

CHAPTER V
COLORECTAL CANCER

COLORECTAL CANCER

GOAL

By 2010, reduce the colorectal cancer mortality rate in California by 40 percent, from a baseline of 17.6 deaths per 100,000 persons.

OBJECTIVES

1. By 2010, increase the percent of Californians over age 50 who have had a flexible sigmoidoscopy or a colonoscopy within the past five years from 40 percent to 58 percent, including women, Asian/Pacific Islanders, African Americans, Latinos, and those of low income.
2. By 2010, increase the percent of colorectal cancer diagnosed at an early stage from 42 percent to 65 percent.

Background and Barriers to Achieving Goals and Objectives

Burden of Colorectal Cancer in California

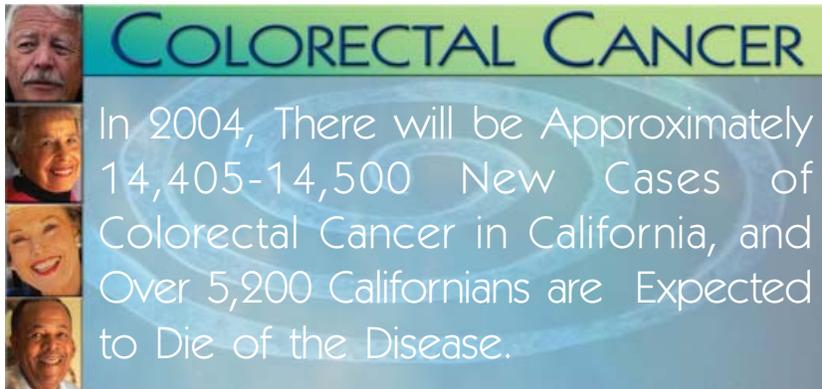
Colorectal cancer is the third most common cause of cancer in California for both men and women, and it is the second most common

cause of cancer death (48).

The importance of finding colorectal cancer at an early stage cannot be overstated. The survival rate is nearly 90

percent when the cancer is caught before it has spread beyond the intestinal wall (1). The overall five-year survival rate for colorectal cancer is 61 percent, much lower than the survival rate for either breast cancer (85 percent) or prostate

cancer (94 percent). This low colorectal survival rate may be related in part to later stage of cancer detection. Screening can detect colorectal



COLORECTAL CANCER

In 2004, There will be Approximately 14,405-14,500 New Cases of Colorectal Cancer in California, and Over 5,200 Californians are Expected to Die of the Disease.

cancer at an earlier stage or even prevent it altogether by detecting precancerous polyps that can be removed before they become cancers.

Risk Factors and Disparity in Burden

Men and women ages 50 and over, regardless of ethnicity, are at greatest risk for development of colorectal cancer, and that risk increases with age. Other risk factors include a history of inflammatory bowel disease, certain hereditary and genetically determined conditions, and having had a personal or family history of colorectal polyps or colorectal cancer. Lifestyle risk factors include a diet low in fruits, vegetables, fiber, and/or high in red meats, obesity and lack of physical exercise, alcohol consumption, and tobacco use (1, 35, 49).

Socioeconomic factors or barriers can also influence who will develop or die from colorectal cancer. Low SES can mean an environment that nurtures the onset of cancer by hindering healthy personal and family behaviors. Many low-income communities lack stores selling affordable healthy foods, and low SES is associated with lack of health insurance that may also result in lack of access to appropriate screening methods for early detection and prevention of colorectal cancer (36).

Age-adjusted colorectal cancer incidence and mortality rates are actually declining in California as they are in the rest of the nation. The biggest decline is among non-Hispanic whites, and the least is among African Americans. African Americans also have the highest mortality rate from colorectal cancer when compared with other ethnic or racial groups (1). The reason for the decline in colorectal cancer incidence and mortality is not fully understood but it may be due in some part to colonoscopy polyp detection and removal, and to dietary and lifestyle changes (1, 49).

Since California, like the rest of the nation, has an aging population, increases in the incidence of colorectal cancer can be expected as the population grows older (2). This expected increase in colorectal cancer incidence and mortality can be avoided largely by improving colorectal cancer screening rates. Ensuring that people of all races, ethnicities, and socioeconomic levels have equal access to screening services will help achieve California's goals.

Screening

The case for focusing state cancer control efforts on prevention, screening, and early detection of colorectal cancer in California couldn't be stronger (1). Average-risk persons without symptoms should undergo regular colorectal cancer screening beginning at age 50. Recommended screening procedures and intervals for the detection of polyps and colorectal cancer include colonoscopy (examining the entire colon) every 10 years, flexible sigmoidoscopy (an endoscopic examination of the lower colon) every 5 years, or fecal occult blood test (FOBT) yearly. A barium enema examination every 5 years has also been recommended for situations where access to the other screening methods is lacking. Diminished sensitivity to the detection of polyps and smaller cancers limits the effectiveness of the barium enema as a screening tool (1).

In 2001, only 42 percent of California adults ages 50 and over reported having had sigmoidoscopy or colonoscopy within the past five years. Persons living in poverty and Asian/Pacific Islanders had the lowest screening rates of Californians (under 28 percent), compared to over 50 percent for non-Hispanic white males earning over 200 percent of federal poverty level (1).

Randomized prospective studies have demonstrated that colorectal cancer screening significantly reduces mortality from colorectal cancer, most likely by removing precancerous

polyps and detecting asymptomatic cancer at an early stage. Increasing access to and affordability of colorectal cancer screening for all Californians, regardless of race, ethnicity or SES, is of primary importance.

A statewide educational program aimed at the public and health care providers, emphasizing early detection and prevention of colorectal cancer through screening and healthful living, would significantly reduce the incidence and mortality of colorectal cancer in California.

Californians, especially those over age 50, should be taught and constantly reminded of the importance of colorectal cancer screening as the primary means of prevention and early detection of this disease. Not only must the generally accepted (e.g., by the American Cancer Society (ACS) and the U.S. Preventive Services Task Force) colorectal cancer screening tests be widely available and accepted by the health care and insurance industries, they must be put into practice. Health care providers and consumer groups need to advocate for increased availability of colorectal cancer screening tests.

Sensitivity to cultural and ethnic diversity and social needs is required in every aspect of colorectal cancer prevention, screening, referral, treatment, and subsequent care. How a patient is guided through the process - clear and culturally sensitive instructions for test preparation, descriptions of the test procedures themselves, and explanations of the test results and follow-up - become the keys to public acceptance.

Evaluation and Treatment

Once cancer is detected, a number of tests are done before treatment to evaluate the stage of the cancer, to help plan treatment, and to rule out additional cancer foci. These tests may include a colonoscopy (if this has not already

been done), blood tests (including for tumor markers such as carcinoembryonic antigen), chest x-rays, computed tomographic (CT) scans, and sometimes more sophisticated studies such as endorectal ultrasound examinations and Positron Emission Tomography (PET) scanning.

The primary treatment for colorectal cancer is surgery. For early-stage cancer, surgical resection alone is often curative. More advanced colon cancer may benefit from the addition of chemotherapy, and more advanced rectal cancer may be treated with radiation as well as chemotherapy. Rectal cancers are often treated with chemotherapy and radiation therapy before surgery. Only rarely today does surgical treatment of colorectal cancer result in a stoma (an opening on the patient's abdomen for fecal waste), and even then the stoma is occasionally only temporary. The treatment of colorectal cancer today is fairly well standardized. These standards have been developed through the systematic application of clinical trials that have demonstrated clear benefits of the use of certain methods and agents for the treatment of colorectal cancer. For this reason, it is essential that all patients with colorectal cancer be treated according to these generally accepted protocols to assure the highest possible survival rates. To help ensure continued progress in the treatment of colorectal cancer, patients of all ethnicities should be encouraged and recruited to participate in clinical trials.

Quality of Life

Quality of life for a cancer patient and his or her family refers to the physical, psychological, social, and spiritual well-being of their lives from diagnosis, through treatment, and for the balance of the patient's life. Not only should patients have access to appropriate quality treatment and follow-up, they and their families should receive help in navigating the health care

system to find resources and services that match their needs (4). All patients deserve accurate, complete, comprehensible, and culturally relevant information, and culturally sensitive and compassionate support goes hand-in-hand with treatment. This will minimize fear and result in patients and families who are partners in their own care.

Quality of life considerations include minimizing suffering through control of pain and anxiety. Patients with advanced, colorectal cancer should receive appropriate end-of-life care, including adequate pain management. There are generally accepted standards of pain control and these should be adhered to, again through quality assurance tracking with acceptable levels mandated by governmental and independent regulatory agencies (4).

Funding Colorectal Cancer Prevention, Screening, Early Detection, Treatment, and Follow-up Care

Elimination of cost as a barrier to quality care should be one of California's highest priorities. Some insurance companies will not pay for some or any of the screening tests, and this needs to change. Although a majority of Californians are covered by some form of health insurance, implementation of additional legislation mandating coverage for colorectal cancer screening and treatment by the state's health insurers is essential toward reducing California's colorectal cancer mortality.

Colonoscopy is now a covered benefit for Medicare patients. Other publicly funded colorectal cancer screening programs to cover the entire uninsured and underinsured population are needed. Universal health insurance coverage for all Californians may be the ultimate solution.

It is not enough for health care providers or insurers to offer colorectal cancer screening. Rates of screening should be subjected to quality assurance tracking, with minimum acceptable levels mandated by National Committee for Quality Assurance (NCQA) and other regulatory agencies as is currently done for breast and cervical cancer screening.

COLORECTAL CANCER - STRATEGIES AND TACTICS

Top Strategies to Achieve Goals and Objectives:

1. By January 1, 2006, develop and support proactive colorectal cancer advocacy groups that will, in turn, support community, state, and national agendas for increasing awareness of colorectal cancer issues.
2. By January 1, 2006, develop and support evidence-based, culturally sensitive public awareness campaigns that focus on the importance of colorectal cancer screening, prevention, and early detection through media, community outreach, and through a collaboration among health care providers and community and voluntary organizations.
3. By January 1, 2006, work toward universal insurance coverage for colorectal cancer screening and treatment.

Additional Strategies:

- › Increase colorectal cancer screening capacity among health care providers and facilities by promoting and encouraging expansion of the base of providers who can offer flexible sigmoidoscopy and colonoscopy to include

primary care physicians, nurses, and physician assistants.

- › Achieve optimal outcomes in the prevention, detection, and treatment of colorectal cancer by promoting evidence-based best practices among health care providers, and by promoting and supporting research and education in colorectal cancer.
- › Develop methods of evaluating the outcomes of prevention, detection, and treatment strategies in colorectal cancer and promote use of these methods.
- › Establish stable funding that will enable state and local public health departments to implement culturally competent colorectal education and outreach at state, county and community levels.
- › Assure that health professionals receive training in all aspects of colorectal cancer as a part of their initial and continuing medical education programs.
- › Require health plans to meet approved colorectal cancer screening guidelines through the licensure process with the California Department of Managed Care.
- › Establish and monitor evidence-based clinical guidelines for colorectal cancer care including quality of life measures, pain management, and palliative care.
- › Provide information and navigation tools and services to colorectal cancer patients, families, and caregivers to help them receive the care and support they need when, and for however long, they need that care and support.
- › Assure that colorectal screening is included in the Health Plan Employer Data and Information Set (HEDIS) guidelines and that promotion of adherence to guidelines are followed.

Tactics for Implementing the Top Strategies:

Strategy 1

By January 1, 2006, develop and support proactive colorectal cancer advocacy groups that will, in turn, support community, state, and national agendas for increasing awareness of colorectal cancer issues.

- › Identify survivors motivated to build an advocacy coalition that also includes physicians, the ACS, other interested groups, and community leaders.
- › Obtain funds from foundations to support advocacy activities from the U.S. Centers for Disease Control and Prevention, The ACS, corporations, and others, e.g. pharmaceutical companies.
- › Create a combined patient support, legislative, and education focus.
- › Develop a State of California Colorectal Roundtable modeled after the National Colorectal Roundtables to promote an on-going dialogue among experts and advocates in colorectal cancer.
- › Explore beyond local level to national and international activities and tie groups together.
- › Partner with a health plan or disease management program dealing with colorectal cancer.

Strategy 2

By January 1, 2006, develop and support evidence-based, culturally sensitive public awareness campaigns that focus on the importance of colorectal cancer screening, prevention, and early detection through media, community outreach, and through a collaboration among health care providers and community and voluntary organizations.

- › Make early diagnosis of colorectal cancer a family issue and heighten awareness through special campaigns.
- › Collaborate with diverse communities and leaders; identify what message(s) will reach different communities and cultures.
- › Obtain funding to support outreach and awareness campaigns.
- › Create and implement a media campaign.

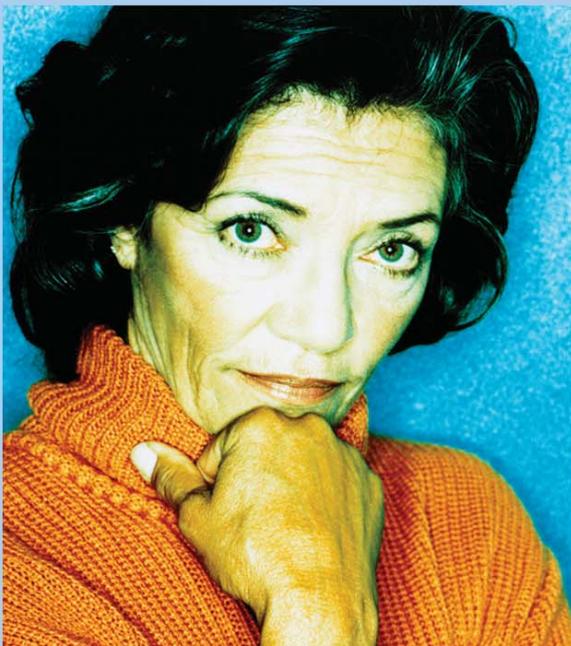
Strategy 3

By January 1, 2006, work toward universal insurance coverage for colorectal cancer screening and treatment.

- › Obtain funding to support an Office of Colorectal Cancer at the DHS to provide outreach, screening, and treatment programs.
- › Work to pass legislation that covers screening and treatment for colorectal cancer. At the federal level, work on supporting the passage of Comprehensive Cancer legislation.
- › Develop advocacy groups to implement this strategy.



EVERY
24 MINUTES
ONE CALIFORNIA
WOMAN IS
DIAGNOSED WITH
BREAST CANCER.



CHAPTER VI
BREAST CANCER

BREAST CANCER

GOALS

1. By 2010, reduce the mortality rate from female breast cancer in California by 36 percent, from a baseline of 130.9 deaths per 100,000 women, through early detection and treatment.
2. By 2010, advance scientific and public understanding of modifiable risk factors, how they affect the incidence of breast cancer, and how breast cancer may be prevented
3. By 2010, reduce the morbidity impact of breast cancer on short and long-term quality of life.

OBJECTIVES

1. By 2010, increase the percent of women in California age 40 and older, particularly those women over 50, who have an annual mammogram and clinical breast examination from 60 percent to 90 percent by increasing breast cancer education and access to services.
2. By 2010, increase the percent of breast cancers diagnosed at an early stage (in situ and localized) from 70 percent to 80 percent, including reducing disparities in stage of diagnosis for the insured and uninsured regardless of race and ethnicity.
3. By 2010 create new ways to continue the breast cancer mortality reduction beyond 2010 at the same rate of decline as outlined in Goal number one through research and improved detection methods.

Background and Barriers to Achieving Goals and Objectives

Breast Cancer Burden in California

Every 24 minutes one California woman is diagnosed with breast cancer (48). It is the most common cancer among women, and for California women it is the leading cause of cancer deaths in women younger than 65 year

of age and the second leading cause of cancer deaths in women older than age 65 after lung cancer. Although women fear it the most, survival is excellent if this cancer is diagnosed early, that is, at the *in-situ* or localized stage.



New breast cancer cases expected in California women in 2004 will number approximately 22,400, while expected deaths will be around 4,200. Fortunately, numbers of cases diagnosed at a late stage are declining as more cancers are detected early. About 68 percent of female breast cancers diagnosed in 1999 were discovered at an early, (*in situ* or localized) stage. The breast cancer mortality rate in 1999 (24.5 per 100,000 women) was 24 percent lower than in 1988 (32.4 per 100,000 women)(1, 48).

Disparity in Burden

African-American women are less likely to get breast cancer than non-Hispanic white women, but they are more likely to die from it. Invasive breast cancer incidence rates have increased about 20 percent for Asian/Pacific Islander women in California over the past decade (1). Clearly, the diagnosis of breast cancer at a late stage remains a particular challenge to overcome among the ethnically diverse and underinsured women in California.

Risk Factors

Women of all ages and population groups need enhanced knowledge of breast cancer risks. Although it is difficult to predict who will develop breast cancer based on exposure to various risk factors, the incidence of breast cancer increases with age and begins a steep rise after age 40. For this reason, California

expects to see an increase of new breast cancer cases as “baby boomers” (individuals born between 1945-1961) grow older (1, 2).

Primary risk factors for breast cancer include:

- › Age (nearly 80 percent of women first diagnosed with breast cancer are over age 50),
- › A family history of breast cancer, and
- › A past personal history of breast cancer.

Risk factors that we can control and that provide a basis for risk reduction strategies include:

- › Obesity,
- › Physical inactivity,
- › Alcohol consumption (2-5 drinks per day), and
- › Long-term use of hormone replacement therapy.

Other risk factors that may or may not be within our control include:

- › Lack of breast feeding (every year of breast feeding reduces breast cancer risk),
- › Early menarche,
- › Delayed childbirth or having no children, and
- › Late menopause.

Poor nutritional habits, that is, a diet low in fruits and vegetables and high in fat, and cigarette smoking are also considered possible risk factors. As with the development of other cancers that may be influenced by poor diet and physical inactivity, low SES may also play a significant role requiring a much broader societal approach (35, 36).

Other more general risks are poorly understood at this time. For example, for yet to be clarified reasons, being well educated and of higher SES appears associated with a higher risk for developing breast cancer (1). This may be due to a concomitant association with other more specific risk factors mentioned above.

We also do not know definitively whether or not a relationship between environmental exposures and the etiology of breast cancer clearly exists. A few epidemiological studies, including the Long Island Breast Cancer Study, have suggested the risk of breast cancer may increase to various extents in women after high exposure to some selected environmental carcinogens such as polycyclic aromatic hydrocarbons. Although disagreement about the role of the environment exists within the scientific and advocacy communities, this issue needs California's attention and additional research (13, 40).

Early Detection

Finding breast cancer at an early stage is key to survival. When found at the early "in situ" or localized stages, the five-year survival rate can be as high as 95 percent compared to 22 percent if the cancer has spread to other organs or tissues outside the breast (1).

Clinical breast examinations by a health care provider starting at age 40 (every three years for women ages 20-39 years) and annual mammograms after age 40 are recommended for early breast cancer detection (1). For women aged 40-49, the evidence that screening mammography reduces breast cancer is weaker, and the absolute benefit of mammography is smaller, than it is for older women.

36 Most, but not all, studies indicate a mortality benefit for women undergoing mammography

at ages 40-49, but the delay in observed benefit makes it difficult to determine the incremental benefit of beginning screening at age 40 versus 50. Mortality can be reduced by up to 30 percent in women age 50 and older if they are screened annually.

Screening Progress

As a result of screening, about 68 percent of female breast cancer cases diagnosed in 1999 were found at an early, localized stage (1). In 2000, 63 percent of women of screening age reported that they had a mammogram within the past year, compared to 39 percent in 1987. Examining screening rates by ethnicity has revealed that non-Hispanic white women, African American women, and Latina women, were likely to have been recently screened but that Asian/Pacific Islander women lagged considerably behind.

In 2000, reflecting a trend seen in recent years, women of poverty were almost as likely to have been screened as women from households with higher income (1). During 2000-2001, over 167,000 or 17 percent of the estimated eligible population of low-income women, largely of color, received free breast cancer screening through California's Cancer Detection Programs: Every Woman Counts (18). This marked progress is a result of the many efforts in California to reach all women for screening. (See Appendix D: California's breast cancer programs.)

Treatment, Recovery, and Quality of Life

Today there are a number of treatment options for women diagnosed with breast cancer. Options range from lumpectomy and radiation to mastectomy for local treatment, and chemotherapy and/or hormone therapy for

systemic treatment. Choice of treatment options depends on the stage of the cancer, family history, the patient's age, reconstruction consideration, available treatments close to where the woman lives, and many other factors (41).

How a woman deals with her diagnosis should be of great importance to her quality of life as is the process by which she chooses her treatment after all of the options have been explained to her. Support can be essential to help her through this stage as well as through her treatment, recovery, follow-up, rehabilitation, and the on-going care she may need for the balance of her life. Community support and education programs can also provide mechanisms that help the patient with improving or maintaining her quality of life. Breast cancer survivors, for example, can answer sensitive questions, listen to her fears and respond, discuss breast reconstruction, and help her find other needed resources.

A more global quality of life issue concerns breast cancer treatment for every woman in California. California must ensure that all women diagnosed with breast cancer have equal access to appropriate, quality, evidence-based treatment and follow-up, and that there are no disparities in treatment.

California must also ensure that breast cancer survivors receive all of the services and help they need in a culturally responsive manner. They need to be able to determine what services are available to them and then navigate the health care system for those services. This includes managing and relieving pain, easing treatment side effects, recovering with social, emotional, psychological, and spiritual assistance, and obtaining the socioeconomic support required to deal with finances, insurability, employment, transportation, and other major concerns of daily living (4).

Health care professionals and community advocates have a responsibility to see that breast cancer survivors are linked to the services they need when they need them, and if such supportive resources do not exist, to organize or create them.

Breast Cancer - Strategies and Tactics

Top Strategies to Achieve Goals and Objectives:

1. By January 1, 2006, begin to conduct statewide tracking of women's breast cancer health care.
2. By January 1, 2006, provide education for health professionals, policy makers, and consumers, including diverse populations, regarding breast cancer risk assessment and risk reduction through a variety of materials and mechanisms developed to increase cultural competency and communication skills.
3. By January 1, 2006, develop a coordinated system and resources to provide access for patients to breast cancer detection, diagnosis, and treatment services which ensures quality of life throughout the continuum of cancer care including recovery and palliative care.

Additional Strategies:

- › Facilitate access to Medi-Cal and Medicare for those individuals who are uninsured and diagnosed with breast cancer.
- › Work to achieve universal healthcare.
- › Provide paid advertising to promote the public's awareness of the importance of breast cancer early detection.
- › Increase reimbursement for all aspects of breast cancer screening, diagnosis, and treatment.
- › Increase research to identify modifiable risk factors for breast cancer.

- › Develop evaluation capacity to measure progress in meeting breast cancer plan goals and objectives.
- › Obtain increased funding for breast cancer research in California.

Tactics for Implementing the Top Strategies:

Strategy 1

By January 1, 2006, begin to conduct statewide tracking of women's breast cancer health care.

- › Map the stage of breast cancer diagnoses and number of cases to identify high need areas based upon stage at diagnosis, mortality, and ethnicity, etc. Map supporting resources and services related to the continuum of cancer care. Resources should include all providers and support services for all women.
- › Develop and fund a statewide, comprehensive database with patient demographics, containing information on CBE, mammography, ultrasound, and biopsies in women age 40 years and older, and correlate this data base with the census. Provide statewide and local data identifying all screening and diagnostic services. Identify geographic areas with gaps in services and resources.

Strategy 2

By January 1, 2006, provide education for health professionals, policy makers, and consumers, including diverse populations, regarding breast cancer risk assessment and risk reduction through a variety of materials and mechanisms developed to increase cultural competency and communication skills.

- › Promote participation of health educators in the DHS' Cancer Detection Section's Professional Education Module, "Healthcare Providers and Women: Partners in Communication." Provide professional education to improve sensitivity and communication skills and cultural competency through medical school curricula and as part of continuing education requirements for state licensure.
- › Disseminate the course, "Clinical Breast Examination: Proficiency and Risk Management," developed by the Cancer Detection Section at the DHS, to all medical schools, nurse practitioner schools, and physician assistant schools in California for use in their respective educational programs.
- › Educate medical professionals treating breast cancer to treat patients following evidence-based medicine and provide access to clinical trials to all patients, even if his or her facility does not offer the particular trial.
- › Continue to fund the DHS to develop statewide educational and outreach materials. Disseminate this information through a variety of media and venues.
- › Identify and/or develop age, literacy level, culturally, and linguistically appropriate breast cancer-related outreach and educational materials. Create a clearing house of these materials in order to compile California-produced resources and linkage to national resources.

Use a wide variety of distribution methods to disseminate.

- › Provide a directory via an 800 number and on the web with the location of all resources and services available to all women statewide and locally.

The directory should include information gathered by the following:

1. Cancer Detection Programs: Every Woman Counts
Regional Cancer Detection Partnerships,
2. The National Cancer Institute,
3. The American Cancer Society
4. Medi-Cal
5. Community health clinics
6. Women's health organizations
7. Other relevant organizations.

Information provided should include:

1. Comprehensive cancer centers serving California,
 2. Resources and services by county, and
 3. Community services and organizations.
- › Fund and partner with the CCR to provide statewide and local data on stage at diagnosis and identify areas with high incidence of late stage at diagnosis.
 - › Develop a cancer orientation packet containing information for lawmakers, policy makers, and community providers that covers the statewide issues regarding breast cancer and also covers issues specific to represented areas.
 - › Identify guidelines and quality benchmarks for early detection, diagnosis, and treatment.
 - › Educate providers and consumers on available clinical trials for treatment as well as risk reduction.

- › Educate consumers and providers about pharmacological agents, such as tamoxifen, that have shown promise in reducing breast cancer risk, and include the considerations involved in deciding whether to use them.
- › Provide health professionals and consumers with information regarding the location and availability of centers that can provide an enhanced complexity of care for cancer treatment.

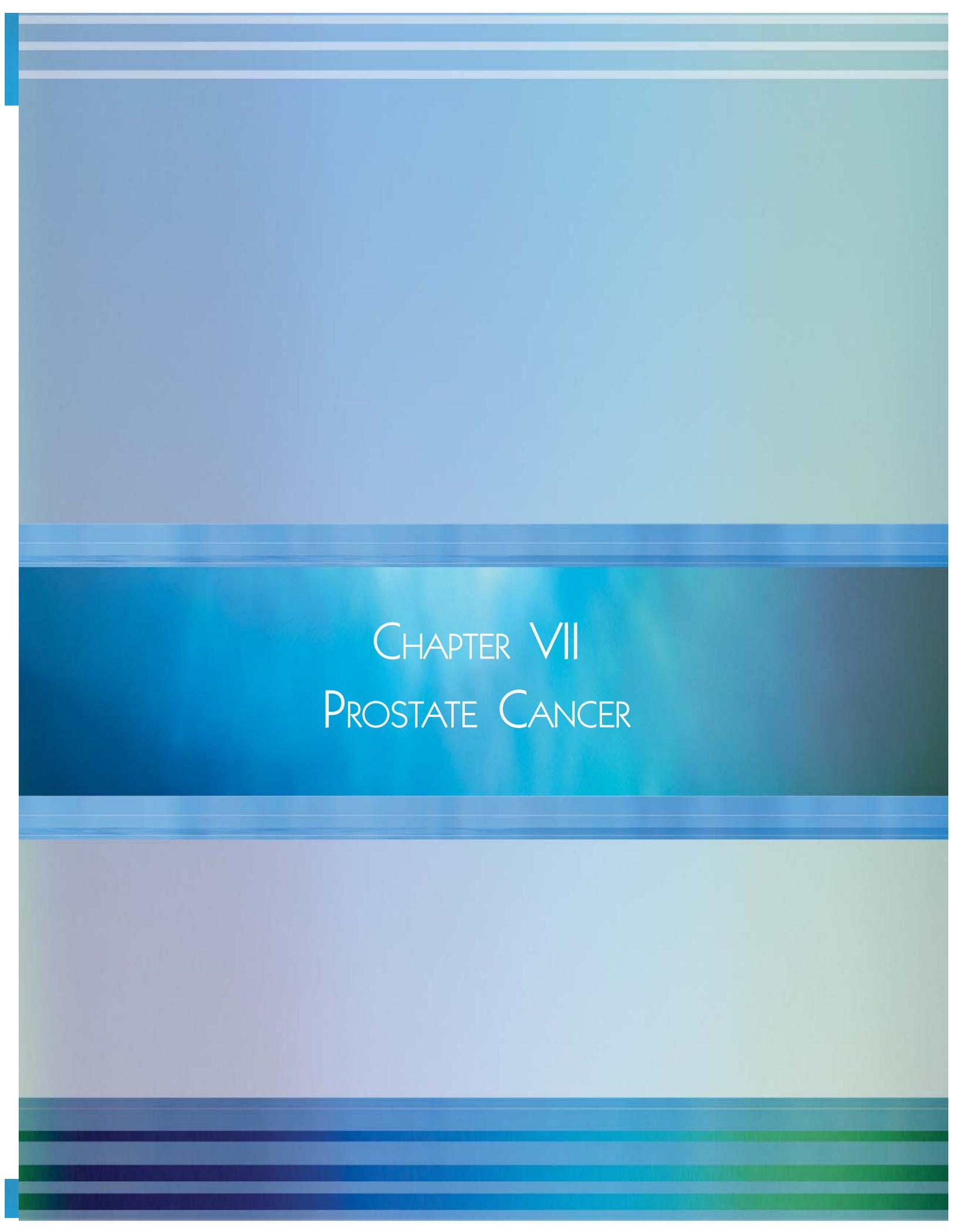
Strategy 3

By January 1, 2006, develop a coordinated system and resources to provide access to breast cancer detection, diagnosis, and treatment services which ensures quality of life throughout the continuum of cancer care including recovery and palliative care.

Develop and provide resources for a high quality, coordinated system of networks that:

- › Makes high quality entry-level screening services widely and easily accessible statewide in the communities where women live,
- › Provides referral and ensure access to progressively more complex levels of high quality care when needed for subsequent diagnostic evaluation, treatment, and/or supportive care, and
- › Deploys resources optimally to fill gaps in communities where there is insufficient entry level screening and referral capacity and to fill gaps or eliminate redundancies in regional capacity for more complex care.
- › Encourages collaboration among DHS, voluntary and community organizations, community clinics, medical professionals, and medical schools in all counties to increase efficiency of services provided.

- › Provides a structure and process to identify and ensure appropriate care or referral for early detection, diagnosis, and treatment to include symptom control, amelioration of pain, rehabilitation, and reduction in the side effects of treatment based upon an appropriate care plan using uniform standards of care.
- › Establish a network for appropriate interventions, such as advocacy, referral and education to address financial, employability, and insurability issues, and access to treatment and follow-up care.
- › Establish a network to provide appropriate care or referral to services and support groups, such as those provided by ACS, the wellness community, hospice services, and others for identified psychological, emotional, and spiritual problems or needs.
- › Enhance the existing system of networks to include all Medi-Cal physicians. The system should work closely with community organizations to provide patient navigation systems and education.
- › Identify areas of need for indigenous patient navigators and train them for culturally specific outreach and patient interaction.
- › Lobby local, state, and federal governments and health insurance carriers to increase funding for early detection, diagnosis, and treatment of breast cancer.



CHAPTER VII
PROSTATE CANCER

PROSTATE CANCER

GOALS

1. By 2010, reduce the prostate cancer mortality rate of California men, including men in high-risk groups, by 23 percent, from a baseline of 27.6 deaths per 100,000 men.
2. By 2010, improve the quality of life of men with prostate cancer and their families while creating measures to monitor and evaluate quality of life improvement.

OBJECTIVES

By 2010, provide all California men diagnosed with prostate cancer timely access to treatment programs and information that will help them make an informed choice among treatment options, including the risks, benefits, and the impact on their quality of life.

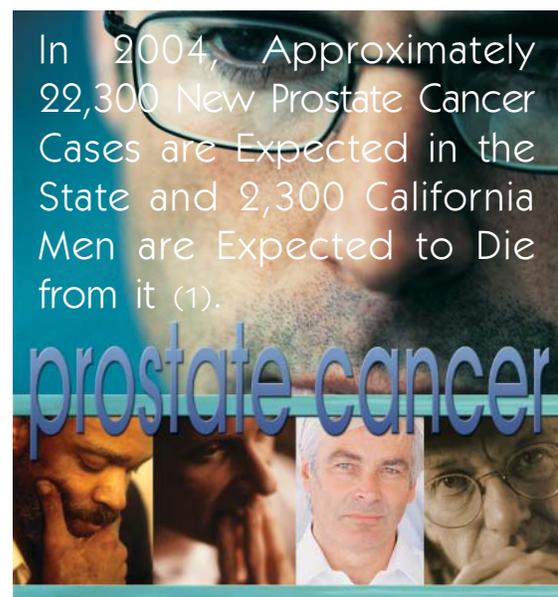
Background and Barriers to Achieving Goals and Objectives

Burden of Prostate Cancer

Prostate cancer is the most commonly diagnosed cancer in California excluding skin cancer. Among California men it is the second most common cause of cancer-related death.

Prostate cancer is common, but the five-year survival rate can be relatively high (at 98 percent) as reflected in data from the 2002 NCI Surveillance, Epidemiology, and End Results (SEER) program. The prostate cancer mortality rate has dropped 20 percent over the past five years, even among African American men who are hit the hardest by this disease. The reason for the 20 percent decline in prostate cancer deaths over the past five years is unclear, although it has

42



been suggested that the previous successful efforts at early detection of prostate cancer may be a contributing cause (1, 48).

Producing a 23 percent reduction in the prostate cancer mortality rate by the year 2010 is definitely a challenge. There are many factors that affect this mortality rate:

- › Lack of prevention information,
- › Lack of a comprehensive early detection program and consistent message,
- › Treatment of late stage and disseminated cancers is frequently ineffective,
- › Lack of universal access to treatment, and
- › Because prostate cancer can be both slow growing and aggressive in nature, the results of treatment and research take years to assess.

Each of these factors needs to be addressed in order to lower the mortality rate of prostate cancer by 2010 and beyond.

Men at Risk and Disparity in Burden

About 75 percent of prostate cancers are diagnosed among men age 65 and older with a median age at diagnosis of 71 years. Only about 12 percent of the U.S. population is age 65 years and older, but as the population ages, this proportion will increase as will the number of prostate cancer diagnoses (1, 45).

African-American men experience by far the highest incidence of prostate cancer of any ethnic group, and are diagnosed at a younger age and later stage of the disease compared to other racial ethnic groups. Although they have seen a 20 percent decline in mortality, they are 65 percent more likely to develop this disease than non-Hispanic white males, twice as likely as Hispanic/Latino men, and three times more likely than Asian/Pacific Islanders (1).

The precise underlying causes of prostate cancer are unknown, but may involve diet, lack of physical exercise, and other lifestyle factors when one looks at differences among cases and the general population worldwide (45).

Screening and Early Detection

In the 1990s, the incidence of prostate cancer increased significantly with the introduction of the prostate-specific antigen (PSA) test that led to an increase in diagnoses. As a direct result of this, incidence rates rose dramatically and peaked in 1992-1993 when the PSA test became more widely used. Rates have decreased since then and are now relatively stable. In all probability, the rise of incidence is attributable to increased screening versus increased risk of the disease (48). Thus the rise in incidence was, in effect, largely a screening artifact.

In 2001, 75 percent of men 50 years of age and older reported having had at least one PSA test. Most of these men were African American and non-Hispanic white men as opposed to Hispanic/Latino and Asian American men. Household income, however, played a discriminating role. Men of all ethnic groups, including non-Hispanic white men, from households above 200 percent of the federal poverty level were more likely to have had a PSA test than men from households below the poverty level (1).

The ACS suggests that men at high risk, such as those with a family history of prostate cancer (two or more affected first-degree relatives) and African American men, get a PSA test and digital rectal examination (DRE) every year beginning at age 45. Other lower risk men need to tailor their screening needs in consultation with their primary care physician.

The Prostate Screening Dilemma

The literature does not clearly establish (using randomized clinical trial data as the gold standard) whether a decrease in mortality from prostate cancer occurs with screening by DRE or the PSA test. Thus, the issue of screening remains controversial, particularly for asymptomatic men.

In 2002, the U.S. Preventive Services Task Force stated that the evidence is insufficient to recommend for or against routine screening for prostate cancer using the PSA test or DRE (46). The apparent value of the PSA test is in its simplicity, objectivity, reproducibility, lack of invasiveness, and relatively low cost.

Despite this prostate screening dilemma, a great deal of screening for prostate cancer is occurring and, therefore, the discrepancy between the state of the science and the state of the practice needs to be reconciled in some rational fashion. The state of the practice regarding prostate cancer screening by PSA unfortunately exceeds what perhaps can be justified by the state of the science.

Treatment

The ability to diagnose prostate cancer is a mixed blessing. Even though it can now be identified early in the course of the disease in some cases, the options for treatment may or may not result in an increase in a man's life span, and may significantly affect his quality of life.

The most common treatments for prostate cancer are surgery, radiation, and hormone therapy. There are also other treatments including cryosurgery and "expectant therapy" (watching and waiting). Treatment, however, depends on age, stage of the cancer at diagnosis, and other medical conditions of the patient as well as his quality of life concerns.

A major problem that accompanies a diagnosis of prostate cancer is the array of treatment options from which a man must choose. At diagnosis, men are often not given complete, unbiased and accurate information about the benefits and risks of their treatment options and the potential impact on their quality of life. This lack of benefit vs. risk translation may leave men confused and feeling a loss of control over their lives and their future (51).

Unfortunately, treatment options presented to a man often reflect the biases of the physician he happens to see first. Men newly diagnosed need a coordinated multidisciplinary approach with treatment options and their rationale presented openly, objectively, and in a forthcoming manner. Optimally his partner should be included in the discussion. Ultimately, the man should be the one who makes a truly informed decision.

Quality of Life

Although many men may be ill-informed about their treatment options, this can and should be changed. Serious quality of life issues that can emerge with some of the treatments include issues of diminished sexuality, impotence, incontinence, and other side effects. These must be addressed with sensitivity - both culturally and otherwise - and include the men's partners and families as well.

Men also need consistent help to navigate the health care system and to obtain the necessary resources for themselves and their families that can support a good quality of life from diagnosis through the balance of their lives (4). The Man to Man program of ACS and Us Too! are good examples of community support programs that offer men and their families the opportunity to speak openly with each other and with health professionals.

Finally, the burden of pain, its management, and its relief are other major quality of life components that must be an integral part of any cancer care from diagnosis thorough end of life care (4). This is a particularly salient concern for advanced prostate cancer, because bone is the most common metastatic site and presents major pain management issues. The ACS estimates that one-third of people living with cancer suffer needlessly from significant pain. This too can and must change.

PROSTATE CANCER - STRATEGIES AND TACTICS

Top Strategies to Achieve Goals and Objectives:

1. By January 1, 2006, educate the public, health professionals, and policy makers regarding major issues relating to prostate cancer including its risks, treatment options and associated quality of life issues, fears, beliefs and perceptions about the cancer and its treatment, lack of trust in the health care system among diverse groups, the need for easier access to prostate cancer detection and care, and lack of accurate, unbiased information conveniently accessible to men within and outside the health care system.
2. By January 1, 2006, increase state funding for prostate cancer research that includes basic, translational, clinical, health services, quality of life, and outcomes research.
3. By January 1, 2006, ensure consistent funding of existing prostate cancer mandates and programs for the low income, uninsured, and underinsured, and ensure that programs are culturally and linguistically appropriate for ethnic communities.

Additional Strategies:

- › By January 1, 2006, encourage and support collaborative prostate cancer research among California cancer centers.
- › Encourage state provision/coordination of universal health care coverage for prostate cancer detection, diagnosis, treatment, recovery, and palliative care. This should be part of a larger effort to provide universal health care coverage for all Californians.
- › The same prostate cancer treatment should be available to all California men regardless of their insurance coverage.
- › Encourage multidisciplinary evaluation of prostate cancer patients.
- › Provide supportive interventions that include partners as part of disease management.
- › Bolster the CCR financially to obtain additional data about prostate cancer to aid decision-making and priority setting.
- › Develop a more comprehensive system to help prostate cancer patients navigate through the health care system and obtain resources for their own care and needs.
- › Encourage healthy diet and physical activity to help prevent prostate cancer.
- › Coordinate collaboration among prostate cancer volunteer organizations.
- › Create a statewide comprehensive prostate cancer resource guide.

Tactics for Implementing the Top Strategies:

Strategy 1

By January 1, 2006, educate the public, health professionals, and policy makers regarding prostate cancer including its risks, treatment options and quality of life, fears, beliefs and perceptions about the cancer and its treatment, lack of trust in the health care system among diverse groups, the need for easier access to prostate cancer detection and care, and lack of accurate, unbiased information conveniently accessible to men within and outside the health care system.

- › Develop a unified and uniform message on prostate cancer to distribute to health professionals in California.
- › Provide information and education to patients through NCI's Cancer Information Service and the ACS's National Cancer Information Center.
- › Develop a unified and uniform message on prostate cancer to distribute to public policy makers in California
- › Work with the American Board of Family Practice to educate primary care physicians about prostate cancer.
- › Encourage the DHS to develop a media campaign, culturally sensitive to all, about prostate cancer education.
- › Incorporate prostate cancer information in material provided to women about breast cancer.
- › Encourage collaboration among those groups interested in the disease to disseminate information about the prostate cancer.
- › Provide education about successful outcomes and treatment for localized prostate cancer.
- › Involve prominent figures, especially those with prostate cancer, to reach the public, e.g., George Foreman - "Real Men Get It Checked" campaign.

Strategy 2

By January 1, 2006, increase state funding for prostate cancer control research that includes basic, translational, clinical, and health services, quality of life, and outcomes research.

- › Restore funding for the California Department of Health Services Cancer Research Program. Seek funding for the infrastructure to implement the comprehensive cancer control plan.
- › Highlight the deficiencies in our knowledge of prostate cancer to policy makers.
- › Identify and aggressively seek funding from private sources for prostate cancer research and education.
- › Encourage organizations like the ACS to provide targeted research funding for prostate cancer.
- › Create an entity dedicated to raising funds for prostate cancer like the Susan G. Komen Foundation for breast cancer.
- › Seek state funding to bring California comprehensive and clinical cancer centers together and formulate a plan for collaboration.

Strategy 3

By January 1, 2006, ensure consistent funding of existing prostate cancer mandates and programs for the low income, uninsured, and underinsured.

- › Restore adequate funding for the state's Prostate Cancer Treatment Program, IMPACT: Insuring Access, Counseling and treatment for Californians with Prostate Cancer.
- › Adequately fund existing prostate cancer mandated programs for the low income, uninsured, and the underinsured.