trials (Developmental)
- 3 Build a statewide clinical trials network supporting investigator-initiated trials and removing barriers, to allow more clinicians to enroll patients easily into clinical trials
- 4 Reduce the proportion of cancer patients who experience difficulty or delays in accessing treatment or who do not receive needed treatment (Developmental)
- Increase the proportion of cancer patients and their families who have access to support systems, including psychosocial support and evidence-based complementary medicine (Developmental)
- 6 Increase the proportion of cancer patients who have access to pain and symptom management during treatment (Developmental)
- 7 Increase to 28 the number of Connecticut acute care hospitals that are accredited by the American College of Surgeons (ACoS)

EMPOWERING SURVIVORS AND THEIR FAMILIES

Goal

To ensure a high quality of life and care for all Connecticut residents living with cancer and for their families

Objectives

- 1 Increase the proportion of cancer survivors and cancer care providers who access and utilize survivor support services (Developmental)
- 2 Increase the proportion of cancer survivors who are knowledgeable about published guidelines for survivorship care (Developmental)
- Increase the proportion of health care providers who are knowledgeable about evidence-based survivorship care (Developmental)

HELP AT THE END OF LIFE

Goal 1

To ensure that high quality palliative and hospice care services are available and accessible to all Connecticut residents

Objectives

- **1-1** Increase the number of health care professionals (physicians, nurses, social workers, and spiritual counselors) who are knowledgeable about palliative and hospice care (Developmental)
- 1-2 Increase the number of health professionals who are board certified in palliative and hospice care
- 1-3 Increase the number of health insurance programs that provide coverage for pain and palliative/hospice services (Developmental)
- 1-4 Increase the proportion of facilities that self-report palliative care programs
- 1-5 Increase the number of hospitals and long term care facilities that have contractual agreements with Medicare-certified hospice programs (Developmental)
- 1-6 Improve end-of-life care in Connecticut State correctional facilities
- 1-7 Assess patient and family satisfaction with palliative and hospice services (Developmental)
- 1-8 Improve end-of-life care services in State Veterans Home (Developmental)

Goal 2

Ensure that Connecticut residents have improved quality of life through effective management of pain and other symptoms

Objectives

- **2-1** Increase legislation and public policy supporting pain, palliative, and hospice care services to achieve Grade C in strength of pain policies in Connecticut
- 2-2 Decrease the prevalence of pain among Connecticut nursing home residents
- **2-3** Demonstrate an increase in patient and family satisfaction with management of pain and symptoms (Developmental)

Goal 3

Ensure that Connecticut residents are more aware of, better prepared for, and more willing to seek palliative and hospice care

Objectives

- **3-1** Increase utilization of palliative and hospice care
- **3-2** Increase the number of referrals to hospice and palliative care, especially among persons from minority and medically underserved populations (Developmental)

CROSS-CUTTING ISSUES

ADVOCATING FOR QUALITY PROGRAMS AND ACCESS

Objective

1 Develop internal structure and tracking instruments to coordinate advocacy efforts for the Connecticut Comprehensive Cancer Control Plan

ADDRESSING HEALTH DISPARITIES

Objective

1 Develop internal structure to coordinate cross-cutting efforts to increase access to health care and reduce health disparities

COMMUNICATING ABOUT THE PLAN AND THE PARTNERSHIP Objectives

- 1 Develop a plan to communicate information about the Connecticut Comprehensive Cancer Control Plan and Connecticut Cancer Partnership
- 2 Create plan for ongoing communications with members
- 3 Prepare campaign for release of Plan
- 4 Identify and train Partners for a Speakers Bureau
- 5 Produce community guides on specific subjects for target group use
- 6 Develop and produce two portable exhibits

STIMULATING AND TRANSLATING RESEARCH Objective

1 Develop internal structure to coordinate cross-cutting research efforts for the Connecticut Comprehensive Cancer Control Plan

DATA, SURVEILLANCE, AND EVALUATION

Goa

To ensure the continued availability of high quality cancer-related data, and support the collection and synthesis of data described in the Connecticut Comprehensive Cancer Plan that are not currently available

Objectives

- 1 Increase the use and timely dissemination of available information to increase knowledge about cancer incidence, prevalence, stage at diagnosis, treatment, hospitalizations, deaths, and related behavioral and environmental risk factors in Connecticut (Developmental)
- 2 Create a mechanism for the Data, Surveillance, and Evaluation Committee to assist other committees in developing data collection tools, implementing data collection, and analyzing data required for setting baselines and targets and for measuring progress on objectives
- 3 Evaluate the implementation of the Connecticut Cancer Plan

Appendix 3 COMMITTEE MEMBERS

Core Committee

Chair:

Andrew Salner, MD Director of Cancer Programs

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Hartford

Committee Members:

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Rosa Biaggi, MPH, MPA

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