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# Welcome to the Colorado Cancer Plan 2010-2015

In Colorado, cancer is the second leading cause of death. Colorado's rate of cancer is too high. Cancer prevention and control activities must remain a priority. The Colorado Cancer Coalition is pleased to present to you the Colorado Cancer Plan. The Colorado Cancer Plan is a critical document that guides our state in making decisions based on cancer prevention, control and care priorities.

Colorado's plan to alleviate the burden of cancer must involve many sectors of our society, including state government, local public health, nursing, medicine, researchers, religious groups, schools and local communities. No agency, profession, service group or foundation can solve this problem alone. Key partnerships are essential. This plan is intended to be a living breathing document, used by organizations both big and small. This plan should be a well-used and essential tool for communities to create, implement, and continue activities that will result in a reduction of cancer incidence and mortality throughout Colorado.

# A Quick Note About Language Use

Labels of racial/ethnic groups are used throughout this plan. The term "white" refers to the standard data collection category of white/non-Hispanic. The term "Hispanic" refers to the standard data collection category of white/Hispanic. The term "black" refers to Blacks, Black/ Hispanics and others who identify themselves in this manner. The Colorado Cancer Coalition recognizes the difficult issue of using labels with regard to racial/ethnic groups.

It is difficult to gain a consensus on the preference of categories such as "people of color/minority community," "American Indian/Native American," "Black/African-American," "Hispanic/Latino (a)," and "Caucasian/white."

We acknowledge that not everyone identifies himself or herself with these categories, and we very much respect the importance of cultural differences in how communities prefer to be defined.

In this plan, many health indicators will be categorized by race and ethnicity. In accordance with the Centers for Disease Control and Prevention, the Colorado Cancer Coalition also recognizes that race and ethnicity are social constructs representing distinct histories and cultures of groups within the United States, and that they are not necessarily distinct biological or genetic categories.

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# INTRODUCTION

# About the Plan

Colorado Cancer Plan objectives for reducing the cancer burden in Colorado are based on Colorado surveillance data, national objectives and issues unique to Colorado. Recommended strategies cover cancer mortality, health disparities, primary prevention, secondary prevention, treatment, rehabilitation, quality of life and surveillance.

Although the reasons for declining cancer rates are multifaceted, the efforts of the Colorado Cancer Coalition play an integral part. The Colorado Cancer Plan goals are to reduce cancer mortality and to influence selected behaviors that relate to cancer mortality. This new set of goals, objectives and strategies is intended as a framework for continued improvements through 2015. Goal setting was completed by consensus among the Colorado Cancer Coalition members working in task forces and public comment from you.

The Colorado Cancer Coalition believes that defining these cancer goals, objectives and strategies will help to empower all of us in Colorado's fight against cancer. New additions to this iteration of the Colorado Cancer Plan include: a chapter dedicated to Pediatric Cancer and enhancement of discussion of Genetics.

The primary purposes of the Colorado Cancer Plan are to:

- \* Promote the collection and use of information about cancer.
- \* Improve healthy behaviors.
- \* Increase screening rates.
- \* Improve access to the full spectrum of cancer diagnosis and care.
- \* Reduce disparities to achieve health equity.
- \* Improve the quality of life of cancer survivors.
- \* Set targets to improve cancer prevention and control.
- \* Support policies to facilitate these efforts.

Thank you for using the Colorado Cancer Plan and thank you for your interest, support and commitment to preventing and reducing the impact of cancer in Colorado.

# Overview

The Colorado Cancer Coalition (CCC) is a consortium of organizations and individuals with interests in the prevention and control of cancer in Colorado.

## The Goals of the Colorado Cancer Coalition Include

- \* Promoting the collection and use of information about cancer
- \* Improving healthy behaviors
- \* Increasing screening rates
- \* Improving access to the full spectrum of cancer diagnosis and care
- \* Increasing health equity
- \* Setting targets to improve cancer prevention and control
- \* Supporting policies to facilitate these efforts

The goals of the Colorado Cancer Plan are to target risk factors and further reduce mortality. In addition, these goals aim to lessen, and eventually eliminate, the disparities in cancer in Colorado.

The CCC places great emphasis on aligning our goals and objectives with our national partners. The National Comprehensive Cancer Control Program at the Centers for Disease Control and Prevention developed the following priorities to be a compass and, like the Colorado Cancer Plan, to be a living document. As the comprehensive cancer control environment evolves and changes, these priorities will be modified accordingly. The National Comprehensive Cancer Control Program priorities include:

- \* Emphasizing the primary prevention of cancer
- \* Coordinating early detection and treatment activities
- \* Addressing the public health needs of cancer survivors
- \* Using policy, systems and environmental changes to guide sustainable cancer control
- \* Promoting health equity as it relates to cancer control
- \* Demonstrating outcomes through evaluation

# History

In 1996, the CCC published the original "Colorado Cancer Prevention and Control Plan 2000." Statewide goals for reductions in cancer death rates for the Year 2000 were defined in the mid-1990s by the CCC based on cancer death rates and trends from the late 1980s to the early 1990s.

This publication assisted cancer prevention and control partners with focusing agreed-upon goals to reduce cancer mortality for all Colorado citizens. The plan included objectives and suggested strategies to reduce cancer mortality, increase surveillance activities, increase primary and secondary prevention efforts, and address the availability of appropriate cancer treatments.

Most of those goals were met or exceeded by the successes in cancer prevention, early

detection, and improved treatment across Colorado. Reductions in death rates between 1991 and 1998 for the major cancer sites were striking. In that seven-year period, breast cancer death rates declined by 29.3%, prostate cancer death rates declined by 27.5%, colorectal cancer death rates declined by 15.7%, and lung cancer death rates declined by 8.8%.

In 2000, the Colorado Cancer Coalition established goals for the Year 2010, which led the effort to update the Colorado Cancer Plan for 2005. This 2005 report included data on cancer incidence and mortality, and described risk factors, screening guidelines, prevention strategies, and treatment recommendations.

Cancer death rates continued to decline from 1998 to 2007. In that nine-year period, breast cancer death rates declined by 19.7%, prostate cancer death rates declined by 7.7%, colorectal cancer death rates declined by 23.8%, and lung cancer death rates declined by 11.1%.

The Colorado Cancer Plan 2010-2015 objectives for reducing the cancer burden in Colorado are based on Colorado surveillance data and the national objectives, as well as issues unique to Colorado. Objectives and their recommended strategies cover cancer mortality, health disparities, primary prevention, secondary prevention, treatment, rehabilitation, quality of life, and surveillance.

Although the reasons for declining cancer rates are multifaceted, the efforts of the Colorado Cancer Coalition play an integral part. The Colorado Cancer Plan goals are to both reduce cancer mortality and to influence selected behaviors that relate to cancer mortality. This new set of goals, objectives, and strategies is intended as a framework for continued improvements by Year 2015. Goal-setting has been created by consensus among the Colorado Cancer Coalition members. These goals and objectives take into account the history and experiences of cancer control in Colorado. The Colorado Cancer Coalition believes that defining these cancer goals, objectives and strategies will help to empower all of us in Colorado's fight against cancer.

# Risk Reduction

Cancer is the second leading cause of death in Colorado. Lifestyle, genetic and non- genetic factors, independently or in combination, can increase an individual's risk of developing cancer. Changes in lifestyle, including reduction in tobacco use and modification of the diet to reduce fat and increase fiber consumption, and early detection and intervention, can significantly reduce mortality from some cancers. Reductions in cancer incidence achieved through risk factor interventions may also reduce cancer morbidity and mortality.

Screening interventions that result in early detection will have a proportionally greater impact upon cancer mortality, because cancer is more likely to respond to treatment when detected

at an early stage. Screening interventions continue to need support. Mammography screening has led to increased early detection and treatment of breast cancer. Endoscopic and fecal occult blood testing, if more widely used, could further decrease mortality from colorectal cancer. The Pap test continues to be a powerful tool for early detection of pre-malignant lesions and cervical cancer in women.

- \* Eliminating tobacco use can decrease the risk for pancreatic, kidney and urinary bladder cancer, as well as for the more familiar lung, colorectal, head and neck, and cervical cancers. Higher-than-moderate alcohol intake can increase the risk for breast, esophageal, and head and neck cancers.
- \* High dietary fat can increase the risk for colon, gallbladder, prostate and breast cancer. Increased fiber, fruit and vegetable consumption may decrease the risk for colon cancer. Regular exercise may decrease the risk of breast and colon cancer.
- \* The Colorado Cancer Coalition would like to ensure that the Colorado public is aware of the beneficial impacts that lifestyle changes have on reducing cancer.

Additional determinants of cancer include genetics and environmental exposures. An individual's genetic background can also be a determinant of cancer risk. It is important to understand that about 5-10% of cancers are related to genetic predisposition. An increased risk for colorectal, breast, prostate, ovarian, and thyroid cancers, as well as malignant melanoma, exists for persons with first- degree relatives with a history of these respective types of cancer. Women who have BRCA1 and BRCA2 gene mutations are at an increased risk for breast and ovarian cancer. The CCC would like to heighten general awareness of these factors.

Testing and mitigation of radon exposure, because of its effect on lung cancer risk, are ongoing processes in the state.

# Incidence

In 2007, 19,592 Coloradans were diagnosed with cancer. Colorado continues to have lower incidence and mortality rates of cancer than the nation. The Colorado Cancer Plan relies on the Colorado Central Cancer Registry for incidence information.

The cancer incidence rates for Colorado and the nation have been decreasing since 1992. The population of Colorado has been getting older, with a median age of 26.2 in 1970, 32.5 in 1990, 34.3 years in 2000 and 35.8 in 2008. Among men and women, men have a higher incidence of cancer (512.9/100,000) than women (388.5/100,000). The incidence of lung cancer in Colorado males is more than 30% higher than that of females.

Among racial groups from 2002-06, non-Hispanic white men had the highest cancer incidence rate, followed in order by black men, white Hispanic men, white non-Hispanic women, white

Hispanic women and black women.

The incidence of cervical cancer in Hispanic women was nearly twice that for white non-Hispanic women and 22% higher than that for black women.

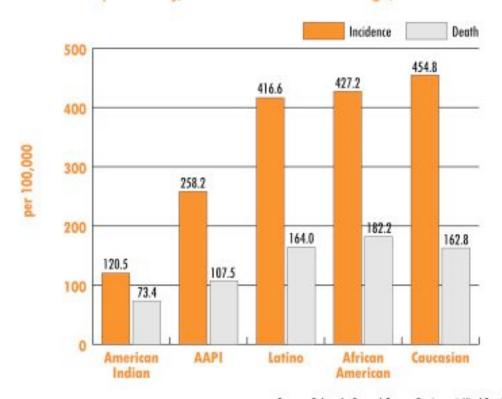
Across groups, the lung cancer incidence rate in black males was 1.8 times the rate for black women, and the lung cancer incidence rate for Hispanic men was 5 times the rate for Hispanic women.

The incidence or prostate cancer in black men was 28% higher than the rate for non-Hispanic whites and 50% higher than the rate for Hispanics.

Colorectal cancer was diagnosed in Hispanic men almost 50% more often than in Hispanic women and 24% more often than in non-Hispanic white men.

Incidence for American Indian (AI) relies on national incidence data. More than half of the Colorado AI population is from Northern and Southern Plains, rates of breast, cervical, colorectal and prostate cancers remain high in these populations.

# Colorado Age-Adjusted Cancer Incidence and Death Rates by Race/Ethnicity, Five-Year Annual Average, 2003-07



Source: Colorado Central Cancer Registry & Vital Statistics

# Prevalence

There are nearly 200,000 Coloradans alive with active cancer or a history of cancer. For individuals recently diagnosed with cancer, 6 of 10 will live five years or longer overall. However, survival varies substantially for different types of cancers. For those diagnosed between 2000 and 2003, 94% of men with prostate cancer survived five years or more, while 89% of women with breast cancer survived at least that long. Only 44% of women with ovarian cancer survived five years or longer.

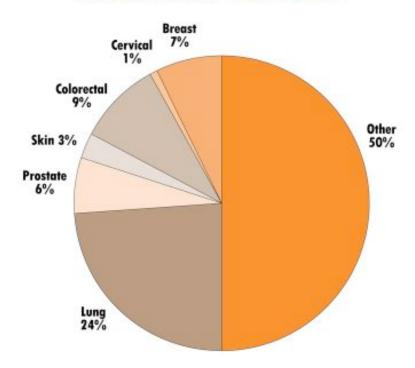
# Mortality

Each day, 18 Coloradans die from cancer. There were a total of 6,709 cancer deaths in 2008. The cancer mortality rate for Colorado in 2007 was 158.5 per 100,000 population, considerably lower than for the nation, which was 181.1 per 100,000 population in 2006 (both rates age-adjusted

to the 2000 U.S. population).

By gender, males have a considerably higher cancer mortality rate than females. In Colorado, the cancer mortality rate for men was 196.2 deaths per 100,000 population versus 135.0 per 100,000 population for females. There are racial differences as well, with blacks having higher cancer mortality rates than non-Hispanic whites, and Hispanics having lower cancer mortality rates than non-Hispanic whites. For specific cancer sites, there also are gender and racial

# **Colorado Cancer Deaths 2007**



Source: Health Statistics Section, Colorado Department of Public Health and Environment

differences. For lung cancer in women for 2002-06, rates for Hispanics were 24% lower, than rates for non-Hispanic whites. For lung cancer in men, rates for blacks were 27% higher, and rates for Hispanics were 15% lower than rates for non-Hispanic whites. The cervical cancer

incidence rate for white Hispanic women was nearly twice that for non-Hispanic white women and the mortality rate was 35% higher for Hispanic women. Black men had nearly twice the mortality rate for prostate cancer, and a 43% higher colorectal cancer mortality rate, compared to non-Hispanic white men.

### EACH DAY, 18 COLORADANS DIE FROM CANCER

Because more than half of the Colorado American Indian population is from Northern and Southern Plains at least include the data from those sections. In the AI population, breast cancer age-adjusted mortality (adjusted to 2000 US Population) are highest among Alaska Natives (21.2), Northern Plains (20.3), and Southern Plains (18.0).

# Top Cancers in Colorado

	By Mortality: (2008)	By Incidence: (2003-2007)
#1	Lung	Breast
#2	Colorectal	Prostate
#3	Breast	Lung
#4	Prostate	Colorectal
#5	Pancreas	Melanoma
#6	Non-Hodgkin Lymphoma	Non-Hodgkin Lymphoma
#7	Leukemia	Bladder
#8	Ovarian	Kidney
#9	Brain	Leukemia
#10	Multiple Myeloma	Thyroid

Source: Colorado Central Cancer Registry and Health Statistics Section, CDPHE

# Terminology

The following are common terms that are used throughout this plan.

#### **AGE-ADJUSTMENT:**

Facilitates comparison of rates between two or more populations that have different age distributions (the percent of individuals in each age group). Age-adjustment may be accomplished by the direct method (by applying rates from the study population to a defined standard population), or the indirect method (by applying standard rates to the study population distribution).

#### CANCER:

A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissue and can spread through the bloodstream and lymphatic system to other parts of the body.

#### CANCER SCREENING:

Checking for changes in tissue, cells, or fluids that may indicate the possibility of cancer when there are no symptoms.

#### **CARCINOMA:**

Cancer that begins in the epithelial tissue that lines or covers an organ. Clinical Trials: Research studies that evaluate the effectiveness of new treatment or disease prevention methods on patients.

#### COLONOSCOPY:

An examination of the rectum and entire colon using a lighted instrument called a colonoscope. A colonoscope allows the physician to remove polyps or other abnormal tissue for examination under a microscope.

#### COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM):

Also referred to as integrative medicine, CAM includes a broad range of healing philosophies, approaches, and therapies. A therapy is generally called complementary when it is used in addition to conventional treatments; it is often called alternative when it is used instead of conventional treatment (conventional treatments are those that are widely accepted and practiced by the mainstream medical community.) Depending on how they are used, some therapies can be considered either complementary or alternative.

#### DIGITAL RECTAL EXAM (DRE):

A test in which the health care provider inserts a lubricated, gloved finger into the rectum to feel for abnormal areas of the prostate. Fecal Occult Blood Test (FOBT): A test to check for small amounts of hidden blood in stool.

#### **GRADE:**

A system for classifying cancer cells in terms of how abnormal they appear under a microscope. The grading system provides information about the probable growth rate of the tumor and its tendency to spread. The systems used to grade tumors vary with each type of cancer. Grading plays a role in treatment decisions.

#### HEALTH DISPARITIES:

Differences or inequalities in health between different populations. Health disparities have often been reported for different races or ethnicities.

#### INCIDENCE RATE:

The number of new cases of cancer diagnosed in one year per 100,000 persons in the population.

#### INVASIVE CERVICAL CANCER:

Cancer that has spread from the surface of the cervix to tissue deeper in the cervix or to other parts of the body.

#### MALIGNANT:

Cancerous.

#### MAMMOGRAM:

An x-ray of the breast.

#### MELANOMA:

Cancer of the cells that produce pigment in the skin.

### MORTALITY RATE:

The number of people who died from a specific cancer in one year, expressed as the number of deaths per 100,000 persons in the population.

#### PAPANICOLAOU (PAP) TEST:

Microscopic examination of cells collected from the cervix. The Pap test is used to detect cancer, changes in the cervix that may lead to cancer, and non-cancerous conditions, such as infection or inflammation.

### PSA (PROSTATE-SPECIFIC ANTIGEN) TEST:

A test that measures the level of an enzyme (PSA) in the blood that increases due to diseases of the prostate gland, including prostate cancer.

#### RELATIVE SURVIVAL RATE:

The ratio of the calculated observed survival rate for patients with a particular cancer to the expected survival rate for the general population. An assumption in using this statistic is that the presence of cancer is the only factor that is different for the two groups (all other characteristics are identical).

#### RISK FACTOR:

Something that increases a person's chance of developing a disease.

#### SIGMOIDOSCOPY:

A procedure in which the physician or health care provider looks inside the rectum and the lower part of the colon (sigmoid colon) through a flexible lighted tube. During the procedure, the physician or health care provider may collect samples of tissues or cells for closer examination.

#### SOCIOECONOMIC STATUS:

A term used to classify an individual or population based on one or more indicators, such as income, assets, employment, occupation, and education.

#### **SQUAMOUS CELLS:**

Flat cells that look like fish scales. These cells are found in the tissue that forms the surface of the skin, the lining of the hollow organs of the body, and the passages of the respiratory and digestive tracts.

#### STAGE AT DIAGNOSIS:

Tumors are categorized according to the extent of spread of disease. Tumors also are described as carcinoma in situ, non-invasive, or high-grade dysplasia. These categories

include neoplastic changes that precede the spread of fully developed cancers. Traditionally, cancers are staged as:

### LOCAL:

The tumor is confined to the organ of origin

#### **REGIONAL:**

The tumor has extended beyond the organ of origin or involves local lymph nodes

#### DISTANT:

The tumor has spread to other vital organs

#### YEARS OF POTENTIAL LIFE LOST:

The number of potential years of life lost by each cancer death occurring before age 75.

# HEALTH EQUITY

# Overview

"Health Equity...is when everyone has the opportunity to "attain their full potential" and no one is "disadvantaged from achieving this potential because of their social position or other socially determined circumstance."

- Centers for Disease Control and Prevention

This opportunity for good health is not uniformly available across Colorado and the United States due to unequal access to quality health care services, safe neighborhoods, affordable healthy food, non-toxic environments and racial/ethnic equality. This unequal access to the necessary elements of what leads to good health is referred to as "health inequity."

This chapter, formally titled "Health Disparities," has been renamed to reflect the growing

consensus supporting our imperative to reduce preventable differences in health outcomes resulting from unjust systemic problems and practices. These differences in health status and health outcomes among socioeconomically underrepresented groups of people experienced over time are known as health disparities. Inequities in health outcomes, such as cancer incidence, stage at diagnosis, survival, mortality and quality of life, are shown to exist across the entire range of social groups. The interrelation of race/ethnicity, socioeconomic status (SES), education level, insurance status, quality health care access, behavioral choices, immigrant status, language and literacy, geographic place of residence, environmental issues, disability status, age, sex and sexual orientation, all contribute to inequalities in cancer health care. These factors, among others, form a complex set of interactions that influence the outcome of cancer health care in a way the



disproportionately affects minorities living in Colorado and throughout the United States.

"Health equity cannot be achieved without addressing the health of all racial and ethnic groups. There is a powerful link between social factors and health. Social and economic policies have a direct impact on the health and well-being of those who live and work under those policies. Interventions and policies that purport to promote health must be based on evidence and result in action, and they must address daily living conditions and issues related to power, money and resources." - 2010 National Plan for Action: Changing Health Outcomes- Achieving Health Equity; National Partnership for Action, U.S. Department of Health & Human Services

Approaches to reducing cancer health inequities must consider the complexity of these factors and should address as many of them as possible simultaneously. For example, while we know that poverty plays a major role in cancer detection and survival rates for Coloradans, an intervention only including financial assistance in accessing health care would not be sufficient to change cancer outcomes because of the impact of additional factors, including health beliefs, health literacy and health service use.

### What Does This Mean?

#### **INCIDENCE:**

The frequency with which something, such as cancer, appears in a particular population or area. The number of newly diagnosed cases occurring during a specific time period.

#### **DEATH RATE:**

The number of deaths in the population divided by the average population (crude death rate).

#### SURVIVAL RATE:

To be determined (reference: MedicineNet.com)

Health inequities in Colorado and the United States are mostly experienced by poor communities, particularly communities of color. Cancer incidence and death rates in Colorado have been measured and reported for blacks (African Americans) and Hispanics (Latinos), showing that each bears an unequal cancer burden when compared to other ethnic groups, particularly whites (Caucasians). For example, the black population of Colorado has the highest lung cancer incidence rate of any population, the highest death rates for cancer overall, and the highest rates for lung, breast, colorectal and prostate cancers. When compared to other racial/ethnic groups in Colorado, Hispanic females have the highest incidence and second highest death rates of cervical cancer. Hispanic males have a higher incidence and death rate of colorectal cancer than males or females of any other race/ethnicity group in Colorado.

Nationally, American Indians and Alaska Natives (Al/AN) have the lowest five-year cancer survival rates of any population in the United States. Similarly, Asian communities have some of the lowest cancer incidence and death rates. Asian women experience very high incidence and the highest death rates from cervical cancer. In Colorado, this issue is compounded by the relatively small numbers of individuals among certain groups who have cancer, the misclassification of race/ethnicity, and data collection and reporting challenges. Institutional challenges in measuring and reporting cancer outcomes in these populations can stymie the

ability to understand the impact of cancer on these groups and design and fund interventions to reach them.

# Social Determinants of Health that Affect Cancer Inequities Across the Cancer Continuum

## Race/Ethnicity

Epidemiological research has found factors associated with race/ethnicity that affect health status and risk, but are independent of biological differences among groups. Historical and current discrimination in the nation's political, economic and social institutions and systems represent some of the determinants of racial/ethnic health disparities. Inequity can be found in the educational system, labor and housing markets, credit and lending institutions, and health care systems. Even bias that is unintentional on the part of medical researchers or providers is potentially harmful. Underlying bias has been shown to result in under-treatment and different treatment recommendations of black adults for particular medical conditions. Analysis of national data-sets have shown that particular groups receive cancer treatments at later times or not at all.

### Education

In Colorado, school-age children of color score significantly lower than white (Caucasian or white, non-Hispanic) children on standardized tests. Gaps in high school graduation rates between white students and students of color are greater than in many other states. Post high school education attainment is lower among black and Latino youth. American Indian data are unmeasured or unknown. The impact of lower educational attainment is profound and long-lasting. Education influences job attainment, income potential, work site benefits and occupation. In addition, a person's ability to read, understand and act on medical information and instructions is hampered at lower educational levels.

Lastly, an important component of health equity work is to diversify the public health and medical services workforce. Increased educational attainment at the post-secondary level is necessary for work in all sectors of the health care industry from medical assistants to public health and research.

#### Income

Income strongly influences health for all people. As income increases, the percentage of people reporting fair or poor health decreases. In all domains, economic disparities limit people's ability to be healthy, both directly (e.g., lacking money to buy medicine) and indirectly (e.g., emotional stress from coping with chronic financial instability). An updated report entitled "Cancer & Poverty in Colorado 1995 - 2006", prepared by the Comprehensive

Cancer Program of the Colorado Department of Public Health and Environment, reveals a stark difference in cancer stage at diagnosis and survival of Coloradans by neighborhood poverty level. The report highlights the reality that Colorado, like the nation as a whole, shows a link between cancer outcomes and poverty. The report delineates two of the social determinants of cancer-related health disparities: race/ethnicity and poverty. Another important element is wealth. Wealth measures assets and the ability of an individual to accumulate property, such as real estate, savings and investments. Wealth can protect individuals and families from life's emergencies, hardships and economic cycles. Particular communities of color have been locked out of the ability to accumulate wealth due to discriminatory practices in home ownership, small business lending and other means to accumulate assets, wealth and protection against poverty.

# **Employment**

Unemployment rates in Colorado are higher for all racial/ethnic minority groups than for the majority population. Unemployment can affect health through a loss of income and health insurance and can cause great mental anguish – all factors that can delay or prevent the detection of cancer at an early stage, when it is most treatable. Because of educational disparities and opportunity limitations, workers of color are under-represented in professional positions and over-represented in manual labor and service jobs that pay less and are much less likely to provide health coverage. Additionally, growing occupational health research indicates that workers of color may disproportionately work in unsafe and unhealthful conditions without proper training, protections or notification of risks.

#### Insurance

Racial/ethnic minority populations in Colorado lack health insurance at higher rates than the majority population. The Hispanic population experiences the highest uninsured rate, with one in four Latinos lacking coverage. The immigrant population, both documented and undocumented, is less likely to receive employer or publicly provided health care. Underinsurance refers to having insurance that does not adequately cover health care costs or has limited benefits. Under-insurance affects access when policies do not cover pre-existing conditions, when co-payments and deductibles cause delays in care, or when certain categories of benefits, such as cancer prevention and early detection services, are not covered.

### **Cultural Beliefs**

Culture is not the same as race/ethnicity, although cultures and cultural beliefs may exist within racial or ethnic groups. Cultural beliefs about health and illness can impact the communication style and relationship between patient and provider in the health care setting. Health care professionals sometimes lack the cultural awareness, sensitivity, cultural competence and training to communicate effectively with people of diverse backgrounds. A

lack of cultural competence on the part of health care providers can negatively affect the care of patients and cause adverse health outcomes that widen the gap in health disparities experienced by communities of color.

A perfect example is seen in American Indian cultures. There are more than 560 federally recognized tribes, with more than 200 different tribes reported to the 2000 Census for Colorado and approximately 100 different tribes reported to the 2000 Census for the Denver metro area. Despite being considered as one American Indian ethnic group, cultural beliefs among these tribes are very diverse.

Cultural beliefs also affect how communities perceive public health messages about disease prevention and health promotion. Sometimes community beliefs are labeled as fatalism, which is often based on real experience. Racial/ethnic communities may be unaware of the strengths and weaknesses of traditional dietary or behavioral choices or other customs. More must be understood about the impact of various cultural beliefs and practices on cancer in order to build upon positive influences and address areas of concern with sensitivity and respect. The field of cross-cultural communication provides communication models for respectful negotiation between the health care provider perspective and the cultural beliefs of the patient.

### Language & Health Literacy

Language barriers may contribute greatly to cancer-related health disparities among people whose primary language is not English. Language factors can delay and/or inhibit access to cancer services, such as prevention, early detection, treatment and quality of life care. Challenges may include lack of information about available services, fear of jeopardizing immigration status, communicating in prevention and treatment settings and comprehending the U.S. health care system. Patients may not know understand printed health information that is not culturally or linguistically relevant or be aware of their right to an interpreter.

### What Does This Mean?

#### HEALTH LITERACY:

The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (Institute of Medicine).

Difficulty in understanding medical terms and navigating the health care system is not unique to non-English speakers. Our health care system has its own culture, language and norms. English-speaking patients often need assistance in making sense of health care instructions, prescriptions, appointment scheduling and other information. Health literacy is the ability to understand and act on the information related to health and health care. About 36% of US

adults have a basic or below basic level of health literacy, according to the 2003 U.S. Department of Education National Assessment of Adult Literacy. This means that a third of American adults would have difficulty understanding most information we use in public health, clinics and hospitals. Instructions, materials and prescription information would be too difficult to understand for a third of all adults. According to the IOM, most people read two grade levels lower than the highest grade they completed. While ethnic minorities are disproportionately represented in low literacy levels, American-born white adults represent the largest number of people in low literacy groups. Tackling health literacy benefits all patients and helps to increase health equity across racial/ethnic and socio-economic groups because of the connection between health literacy, safety and health care quality.

### Environment

Physical environment, such as living in substandard housing, unsafe neighborhoods or areas with more environmental toxins can contribute to health inequities.

### Urban

Ongoing issues in certain urban neighborhoods include access to healthy foods or safe places for physical activity and close proximity to industrial centers, major highways and high-crime areas. Groups impacted by disparities reside in these neighborhoods. There are fewer grocery stores where fresh fruits and vegetables are available at a reasonable price. Many families depend on corner convenience shops that primarily sell processed food high in carbohydrates and salt and low in nutritional value. In regard to the physical activity, poorer areas have fewer community recreation centers and even fewer sidewalks, a must for safe neighborhood activity.

#### Homelessness

African Americans/Blacks and American Indians are overrepresented in the Colorado homeless population. Homeless patients experience multi-leveled barriers to cancer screening, treatment and survivorship services. One classic example is that not having a postal address makes it difficult to apply for and obtain basic benefits, like those available for veterans. Social Security, Medicaid and other benefit programs.

### Rural

People living in remote areas can experience difficulty accessing health care due to lack of health care providers, transportation barriers, and financial and unemployment issues. For example, uncontrolled diarrhea, a side effect of cancer treatment, is made more difficult when the only transportation option is a long bus ride.

Immigrant and refugee communities are found throughout rural Colorado. Rural providers and

the public health and educational system face linguistic and cultural challenges in delivering the same level of service experienced in diverse urban environments.

# Objectives: Health Equity

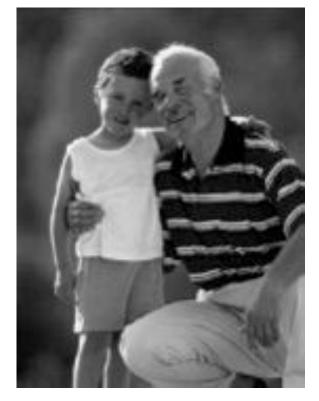
# Health Equity 1

INCREASE PUBLIC AND PROFESSIONAL AWARENESS ABOUT CANCER-RELATED HEALTH INEQUITIES EXPERIENCED BY COLORADO POPULATIONS.

## Strategies:

Collaborate with government agencies, academic health centers, community and faith-based organizations, and private foundations to educate the public about topics relating to health equity and cancer.

- \* Educate policy makers, community, and health professionals about the overall financial burden of being a cancer patient or the family member of a cancer patient.
- \* Promote and support health care provider, medical school and School of Public Health curricula training on cancer disparities, including strategies that providers can incorporate into their practice to address and reduce disparities.
- \* Identify and disseminate a set of core competencies for health professionals regarding knowledge and understanding of the contributing factors to health disparities.
- \* Identify and disseminate a set of core competencies for health professionals aimed at increasing cultural competence among health professionals.



\* Convene a meeting of health care providers, cancer survivorship experts, researchers and programmatic staff to develop strategies to educate policy makers about the unmet needs for cancer screening and treatment for those that are uninsured and under-insured.

\* Utilize existing data tools that provide group level information in funding applications to identify health inequities at the local level. An example of a data tool is the Colorado Health Disparities Profiles.

# Health Equity 2

EXPAND CULTURALLY-RELEVANT AND PATIENT-CENTERED CANCER HEALTH EDUCATION, OUTREACH PROGRAMS, AND CANCER-RELATED INTERVENTIONS.

## Strategies:

- \* Develop, modify, implement and evaluate a clearinghouse of culturally, linguistically and literacy appropriate cancer education and promotion materials and resources in collaboration with relevant community-based organizations.
- \* Educate community members on how to access and evaluate available cancer information and resources and make appropriate to groups.
- \* Promote the development, dissemination, and evaluation of culturally relevant, linguistically competent cancer care guidelines to the general public via websites, portals, or other mechanisms.
- \* Promote and expand the use of both clinical and community health navigators in comprehensive cancer programs.
- \* Provide evidence-based education and promising educational practices on personal health and lifestyle behaviors that influence disease risk, including cancer risk. This education should access existing resources in the community such as families, schools and develop new resources when non-existent.
- \* Implement and evaluate interventions addressing lifestyle/behavioral and biological factors that increase cancer risk among disparate communities.
- \* Promote the use of the National Culturally and Linguistically Appropriate Services (CLAS) standards, including obligation to provide interpretation services.

# Health Equity 3

DEVELOP SPECIFIC STRATEGIES TO ADDRESS PATIENT ACCESS BARRIERS ACROSS THE CANCER CONTINUUM FOR UNDERSERVED COMMUNITIES.

# Strategies:

- \* Disseminate the results of existing needs assessment to identify patient access needs across the cancer continuum for medically underserved populations.
- \* Support the adoption of Patient Navigator and Community Health Worker models for use in a variety of settings to address barriers to access, culturally therapeutic compliance, services utilization, cancer risk management and health education.

- \* Identify and disseminate information on available resources for medically under-served communities.
- \* Ensure the availability of web-based educational and support interventions and systems to communities statewide at no cost to the public. Support, expand, and promote the availability of transportation services for cancer patients, particularly in rural areas. Transportation services need to be available throughout the cancer care continuum.
- \* Monitor and improve transportation assistance to cancer patients throughout the state. Ensure transportation assistance throughout the cancer continuum including survivorship phase (rehabilitation phase).



- \* Support the development of a certified lay health education model for use in a variety of settings to address barriers to access, culturally sensitive treatment compliance support, service utilization, cancer risk management and health education.
- \* Maintain, promote and evaluate patient navigation systems that can facilitate optimum cancer care throughout the continuum of cancer related health services.

# Health Equity 4

DEVELOP SYSTEMS AND INFRASTRUCTURE TO SUPPORT THE DELIVERY OF THE LATEST, MOST APPROPRIATE CANCER PREVENTION, EARLY DETECTION, TREATMENT, AND QUALITY OF LIFE CARE FOR UNDERSERVED COMMUNITIES.

## Strategies:

- \* Determine and utilize resources to identify and disseminate "best practices" and "promising practices" such as Cancer Control PLANET (http://cancercontrolplanet.cancer.gov/)
- \* Encourage the use of Patient Navigator and/or Community Health Worker training programs. Provide grant writing training and technical assistance to help disparate communities access funding streams and develop and/or access training programs.
- \* Create, monitor and expand capacity for cancer screening, diagnostic, and treatment services in rural Colorado.

- \* Implement increased use of mobile units in rural and under-served communities for evidenced-based cancer screening.
- \* Extend state-of-the art cancer care to rural, frontier, and other under-served areas by expanding the use of telemedicine and reinforce a reimbursement system that facilitates expansion of telemedicine to geographically under-served areas.
- \* Expand cancer data collection systems in the Colorado Central Cancer Registry to include socioeconomic status (e.g. level of education), disability, and primary language.

# Health Equity 5

EXPAND THE COLORADO WORKFORCE TO INCLUDE EQUITABLE REPRESENTATION OF INDIVIDUALS FROM GROUPS IMPACTED BY HEALTH DISPARITIES.

## Strategies:

\* Support mechanisms to encourage and enable individuals from groups impacted by health inequity to enter careers related to the achievement of health equity including public health, medicine, biomedical science, behavioral sciences and health communications.

\* Initiate training programs that create a diverse and culturally competent health care

workforce that is representative of the Colorado community it serves.

\* Support networks for college and graduate students pursuing health careers and financial incentives that will enable Native American health professionals to establish and maintain financially viable careers in rural areas.

- \* Increase patient education and access to participation in high quality clinical trials for low-income and uninsured or under-insured populations.
- \* Conduct and post an inventory of state and national resources such as federal training resources, private and local.
- \* Partner closely with the Colorado Public Health Association on efforts of student of color recruitment efforts for the public health education and careers.
- \* Encourage the growth of programs to support local development of a diverse cancer workforce at the medical,

nursing, pharmacy, rehabilitation and public health schools.



# Health Equity 6

DEVELOP, IMPLEMENT, AND EVALUATE PUBLIC EDUCATION INITIATIVES THAT FOCUS ON HOW CANCER INCIDENCE AND MORTALITY RATES IN COLORADO DIRECTLY CORRELATE WITH A PERSON'S BUILT ENVIRONMENT (THE PLACES A PERSON LIVES, WORKS AND PLAYS), WITH SOCIOECONOMIC STATUS, LEVEL OF EDUCATION ATTAINMENT, AND OTHER SOCIAL DETERMINANTS OF HEALTH.

### Strategies:

- \* Collect data illustrating ties to cancer incidence and mortality that are based on geographic location and poverty levels, in addition to other demographic information.
- \* Provide background knowledge and training to government agencies, policy makers, academic health centers, private foundations, and community and faithbased organizations on the issues surrounding environmental health inequities.
- \* Support community education efforts related to risk reduction measures.
- \* Collaborate with state agencies, community organizations, and other public health partners that promote policies to eliminate environmental health inequities.
- \* Align cancer control efforts with the State Tobacco Education and Prevention Partnership Strategic Plan.



# Health Equity 7

EXPAND THE DEVELOPMENT OF COMMUNITY-DRIVEN AND COMMUNITY-BASED PARTICIPATORY RESEARCH ON COLORADO DISPARITIES IN THE CANCER CARE CONTINUUM.

# Strategies:

\* Support efforts to identify key research questions, and enact (or test) strategies to eliminate health inequities, involving community members, researchers, policy makers, community agencies and state and local health care providers and public health departments.

- \* Encourage the dissemination of community-based participatory research cancer research, best practices and promising innovative interventions to eliminate cancer inequities.
- \* Involve the communities impacted by cancer inequities in the planning, implementation, analysis and dissemination of cancer research.
- \* Involve community organization and public health agencies in the development and dissemination of research results. Utilize existing opportunities to support linkages between research and community (i.e. CCTSI).

# **PREVENTION**

# General Cancer Risk & Risk Reduction

Cancer is the second leading cause of death in Colorado. Lifestyle, environmental and genetic factors, independently or in combination, can increase an individual's risk of developing cancer. Poverty continues to be an important factor that increases risk of getting cancer, of having cancer diagnosed at a later stage and of dying due to cancer in Colorado.

Lifestyles have the biggest impact on prevention and risk. Changes in lifestyle (including reduction in tobacco use, and diet modification to reduce fat consumption and increase fiber consumption), as well as early detection and intervention, can significantly reduce cancer mortality for some cancers. Reductions in cancer incidence achieved through risk factor interventions will reduce cancer morbidity and mortality. Screening interventions, that result in early detection will have a proportionally greater impact on cancer mortality since early-stage disease is more likely to be cured by treatment.

# Objectives: General Cancer Risk

# General Risk 1

INCREASE KNOWLEDGE OF THE BENEFITS OF SCREENING FOR THE EARLY DETECTION OF CANCER.

# Strategies:

- \* Disseminate information on the benefits of screening for early detection to the public and health care providers. Current evidence-based screening tests include:
  - Mammography for breast cancer
  - Endoscopy and/or fecal occult blood testing for colorectal cancer
  - Pap tests for cervical cancer
  - Skin self-examination and physical examination for skin cancer
- \* Other screening tests as developed
- \* Emphasize screening education in communities with identified inequities

## General Risk 2

INCREASE KNOWLEDGE OF CANCER RISK DUE TO SELECTED PREVENTABLE FACTORS.

# Strategies:

- \* Disseminate information on increased risk of:
  - Diets low in fruits and vegetables, as diet is related to 30% of all cancers
  - Breast, esophageal, and head and neck cancer with more-than-moderate alcohol use
  - · Colon and breast cancer with high dietary fat
  - Lung cancer with radon exposure
  - Lung, breast, cervical, kidney, head and neck, pancreas, colorectal and bladder cancer with tobacco use, from both primary and second-hand smoke exposure as tobacco exposure is related to 30% of all cancers
  - Skin cancer with ultraviolet exposure
  - Support programs increasing the general population's knowledge regarding familial risk, genetic testing and counseling, treatment options, and best practices.
  - Provide education to health care providers to increase use of appropriate family history risk assessment tools for individuals in the following high risk groups:

Personal History Of:	With Personal and/or Family History Of:
Breast Cancer	Breast Cancer, especially under age 50
	Male Breast Cancer
	Ovarian Cancer at any age
	Jewish Ancestry
	Non-medullary Thyroid Cancer
	Hereditary Breast/Ovarian Cancer (HBOC); Cowden Syndrome; Li- fraumeni Syndrome; or Neurofibromatosis type 1
	Inherited Mutations in BRCA1/2, PTEN, p53, or NF1 genes
	Colorectal and/or Endometrial Cancers, especially under age 60

Personal History Of:	With Personal and/or Family History Of:
Colorectal Cancer	Ovarian Cancer at any age
	Multiple Colon Polyps (10 or more on a single screening)
	Hereditary Non-Polyposis Colon Cancer (HNPCC, aka Lynch Syndrome); Familial Adenomatous Polyposis (FAP); or MYH- Associated Polyposis (MAP)
	Inherited Mutation in MLH1, MSH2, MSH6, PMS2, APC, OR MYH genes
	Breast Cancer, especially under age 50
Ovarian Cancer	Ovarian Cancer at any age
	Male Breast Cancer
	Jewish Ancestry
	Hereditary Breast/Ovarian Cancer (HBOC); Hereditary Non- Polyposis Colon Cancer (HNPCC, aka Lynch syndrome)
	Inherited Mutations in BRCA1/2, MLH1, MSH2, MSH6, or PMS 2 genes
Melanoma	Melanoma
Thyroid Cancer	Thyroid or Breast Cancer
	Multiple Endocrine Neoplasia type II; Cowden Syndrome
	Inherited Mutation in RET or PTEN genes
Prostate Cancer	Prostate Cancer
Endometrial Cancer	Colorectal and/or Endometrial Cancers, especially under age 60
	Ovarian Cancer at any age
	Hereditary Non-Polyposis Colon Cancer (HNPCC, aka Lynch Syndrome)
	Inherited Mutation in MLH1, MSH2, MSH6, or PMS2 genes

## General Risk 3

INCREASE KNOWLEDGE OF THE SIGNIFICANCE OF A FAMILY HISTORY OF CANCER AND THE USEFULNESS OF GENETIC TESTING.

### Strategies:

- \* Provide education to health care providers to increase use of appropriate assessment tools in the following high- risk groups:
  - Breast cancer in women with first- degree relatives with breast cancer, especially under age 50 and/or ovarian cancer at any age
  - Breast and ovarian cancer in women with BRCA1 and BRCA2 gene mutations
  - Colorectal cancer in persons with first- degree relatives with colorectal cancer, especially at age less than 60
  - Melanoma in persons with first-degree relatives with melanoma
  - Prostate cancer in men with first- degree relatives with prostate cancer
  - Thyroid cancer in persons with first- degree relatives with thyroid cancer or multiple endocrine neoplasia type II
- \* Support programs increasing the general population's knowledge regarding familial risk, genetic testing and counseling, treatment options, and best practices.

# General Risk 4

TO INCREASE KNOWLEDGE OF, AND ENROLLMENT IN, ONGOING CLINICAL TRIALS IN CHEMO-PREVENTIVE MEASURES FOR PERSONS AT HIGH RISK OF CANCER.

# Strategies:

- \* Disseminate information on clinical trials via the Colorado Cancer Coalition website at www.coloradocancercoalition.org about ongoing clinical trials in chemo prevention at the following sites; UCCC, CCRP, and RMCC.
- \* Support establishment of professional training mechanisms, which will increase knowledge about clinical trials.

# Tobacco

Lung cancer is the most common cause of cancer death for both men and women. About 1,400 cases of lung cancer are diagnosed in Colorado each year.

Objectives and strategies for tobacco prevention in Colorado are coordinated through a

comprehensive network of partners and organizations in which the Colorado Cancer Coalition participates. To decrease duplication and increase coordination, the Colorado Cancer Coalition uses these same strategies.

With our partners in tobacco prevention, The Colorado Cancer Coalition developed tobacco prevention and control objectives and strategies aligned with its goals. This information can be accessed through the State Tobacco Education and Prevention Partnership Strategic Plan.

# AVOIDANCE OF TOBACCO USE AND EXPOSURE TO SECONDHAND SMOKE ARE THE KEY TO REDUCING LUNG CANCER, MORBIDITY & MORTALITY.

Avoidance of tobacco use and exposure to second hand smoke is the key to reducing lung cancer morbidity and mortality. Tobacco excise taxes have been proven to be the the most effective, population-based prevention tool to reduce tobacco use. Morbidity and mortality from heart disease and cancer will be reduced significantly if the prevalence of smoking is decreased. Despite the known adverse effects of tobacco use, approximately 650,000 adult Coloradans still smoke. Environmental tobacco smoke, commonly known as secondhand smoke, also contributes to lung cancer risk.

In addition to its association with deaths due to lung cancer, heart disease and stroke, cigarette smoking also is a risk factor for the development of cancers of the bladder, cervix, colon/rectum, esophagus, kidney, larynx and pancreas.

Nearly 70% of current adult smokers are more likely to quit if encouraged by their health care provider. Most adult smokers begin to smoke regularly before age 20. There are approximately 200,000 youth who are current smokers in Colorado.

Experimentation with smoking is occurring at younger and younger ages, and initiation now occurs almost entirely during adolescence. Preventing young people from starting to smoke should be a major focus of efforts to reduce the prevalence of cigarette smoking.

# EXPERIMENTATION WITH SMOKING IS OCCURRING AT YOUNGER AND YOUNGER AGES, AND INITIATION NOW OCCURS ALMOST ENTIRELY DURING ADOLESCENCE.

Oral cancer has been shown to occur several times more frequently among smokeless tobacco users than among non- users, and may be 50 times as frequent among long-term spit tobacco users. The consumption of smokeless tobacco in the United States increased 40% between 1970 and 1986. Most new users of smokeless tobacco products are adolescent males. Approximately 140,000 adults are current smokeless tobacco users.

In August 1999, the Centers for Disease Control and Prevention (CDC) released a guidance document which outlines minimum and maximum funding ranges and programmatic recommendations for state tobacco-control initiatives. The funding required for implementing

programs varied depending on state characteristics, demographics, tobacco use prevalence and other factors. CDC's recommended standards for Colorado in fiscal year (FY) 2005-06 had a budget of approximately \$29 million for tobacco control, the first time that funding is within CDC's recommended range.

### The Overarching, Strategic Goals for Tobacco Prevention are:

- \* Prevent and reduce tobacco use by adolescents.
- \* Reduce tobacco use by adults.
- \* Eliminate exposure to secondhand smoke.
- \* Reduce tobacco-related disparities.

# Nutrition & Physical Activity

Studies suggest that 30% to 35% of cancers are diet-related. Risk varies with the type of diet.

The International Agency for Research on Cancer (UARC) recently published a report that documented the preventive effect of fruit and vegetable consumption on cancer. The evidence is conclusive for cancer of the mouth and pharynx, esophagus, larynx, lung, stomach, kidney, colon rectum, ovary (vegetables only) and bladder (fruit only).

# STUDIES SUGGEST THAT 30% TO 35% OF CANCERS ARE DIET-RELATED. RISK VARIES WITH THE TYPE OF DIET.

The Colorado Cancer Coalition created physical activity and nutrition objectives and strategies in collaboration with our partners to meet coalition goals. This information can be accessed through the Colorado Physical Activity and Nutrition Program and Livewell Colorado.

Vegetables (including legumes such as dry beans and peas), fruits and grains are generally low in fat, and are good sources of antioxidants, vitamins, minerals, complex carbohydrates and dietary fiber. Phyto-chemicals in plant foods, such as carotenoids, indoles, and flavonoids, also may contribute to the observed protective effect.

Regular physical activity has been shown to reduce the risk of colon, breast, and possibly endometrial and prostate cancers. Physical activity also helps maintain a healthy weight. In 2003, 41% of Colorado adults age 18 or older exercised for at least 30 minutes, five or more times per week. White, non-Hispanic adults were more likely to exercise than were Hispanic adults (42% and 35%, respectively).

Physical activity can also help mitigate obesity, a nationwide concern linked to many cancers. According to the American Cancer Society's Cancer Prevention and Early Detection Facts and

Figures 2004, the current obesity and overweight patterns in the U.S. could account for approximately one in seven cancer deaths in men and one in five in women.

Objectives and strategies for nutrition and physical activity for Colorado are coordinated through a comprehensive network of partners and organizations in which the Colorado Cancer Coalition participates. In order to decrease duplication and increase coordination, the Colorado Cancer Coalition uses these same strategies.

# SELECTED CANCERS

### Breast Cancer

One in seven Colorado women will have breast cancer at some point in their lifetime. Breast cancer is the most common lifethreatening cancer in Colorado women and the third leading cause of cancer death (after lung cancer and colorectal cancer). Despite these numbers, breast cancer mortality rates are actually declining in Colorado. Breast cancer mortality rates have decreased about 1% per year for Caucasian and Hispanic women, and about 7% per year for African American women. In 2007, the overall mortality rate had decreased 15% compared to the 2002-2006 time period. Compared to national rates, Colorado breast cancer mortality rates are 9% lower (Cancer in Colorado 1997-2007, Colorado Central Cancer Registry). According to the National Cancer Institute, approximately 63 percent of all American Indian (AI) and Alaska Native (AN) breast cancer patients are alive five years after diagnosis. This is the poorest five year relative survival of any ethnic and minority group in the United States.

During 2002-2006, Colorado's overall breast cancer incidence rates (new diagnoses) were 1% higher than national rates. For Hispanic women, the Colorado rate was 15% higher than the national rate, but for African American women the rate was 16% lower. In contrast to these findings, 2007 data showed a sharp increase (46%) in the incidence rate for African American women. National data for 2007 are not yet available so it is unknown whether a similar increase occurred nationally (Cancer in Colorado 1997-2007, Colorado Central Cancer Registry). Incidence for American Indian (AI) relies on national incidence data. More than half of the Colorado AI population is from Northern and Southern Plains, rates of breast cancers remain high in these populations.

According to the American Cancer Society, breast cancer is about 100 times less common among men than among women. For men, the lifetime risk of getting breast cancer is about 1 in 1,000. The number of breast cancer cases in men, relative to the population, has been fairly stable over the last 30 years. Men and women with the same stage of breast cancer have a fairly similar outlook for survival.



The breast cancer plan for Colorado has three objectives aimed at decreasing breast cancer morbidity and mortality for Colorado women and men. Objectives include increasing mammography screening rates, increasing compliance with complete diagnostic evaluation and supporting the development and implementation of cancer survivorship care plans. Each objective is discussed based on social determinants of health, evidenced-based interventions and community collaborations with potential impact for change. Social determinants of health are the economic and social conditions in which people live that have an effect on their health conditions. Examples of social determinants include factors such as race/ethnicity, educational attainment, income level, risky health behaviors, access to quality health care and the physical environment in which people live.

### Mammography Screening

Detecting breast cancer early saves lives and increases an individual's treatment options. About 72% of Colorado women are detected at the in situ or localized stage of disease (before the cancer has spread beyond the breast). Regular screening with mammography can lead to early detection of breast cancers. According to 2008 Colorado Behavioral Risk Factor Surveillance System (BRFSS) data, 73% of Colorado women reported having a mammogram within the past two years. This percentage is the same as in 2006, up from 71% in 2004 and down from 74% in 2002.

Recent national studies indicate that racial/ethnic disparities in mammography use have largely disappeared and that emphasis on specific racial/ethnic minority populations for screening may no longer be warranted (Williams, 2002). National BRFSS data for 2008 show that about 79% of Caucasian women have had a mammogram in the past two years, compared to 82% of African American women and 84% of Hispanic women. Colorado BRFSS data for 2008 show that about 70% of Caucasian women have had a mammogram in the past two years, compared to 72% of African American women and 67% of Hispanic women. These findings indicate that Colorado is screening fewer women than other states and that inequity for African American and Hispanic women exists.

Early detection of breast cancer has changed very little over the past decade for Colorado women. However, for African American and Hispanic women, the early detection rate is worse. Compared to Colorado's early detection rate of 72%, in 2007, 66% of breast cancers in Hispanic women were detected early, and 62% of breast cancers in African American women were detected early. For African Americans, this represents a decrease of 8 percentage points compared to the 2002-2006 time period (Cancer in Colorado 1997-2007, Colorado Central Cancer Registry).

Other social determinants have been associated with decreased screening rates, including low income, less than a high school education, lack of health insurance and reduced access to health-care (Crawford, Jones & Richardson, 2008, Harris, Miller & Davis, 2003, Schootman,

Jeffe, Reschke & Aft, 2003, O'Malley, Earp, Hawley, Schell, Mathews, & Mitchell, 2001). According to Colorado BRFSS data from 2008, 56% of women with a household income of less then \$25,000 (2009 Federal Poverty Guidelines place the poverty level at \$27,075 for household of one person) had a mammogram within the last two years, compared to 66% of women with incomes between \$25,000 and \$49,999 and 78% of women with incomes above \$50,000. Similarly, 53% of women report having had a mammogram with in the last two years have less then a high school education, 66% were high school graduates and 72% had some college or more (BRFSS, 2008). It is clear that many health inequities exist among Colorado women for breast cancer screenings; focus on these social inequities should remain a focus of the health-care system.

### Follow-up on Abnormal Findings

Decreasing the delay in diagnostic evaluation after an abnormal mammogram or clinical breast exam (CBE) will have positive effects on cancer outcomes attributed to earlier stage identification at the time of diagnosis (Jones, Dailey, Calvocoressi, Reams, Kasl, Lee & Hsu, 2005, Vourlekis, Ell & Pagett, 2005). In the U.S., approximately 8% of mammograms are abnormal and in Colorado's low-income, uninsured population, 10-24% of women require additional follow-up (Komen and WWC, 2009). Inadequate follow-up for abnormal cancer screenings may range from 18% - 39% of women (Jones et al., 2005). The only known source of baseline data on this objective for Colorado is for low-income, uninsured or underinsured women, ages 40-64 enrolled in the WWC program. In the 2009 fiscal year, 96% of women completed follow-up on abnormal breast findings within 60 days or less, compared to 93% from 2008, and 94% from 2007, and 93% from 2006.

### Social Determinants Associated with Timely Follow-up on Abnormal Findings

Few studies have addressed social determinants associated with non-compliance on recommended follow-up. Jones et al. (2005) suggests that African American women are significantly less likely to receive adequate follow-up on abnormal mammograms. Other social determinants of inadequate follow-up on abnormal mammograms include lower educational level (Harris et al., 2003), lacking a usual provider for health-care and experiencing pain during the initial mammogram (Jones et al., 2005).

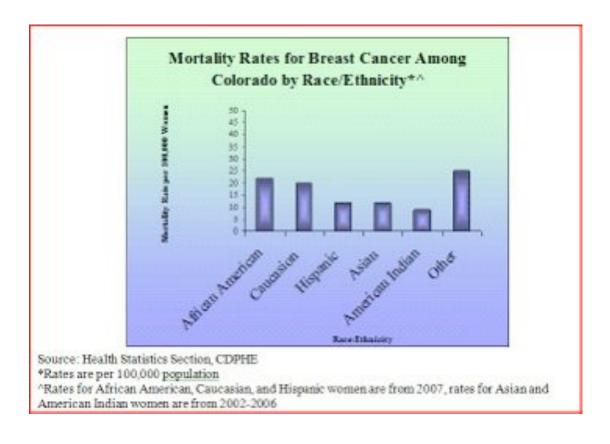
### Breast Cancer Survivorship

With the growing number of breast cancer survivors in Colorado (estimated at 45,000), the quality of care provided in cancer survivorship has gained recognition as an important component of the cancer continuum (Gilbert, Miller, Hollenbeck, Montie & Wei, 2008). Five-year breast cancer survival in Colorado women is 89% for all stages combined, but even at 10 years, 76% of women are still alive. For women diagnosed at the earliest stages, survival increases to 96% at 5 years and 83% at 10 years (Colorado Cancer Registry, 2009).

Many individuals diagnosed with breast cancer continue to face complicated care issues long after cancer treatment is complete (Miller, 2007). The current U.S. health care system is not routinely using or planning for coordinated follow-up care after cancer treatment is complete. The Institute of Medicine (IOM) recommends that every cancer survivor should have a "comprehensive care summary and follow-up plan" once their cancer treatment is completed (2005).

#### Social Determinants Associated with Cancer Survivorship Care Plans

Colorado breast cancer survival differences exist across racial/ethnic groups. For example, while 89% of Caucasian women survive five years, only 83% of Hispanic women and 81% of black women survive that interval. Even accounting for different stages of disease at diagnosis, Hispanic and black women have survival deficits. Whether early stage (localized) or later stage (regional), Hispanic survival is 3-10 percentage points worse than white survival and black survival is 5-9 percentage points worse (Cancer in Colorado 1997-2007, Colorado Central Cancer Registry).



These disparities may be explained to some extent by differences in breast cancer mortality rates. National data indicate that African American women have higher breast cancer mortality rates compared to white women (Jones et al., 2005). In Colorado, the mortality

rates in 2007 were similar for African Americans and Caucasians. Mortality rates for African American women have decreased substantially since the late 1990s in Colorado when mortality rates were 60% higher than Caucasians. The 2007 mortality rate for breast cancer among African American women was 22 deaths per 100,000 population compared to 20 for white women, and 12 for Hispanic women. For 2002-2006, the rate was 12 for Asian women and 9 for American Indian women (Health Statistics Section, CDPHE).

Furthermore, uninsured, African American, Hispanic and low-income individuals are less likely to receive recommended cancer care and experience significant delays in completing cancer care. Several studies have identified patient, provider and health system barriers (Schwaderer et al., 2008; Wells et al., 2008) including high out-of-pocket payments, lack of health insurance, ignorance of available resources, and poor social support (Petereit et al., 2008; Schwaderer et al., 2008). There is also some evidence showing that physicians provide less informational support to minority women with breast cancer. These women have less access to cancer support groups and have the most difficulty understanding information related to their breast cancer diagnosis (Janz et al., 2008).

# Objectives: Breast Cancer

### Breast Cancer 1

BY 2015, INCREASE TO 80% THE PROPORTION OF WOMEN AGE 40 AND OLDER REPORTING THAT THEY RECEIVED A MAMMOGRAM IN THE PAST TWO YEARS.

### Strategies:

According to the Community Guide (usa.gov, 2009), evidence-based interventions shown to increase breast cancer screenings include:

#### CLIENT REMINDER SYSTEMS

16 studies confirm that client reminder systems increase breast cancer screening. Interventions may include use of letters, postcards or phone calls to alert clients that it is time for their cancer screening.

#### SMALL MEDIA

17 studies confirm that small media efforts (such as videos, printed materials, letters, brochures and newsletters) increase breast cancer screening. Tailored interventions may include videos and printed materials geared towards specific individuals, specific populations or general audiences.

#### ONE-ON-ONE EDUCATION

25 studies confirm that one-on-one education increases breast cancer screening. Health care providers can deliver one-on-one education in clinical settings, at home, by phone or in local gathering places. Some studies indicate that physicians may be less likely to recommend mammography to low-income, less educated women (O'Malley et al., 2001).

#### REDUCING STRUCTURAL BARRIERS

Seven studies confirm that reducing structural barriers increases breast cancer screening. Barriers include distance from screening location, limited hours of operation, lack of day care for children, and language and cultural factors. Other barriers identified in Colorado include fear of diagnosis/treatment, immigrant status and lack of understanding medical terminology (Komen Community Profile Report, 2009).

#### REDUCING OUT-OF POCKET COSTS

Eight studies confirm that reducing out-of-pocket costs increases breast cancer screening. Interventions may include providing free or low-cost services, reimbursing clients or clinics, and/or reducing health insurance premiums or co-payments.

Information about why these strategies are important can be found in the references and resources section.

### Breast Cancer 2

BY 2015, INCREASE TO 98% THE PROPORTION OF WOMEN WHO COMPLETE DIAGNOSTIC EVALUATION OF ABNORMAL BREAST FINDINGS IN 60 DAYS OR LESS.

#### Strategies:

Evidence-based Interventions to Increase Timely Follow-up on Abnormal Findings

Few studies have evaluated interventions that may improve women's compliance with followup on abnormal breast cancer screenings, but amongst those studies some strategies are outlined including:

#### REDUCING ANXIETY AFTER AN ABNORMAL RESULT

Nearly 50% of women who have abnormal mammograms report symptoms of anxiety three weeks after completing follow-up. Interventions to reduce this anxiety include immediate feedback from the mammography facility and avoiding periodic follow-up 3-6 months after the initial screening. Educational interventions did not decrease women's anxiety after an abnormal result (Barton, Morley, Moore, Allen, Kleinman, Emmons & Fletcher, 2004).

#### CASE MANAGEMENT/PATIENT NAVIGATION

Women who receive evidenced-based case management services are 6.4 times more likely to be to be adherent with completing follow-up care (Vourlekis, Ell & Padgett, 2005) and are more likely to complete follow-up care in a timely fashion (Wells et al, 2008; Psooy, Schreuer, Borgaonkar & Caines, 2004). Interventions may include making telephone reminders, providing systems navigation, performing assessments of individual-level barriers and mental health assessments. Individual-level barriers may include lack of understanding what follow-up procedures are required, fear of cancer, cultural beliefs, emotional state, competing priorities, lack of social support and lack of usual source of health care (Vourlekis, et al., 2005).

Several studies have found that patient navigation services provide better outcomes for breast cancer patients; however, studies are limited and provide little information regarding their efficiency or cost-effectiveness (Wells et al, 2008). One study reported that the length of time from diagnosis to treatment was shorter for women receiving patient navigation services (Schwaderer et al., 2008). Women may also experience fewer treatment interruptions when receiving patient navigation services (Peteriet et al., 2008). According to Wells et al. (2008), patient navigators may assist with:

- \* Overcoming health system barriers such as coordinating care with multiple providers and facilitating patient provider communication
- \* Providing health education on topics like genetic testing, treatment options and treatment side-effects
- \* Overcoming patient barriers by addressing issues such as lack of transportation, financial and insurance barriers, lack of child care or language translation, and low health literacy.
- \* Providing psychosocial support that may be done either directly or by referring patients to social workers or cancer support groups

Information about why these strategies are important can be found in the references and resources section.

### Breast Cancer 3

BY 2015, SUPPORT THE DEVELOPMENT AND IMPLEMENTATION OF CANCER SURVIVORSHIP CARE PLANS.

#### Strategies:

Evidence-based Interventions Associated with Cancer Survivorship Care Plans

Establishing a more comprehensive cancer survivorship plan is one way to prevent the disconnect between initial cancer treatment, long-term survivorship issues and reducing

breast cancer mortality. Treatment of breast cancer is a complex process that requires consultation with multiple medical specialists in multiple settings. The use of cancer survivorship care plans cannot be considered an evidence-based practice that improves health outcomes yet, more research is needed to demonstrate the effectiveness of this strategy (Gilbert et al., 2007). However, the Institute of Medicine (2005) and the National Institutes of Health (2008) recommend that certain key components be addressed in cancer survivorship care plans:

- \* Summary of all cancer treatments received with short and long-term side effects and toxicities, and contact information from treating institutions and providers
- \* Detailed cancer specific information such as tumor sites, stage, grade, hormonal status, and marker information
- \* Likely course of recovery
- \* Recommended preventative treatments
- \* Language about what each health care provider is responsible for
- \* Evidenced based standards of care for future cancer screenings
- \* Psychosocial, nutritional, and other supportive services required
- \* Identification of key point of contact and coordinator for continuing care

Information about why these strategies are important can be found in the references and resources section.

## Cervical Cancer

Cancer of the cervix is the 13th most commonly diagnosed cancer among females in Colorado. Cervical cancer mortality declined by more than 70% in the U.S. since adoption of the Papanicolaou test in the 1940s. The Papanicolaou test (also called Pap smear, Pap test, cervical smear, or smear test) is a screening test used in gynecology to detect premalignant and malignant processes in the cervix. The test aims to detect potentially pre-cancerous changes such as cervical intraepithelial neoplasia (CIN) or cervical dysplasia, both of which are usually caused by sexually transmitted human papillomaviruses (HPVs). The test is inexpensive to do and remains an effective, widely used method for early detection of precancer and cervical cancer.

Smoking and age influences both cervical cancer incidence and death rates. Smoking exposes the body to many cancer-causing chemicals. Tobacco by-products have been found in the cervical mucus of women who smoke. Women who smoke are about twice as likely as non-smokers to get cervical cancer. In Colorado, the majority (more than two-thirds) of invasive cervical cancers are diagnosed in women age 20 to 54. While a smaller number of cases are diagnosed in women age 55 and older, older women are more likely than younger women to be diagnosed at later stages of the disease and to die from it.

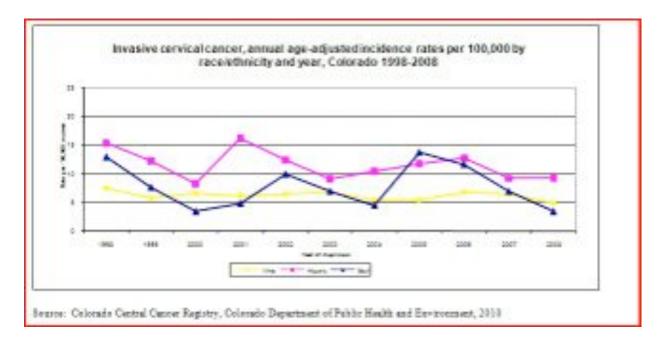
High-risk HPV types, specifically 16, 18, 31, 33 and 45, act as carcinogens in the development of cervical and other anogenital cancers. Infection with a high-risk HPV type is considered necessary for the development of cervical cancer. Seventy percent of cervical cancers worldwide are caused by high-risk HPV types 16 and 18. More than a decade ago, standards were introduced to guide the delivery of vaccinations for children and adults. Under the leadership of the National Vaccine Advisory Committee, standards were revised with a focus on making vaccines easily accessible, effectively communicating vaccination information, implementing strategies to improve vaccination rates and developing community partnerships to reach target patient populations. There are two HPV vaccines approved by the Food and Drug Administration (FDA) for the prevention of infection: Gardasil™ (Merck) and Cervarix™ (GlaxoSmithKline). Vaccine administration recommendations are available on the Centers for Disease Control and Prevention (CDC) website at http://www.cdc.gov/vaccines/.

The U.S. Preventive Services Task Force (http://www.ahrq.gov/clinic/uspstf/uspscerv.htm ) strongly recommends screening for cervical cancer in women who have been sexually active and have a cervix. Other organizations, such as American Cancer Society (ACS) and the American Academy of Family Physicians (AAFP), have similar recommendations. They may differ on when screening begins as well as the screening interval based on type of test used. In general, cervical cancer screening is advised at least every three years, and there is evidence that low-risk older women can stop screening after age 65 if they have had adequate recent screening with normal Pap smears and are not otherwise at high risk for

cervical cancer. Interestingly, Colorado Central Cancer Registry data show that age-specific cervical cancer rates do not begin to decline until after age 80.

#### Colorado Burden

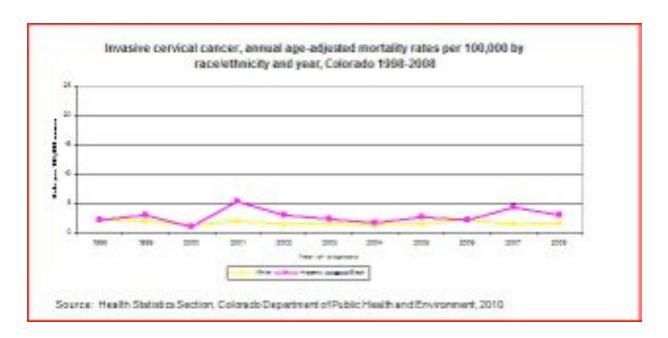
Despite the fact that nearly all cervical cancer cases can be prevented, Colorado still averages about 160 new cervical cancer cases and about 40 cervical cancer deaths each year. Incidence rates for invasive cervical cancer differ by race/ethnicity in Colorado women. Although rates fluctuate from year to year, blacks and Hispanics in Colorado generally have higher rates compared to whites. Compared to the United States., Colorado incidence rates are significantly lower in all race/ethnicity groups.



Mortality rates for cervical cancer in Colorado are significantly lower than U.S. rates for whites and blacks; rates for Hispanic women are similar. In Colorado, death rates for Hispanic women are generally higher than those for whites. Annual rates for blacks cannot be calculated due to small numbers (fewer than 3 deaths per year).

While the cost for cervical screening is relatively inexpensive as compared to other cancer screening tests, women may not be taking full advantage of this screening due to barriers such as lack of insurance, obesity, disability and cultural issues.

For women without insurance, there are public programs, such as the Women's Wellness Connection that will fully cover the cost of testing. Women enrolled in this public health program may be eligible for treatment if a cervical cancer is diagnosed. Low-cost or free screenings can also be obtained through Family Planning agencies and community health centers.



Insurance coverage does not automatically translate to adequate screening rates. As reported in the Colorado Health Plan & Hospital Quality Report Health Matters 2009, health plans have opportunities to increase rates of cervical screening among their insured population. Of the seven health maintenance organizations reporting rates of cervical screening using the Health Plan Employer Data and Information Set (HEDIS), five were below standard; one was at standard; and one reported above the National Committee for Quality Assurance (NCQA) benchmark. (NCQA is a nationally recognized assessment of key measures of health care quality; http://www.ncqa.org/).

Although Colorado has lower incidence and mortality rates than the United States, Colorado must still focus on eliminating this preventable cancer. In accordance with Healthy People 2020 proposed goals, the overarching goals for Colorado are to decrease the incidence and mortality of cervical cancer in Colorado women by focusing on two major complementary and synergistic objectives: 1) Increase screening for cervical cancer with Pap smears; and 2) Increase the number of young women receiving more than one dose of HPV vaccine.

# Objectives: Cervical Cancer

#### Cervical Cancer 1

BY 2015, INCREASE TO 90% THE NUMBER OF COLORADO WOMEN AGE 18 AND OLDER REPORTING HAVING HAD A PAP SMEAR IN THE PAST THREE YEARS.

- \* Implement evidence-based community interventions to increase screening and modify risk behaviors into the Colorado health care system.
- \* Educate primary care screening providers (generalists, OB/Gyn, Family Practice) on client evidenced-based strategies that increase screenings.
- \* Actively refer eligible women to Women's Wellness Connection (WWC) who will provide services for low income, uninsured women between 40 and 64 years of age.
- \* Provide cervical cancer education to women that are not routine users of the health care system and may have disparities that prevent access to the health care system.
- \* Develop partnerships with STD clinics, correctional, domestic abuse, homeless shelters and other community-based organizations that may have contact with women who are rarely or never screened for cervical cancer. Provide assistance to organizations on where screening services



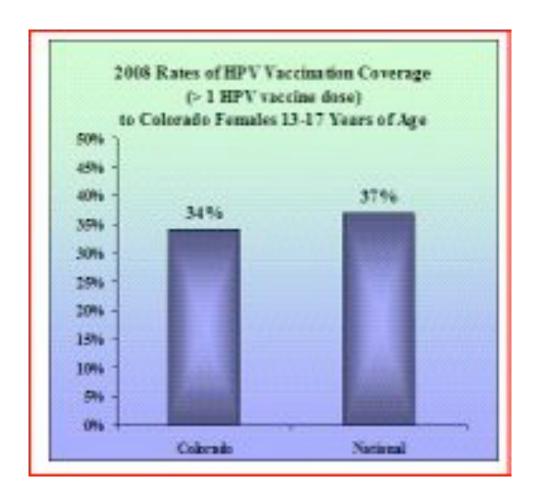
can be obtained in the Colorado health care system.

#### Cervical Cancer 2

BY 2015, INCREASE HPV VACCINATION COVERAGE (>1 HPV VACCINE DOSE) TO 44% FOR FEMALES 13-17 YEARS OF AGE.

#### Baseline Data

The National Immunization Survey (NIS) is sponsored by the National Center for Immunizations and Respiratory Diseases (NCIRD) and conducted jointly by the NCIRD and the National Center for Health Statistics (NCHS). In 2007, NIS HPV vaccination coverage was reported for the first time and showed that 25.1% of U.S. females 13-17 years of age had received at least one HPV vaccination. In 2008, the NIS assessed state-level vaccination coverage and reported Colorado's HPV vaccination (>1 HPV vaccine dose) coverage level for females 13-17 years of age is 34% compared to the national rate of 37%.



#### Social Determinants Associated with HPV

There are several emerging studies that demonstrate differences in populations that receive the vaccine, those that need and are receptive to education about the vaccine, and persistent myths about HPV vaccine.

- \* Vaccine awareness differs by race, education and income. Interventions to increase awareness of HPV could benefit from tailoring information to pre screening age, screening age, and post-screening-age women. (The Impact of Human Papillomavirus Information on Perceived Risk of Cervical Cancer. Hughes, et al. Cancer Epidemiol Biomarkers Prev. Feb 3, 2009.)
- \* Barriers to vaccination are cost and access to vaccine and concern that immunization with the vaccine may promote adolescent sexual behavior. HPV vaccine programs should emphasize high vaccine effectiveness, the high likelihood of HPV infection, and physicians' recommendations, and address barriers to vaccination. (Predictors of HPV vaccine acceptability: a theory-informed, systematic review. Brewer NT, Fazekas KI. Preventive Med. 2007 Aug-Sep;45(2-3):107-14. Epub 2007 Jun 2.)
- \* Given information, mothers of teens in Mexico had high acceptance rates of vaccinating their adolescent children against HPV. (Parental Attitudes About Sexually Transmitted

- Infection Vaccination for Their Adolescent Children. Gregory D., et al. Arch Pediatr Adolesc Med. 2005;159:132-137.)
- \* Teenage girls surveyed indicated no increased interest in risky sexual behavior if they were to be vaccinated. (Attitudes about human papillomavirus vaccine in young women. (Kahn JA, et al. Int J STD AIDS. 2003 May;14(5):300-6.)

#### Evidenced-Based Interventions to Increase HPV Vaccination Rates

According to findings of the CDC Guide to Community Preventive Services (http://www.thecommunityguide.org/index.html), there are no specific evidence-based interventions for increasing HPV vaccination at this time. Therefore, the following proven interventions are being recommended for increasing HPV vaccination coverage:

- \* Provider Reminder Systems: Provider reminders let providers or other appropriate staff knows when individual clients are due for vaccinations, through notations, stickers, or other prompts in clients' charts, or through computer databases or registries. Reminders can be directed to the primary healthcare provider or clinic staff.
- \* Interventions that should be implemented in combination:
- \* Expanded access in healthcare settings;
- \* Reducing patient out-of-pocket costs;
- \* Patient or family incentives;
- \* Patient reminder/recall systems;
- \* Clinic-based patient education;
- \* Community-wide education;
- \* Vaccination requirements:
- \* Provider assessment and feedback;
- \* Provider education; and
- \* Standing orders

For detail on individual strategies, please go to The Community Guide, Vaccinations for Preventable Diseases: Targeted Coverage at (http://www.thecommunityguide.org/vaccines/targeted/index.html).

# Based on Information Presented, the Following are Cervical Cancer Plan 2015 Strategies to Increase HPV Vaccination Coverage:

- \* Educate healthcare providers about the Advisory Committee on Immunization Practices (ACIP) recommendations for HPV vaccination.
- \* Provide technical assistance to healthcare providers to implement the Standards for Child, Adolescent, and Adult Immunization Practices.
- \* Recruit non-traditional vaccination providers (OB/GYNs, etc.) into the Vaccines for Children (VFC) Program to increase HPV vaccination coverage among uninsured and underinsured females 18 years of age and under.

- \* Support activities that recruit non-traditional vaccination providers into the Colorado Immunization Information System (CIIS) so that HPV vaccination records are accurate, complete, and accessible.
- \* Educate providers about the importance of implementing systems to remind parents/guardians, patients, and staff when vaccinations are due.
- \* Develop targeted, culturally specific media messages about HPV vaccination and disseminate through provider offices, health departments and community organizations. Messaging should focus on:
  - Emphasizing the high likelihood of HPV infection if sexually active;
  - Educating parents of adolescents about high vaccine effectiveness;
  - Educating parents about the myths related to increase sexual activity in vaccinated adolescents;
  - Addressing barriers to vaccine access; and
  - Educate vaccine recipients about the need for continued regular screening with Pap tests.

### Colon & Rectum Cancers

Cancer in the colon or rectum (colorectal cancer) is a condition in which cells that line the colon or rectum mutate in ways that allow them to multiply in an uncontrolled way and invade other tissues. These rapidly growing cells then form into masses of tissue that can interfere with the normal function of the colon or rectum, causing bleeding or obstruction. Colorectal cancer takes many years to develop. Most colorectal cancers arise from polyps, which are small mushroom-type growths on the interior lining of the colon or rectum. Polyps are usually present for many years before the cells within them further mutate to allow the cancerous behavior of invasion and spreading to other tissues to become apparent.

SEVERAL LIFESTYLE FACTORS HAVE BEEN SHOWN TO AFFECT ONE'S RISK OF FORMING COLORECTAL CANCER, INCLUDING OBESITY, INADEQUATE PHYSICAL ACTIVITY, AND DIETS HIGH IN RED MEAT AND LOW IN VEGETABLES.

As with most other cancers, advancing age is the biggest risk factor for cancers of the colon or rectum. Men are at higher risk than women, but this gender difference is modest compared to other cancers. Blacks are at higher risk and Hispanics at lower risk. Those with a history of colorectal cancer or colorectal polyps in their family (first degree relatives) are at twice the risk of those with no family history, and are at risk at a younger age. Five to 10% of colon cancers are thought to be caused by inherited predispositions which may be detected by genetic testing.

Several lifestyle factors have been shown to affect one's risk of forming colorectal cancer, including obesity, inadequate physical activity, and diets high in red meat and low in vegetables. Taking estrogen replacement therapy, aspirin or other non-steroidal anti-inflammatory (NSAID) drugs reduces risk.

Randomized, controlled trials have proven that screening for blood in the stool (Fecal Occult Blood Testing with colonoscopic follow-up of all positive tests) reduces the risk of dying of colorectal cancer. The best evidence from many studies concludes that endoscopic screening (sigmoidoscopy or colonoscopy) can substantially reduce the risk of dying from colorectal cancer. Because endoscopic examinations can also allow for polyp removal, endoscopic colorectal screening is both an early detection method and also a cancer prevention method. Research studies on other screening methods, including virtual colonoscopy and testing stool samples for abnormal genes, have not yet shown to be ready for recommendation to the general public. The identification and removal of colorectal polyps is the single most effective strategy to prevent colorectal cancer.

THE IDENTIFICATION AND REMOVAL OF COLORECTAL POLYPS IS THE SINGLE MOST EFFECTIVE STRATEGY TO PREVENT COLORECTAL CANCER.

Colorectal cancer death rates will likely continue to fall in Colorado in the years to come. If we can reverse the adverse obesity trends in Colorado and increase colorectal screening rates, we could see substantial reductions in colorectal cancer death rates in the years to come.

# Objectives: Colon & Rectum Cancers

#### Colorectal 1

BY 2015, 80 % OF COLORADANS AGES 50 AND OLDER WILL BE IN COMPLIANCE WITH ACS COLORECTAL CANCER SCREENING GUIDELINES.

#### Strategies for the Public:

- \* Facilitate/encourage public awareness at the local level, across all populations, about colorectal cancer:
  - Include messages both for average risk persons and for persons at higher risk due to their family history of colorectal cancer or adenomas.
  - Engage advocates, such as survivors, caregivers, and navigators in development and distribution of CRC screening messaging.
  - Develop and use messaging that is consistent with other organizations in Colorado, as well as nationally, including ACS/CCGC/USPSTF guidelines.
  - Determine outreach to populations who are pre-screening age to begin to raise awareness.
  - Include messaging to ensure public awareness about new Colorado legislation mandating colorectal cancer screening
  - Encourage the use of evidence-based strategies for community mobilization.
  - Hold regular meetings with key stakeholders to update progress and introduce newer strategies.
  - Coordinate lifestyle messaging with other organizations, such as Colorado on the Move and LiveWell Colorado, with similar goals.

### Strategies for Providers:

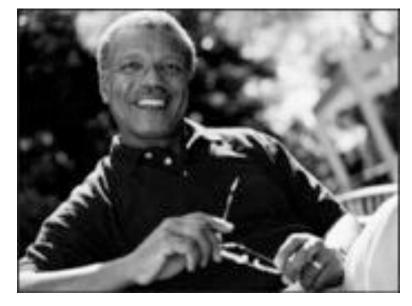
- \* Continue the statewide educational campaign to increase knowledge of Colorado health care providers about colorectal screening options, specifically including information about guidelines for the use of high sensitivity FOBT's and the age for stopping screening.
  - Collection of comprehensive family history.

- Communicate ACS/CCGC/USPSTF screening guidelines, emphasizing commonalities of recommendations.
- \* Encourage practice changes that facilitate increased screening through measures such as:
  - Patient education about the importance of screening and the screening process.
  - Patient navigation scheduling, education, coordinate services, assistance with barriers to screening, follow-up.
  - In-reach to eligible patient populations.

\* Support the development and use of easy-to-use tools to assist physicians reaching

high-risk populations.

- \* Support the incorporation of quality standards for endoscopic screening into electronic endoscopy reports.
- \* Educate the primary care provider community to recognize and expect to be provided with data documenting high-quality endoscopic screening.
- \* Assist the endoscopic provider community to ensure that the data to assess the quality of



- endoscopic services is available to endoscopists and their referral network.
- \* Facilitate provider-generated strategies to increase screenings and preventative care

### Strategies for Health Care Systems:

- \* Support development of "in-office pathways" that reduce delays in diagnosis of colorectal cancer (iron deficiency, positive stool test, etc.)
- \* Collaborate with employers and health insurers, such as the Colorado Business Group on Health and Association of Health Plans, to increase screening rates among their insured, particularly the underinsured.
  - Reduce or eliminate co-pays for CRC screening.
  - Collaborate with employers to improve benefit selection and reduce and /or eliminate cost barriers for CRC screening.

- \* Sustain funding for a program to provide colorectal screening for uninsured and underinsured Coloradans.
- \* Encourage the next revision of CCGC guidelines to address quality of endoscopic screens.
- \* Assure adequate capacity in Colorado for colorectal screening services:
  - Encourage lower fees for self-pay patients.
  - Increase CRC screening capacity in rural Colorado and ensure high quality screenings.
  - Promote preventative colorectal screening in the primary care environment, via a medical home.
- \* Encourage the development of cost-effective strategies for CRC screening.

#### Strategies for Policy/Advocacy:

- \* Ensure screening for uninsured and undocumented Coloradans.
- \* Engage survivors and family members to become advocates for education and screening.
- \* Develop messaging addressed to legislators, funders, insurers, employers, etc. to create the business case for CRC screening.
- \* Support development of policy and legislation to secure payment coverage for diagnostic and treatment services for low-income, uninsured Coloradans diagnosed with colorectal cancer.
- \* Support development of policy and legislation to pay for patient navigation and community health workers in the primary care setting.

Increase the Number of Individuals Receiving Genetic Counseling who have a Risk of Carrying an Inherited Predisposition to Colorectal Cancer. This Includes those with a Personal or Family History of:

- \* Colorectal cancer, especially under age 60
- \* Endometrial cancer, especially under age 60
- \* Ovarian cancer at any age
- \* Multiple colon polyps (10 or more on a single screening)
- \* Hereditary Non-Polyposis Colorectal Cancer (HNPCC, aka Lynch syndrome); Familial Adenomatous Polyposis (FAP); or MYH-Associated Polyposis (MAP)
- \* Inherited mutations to MLH1, MSH2, MSH6, PMS2, APC, or MYH genes

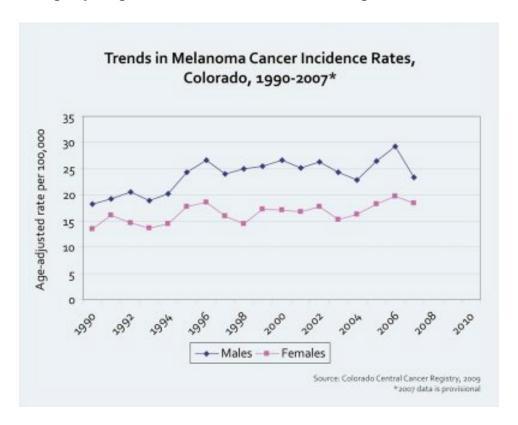
Two to Four Percent of aAll Colorectal Cancer Diagnoses are Due to an Inherited Predisposition to Colorectal and Endometrial Cancers. Important Screening Tools for Lynch Syndrome Include:

- \* Family history as outlined above
- \* Screening colon tumor tissue with MSI, IHC, and/or BRAF lab testing. Tissue screening is more sensitive and specific than family history in detecting Lynch syndrome. Tissue lab screening can be coordinated through most pathology labs. (Genetics In Medicine Volume 11, Number 1, January 2009, pp 35-41.)

Skin cancer is the most common form of cancer in the United States. It impacts millions of Americans each year and its incidence continues to rise. Most skin cancers are non-melanomas (basal cell and squamous cell skin cancers) that rarely spread and are highly curable. Exposure to ultraviolet (UV) radiation appears to be the chief preventable risk factor for non-melanoma skin cancer and may be responsible for more than 90% of cases.



The most serious form of skin cancer, melanoma, impacts fewer people each year but can be fatal. It has a high potential to metastasize but can be treated effectively when diagnosed early. According to the American Cancer Society (ACS), rates for melanoma are 10 times higher in whites than African Americans. Among whites, rates are more than 50% higher in men than in women. The ACS also reports that recently melanoma has been increasing in young white women and white adults age 65 and older.

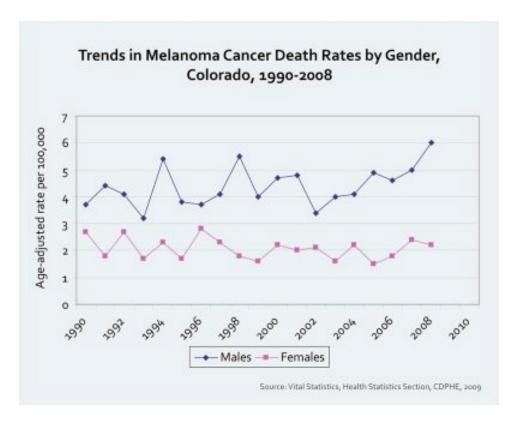


Nearly 9,000 Americans died from melanoma in 2010. Mortality rates for melanoma in Colorado have been significantly higher than U.S. rates for several years. The 2000-2006 Colorado melanoma incidence rate was 18% higher for males than the U.S. rate, and 22% higher for females. In Colorado, melanoma survival varies substantially by stage, with a five-

year survival rate of 90% for localized disease and 19% for distant metastatic disease (CCCR, 2004).

Over a 12- to 13-year span, data collected in Colorado shows a gender disparity between men and women in relation to melanoma incidence and death. From 1995 to 2006, the incidence rate was higher for men than for women. From 1995 to 2007, the death rate for melanoma was also higher for men than for women. For this reason, it is important for statewide prevention and early detection efforts to particularly target males.

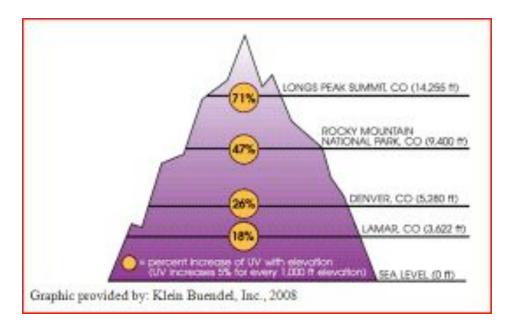
Data indicate that non-melanoma skin cancer is related to cumulative UV exposure throughout life, whereas intense exposure (sunburns) in childhood may be a more important predictor for melanoma later in life. Studies indicate that even a few severe sunburns early in life may double the risk of malignant melanoma. For this reason, it is important to reduce the proportion of children who have had severe sunburns (i.e., blistering or painful burn lasting more than three days) during childhood or adolescence. Artificial tanning appears to also impact melanoma incidence. A recent study found that indoor tanning is associated with a 74% higher risk of developing melanoma. Research shows that people who use tanning devices may also have a significantly increased risk of squamous and basal cell skin cancers.



National and international authorities (AAD, AAP, ACS, ASHA, CDC, NCI, NASBE, and WHO) strongly recommend reducing UV exposure to prevent skin cancer, eye damage, and skin damage. And yet, in 2006, only 66% of adults in Colorado reported using at least one method

of sun protection. For children, the rate was 73%. Further, about 40% of adults in Colorado reported having been sunburned in 2006. Nearly 51% of children experienced sunburns in the same time period.

Colorado requires special care for UV protection because of its high elevation and 300+ days of sunshine per year. UV intensity increases about 5% for every 1,000 feet gained in elevation. So, Denver's UV intensity is 26% higher than at sea level. Coloradans should be aware of the dangers of sun exposure year-round at high altitude and take appropriate precautions. Reflective surfaces such as fresh snow can reflect UV from the earth's surface and increase exposure up to an additional 90% on a bright sunny day. Preventive actions are strongly encouraged when the sun's rays are most intense during midday hours and during the high UV months of April through October.



Sun safety prevention programs are recommended in a wide range of environments across Colorado. Parents and caregivers are encouraged to limit sun exposure for infants and children. In addition, facilities providing services to children (e.g., child care centers, schools and recreation programs) are urged to create sun-safe environments and policies. Workplaces are also encouraged to implement sun protection policies and strategies for their employees, including educating them on the risks of UV exposure and providing shade, protective apparel and sunscreen.

Several simple ways to reduce UV exposure are recommended. These everyday precautions include:

- \* Limiting unprotected sun exposure during midday hours on sunny and cloudy days
- \* Using natural and portable shade (e.g., trees, umbrellas, picnic shelters)
- \* Wearing cover-up clothing, wide-brimmed hats and sunglasses

\* Applying sunscreen with SPF 15 or higher (excluding infants less than 6 months of age) to all exposed skin and SPF 15 or higher lip balm.

In addition, individuals should avoid unnecessary UV exposure from artificial sources such as sunlamps and tanning beds. The WHO now recommends against the use of UV tanning devices for cosmetic purposes. WHO also recommends that no person under 18 use an artificial tanning device.



# Objectives: Melanoma

#### Melanoma 1

BY 2015, INCREASE BY 5% THE PERCENTAGE OF SCHOOLS THAT HAVE ESTABLISHED SUN SAFETY GUIDELINES, PROCEDURES OR POLICIES FOR THEIR STUDENTS. (BASELINE: 62%, 2007 SUN SAFE SCHOOLS PROJECT)

- \* Maintain and promote the Sun Safe Colorado website for access by schools and parents.
- \* Conduct outreach and provide resources for schools and school districts.
- \* Support schools and school districts in the adoption and implementation of sun safety guidelines, procedures or policies.
- \* Support the development of a sustainable mechanism for collecting the data needed to monitor the objective.



BY 2015, REVISE STATE LEGISLATION TO RESTRICT INDOOR UV TANNING USAGE BY MINORS. (BASELINE: NO COLORADO AGE RESTRICTIONS, 2010)

#### Strategies:

- \* Increase public knowledge about the skin cancer risks associated with indoor tanning.
- \* Encourage development of, secure sponsorship for, and promote passage of legislation.
- \* Educate indoor UV tanning facility operators about state regulations and legislation.
- \* Support the development of a sustainable mechanism for collecting the data needed to monitor the objective.

#### Melanoma 3

BY 2015, INCREASE BY 5% THE PERCENTAGE OF WORKPLACES THAT HAVE ESTABLISHED SUN SAFETY GUIDELINES, PROCEDURES OR POLICIES FOR THEIR OUTDOOR WORKERS. (BASELINE: 50%, 2007 COLORADO SUN PROTECTION WORKPLACE SURVEY)

#### Strategies:

- \* Maintain and promote the Sun Safe Colorado website for access by workplaces and employees.
- \* Conduct outreach and provide resources for workplaces with outdoor workers.
- \* Support employers in the adoption and implementation of sun safety guidelines, procedures, or policies.
- \* Support the development of a sustainable mechanism for collecting the data needed to monitor the objective.



#### Melanoma 4

BY 2015, REDUCE TO 35% THE PERCENTAGE OF ADULTS WHO REPORT HAVING HAD SUNBURN IN THE PAST YEAR. (BASELINE: 40.4%, 2006 COLORADO BRFSS)

- \* Implement educational programs and distribute information to educate adults about sunburns and skin cancer prevention.
- \* Support the distribution of sun protection products at public events, parks and other outdoor venues.
- \* Maintain and promote the Sun Safe Colorado website for access by workplaces and employees.

- \* Promote the installation of shade structures in areas where people congregate for social or recreational purposes.
- \* Support the development of a sustainable mechanism for collecting the data needed to monitor the objective.

BY 2015, REDUCE TO 45% THE PERCENTAGE OF PARENTS REPORTING THEIR CHILDREN HAVING HAD A SUNBURN IN THE PAST YEAR. (BASELINE: 50.7%, 2006 CHILD HEALTH SURVEY)

#### Strategies:

- \* Implement educational programs and distribute information to educate children and adolescents about sunburns and sun safety.
- \* Support the distribution of sun protection products at public events, parks and other outdoor venues.
- \* Maintain and promote the Sun Safe Colorado website for access by schools and parents.
- \* Promote the installation of shade structures in areas where people congregate outdoors for social and recreational purposes.
- \* Support the development of a sustainable mechanism for collecting the data needed to monitor the objective.

### Melanoma 6

BY 2015, INCREASE TO 72% THE PERCENTAGE OF ADULTS REPORTING USE OF AT LEAST ONE METHOD OF SUN PROTECTION WHEN OUTSIDE DURING A SUNNY SUMMER DAY FOR MORE THAN ONE HOUR. (BASELINE: 66.3%, 2006 COLORADO BRFSS)

- \* Implement educational programs and distribute information to educate adults about sun protection strategies.
- \* Support the distribution of sun protection products at public events, parks and other outdoor venues.
- \* Maintain and promote the Sun Safe Colorado website for access by workplaces and employees.
- \* Promote the installation of shade structures in areas where people congregate outdoors for social and recreational purposes.
- \* Support the development of a sustainable mechanism for collecting the data needed to monitor the objective.



BY 2015, INCREASE TO 78% THE PERCENTAGE OF CHILDREN USING AT LEAST ONE METHOD OF SUN PROTECTION WHEN OUTSIDE FOR MORE THAN 15 MINUTES BETWEEN 11 AM AND 3 PM ON A SUNNY SUMMER DAY. (BASELINE: 73.1%, 2006 CHILD HEALTH SURVEY)

#### Strategies:

- \* Implement educational programs and distribute information to educate adults about sun protection strategies.
- \* Support the distribution of sun protection products at public events, parks and other outdoor venues.
- \* Maintain and promote the Sun Safe Colorado website for access by schools and parents.
- \* Promote the installation of shade structures in areas where people congregate outdoors for social and recreational purposes.
- \* Support the development of a sustainable mechanism for collecting the data needed to monitor the objective.



#### Melanoma 8

BY 2015, INCREASE THE PROPORTION OF MELANOMAS DETECTED "EARLY" BY PHYSICIANS TO 84%; "EARLY" IS DEFINED AS LESS THAN OR EQUAL TO 1.00 MM BRESLOW DEPTH OR IN-SITU STAGE. (BASELINE: 79%, 2006 COLORADO CENTRAL CANCER REGISTRY)

- \* Implement educational programs and distribute information to educate adults about early detection of skin cancer.
- st Maintain and promote the Sun Safe Colorado website.
- \* Promote skin selfexamination by persons at high risk of developing skin cancer.
- \* Support skin cancer screenings for the public.
- \* Increase physician education.



BY 2015, INCREASE BY 5% THE PERCENTAGE OF PRESCHOOLS AND CHILD CARE CENTERS THAT HAVE ESTABLISHED SUN SAFETY GUIDELINES, PROCEDURES OR POLICIES FOR THEIR STUDENTS. (BASELINE: 81%, 2010 SURVEY OF CHILD CARE CENTERS)

- \* Conduct statewide outreach and provide resources for preschools and child care centers.
- \* Support preschools and child care centers in the adoption and implementation of sun safety guidelines, procedures, or policies.
- \* Support the development of a sustainable mechanism for collecting the data needed to monitor the objective.
- \* Maintain and promote the Sun Safe Colorado website for access by preschools, child care centers and parents.

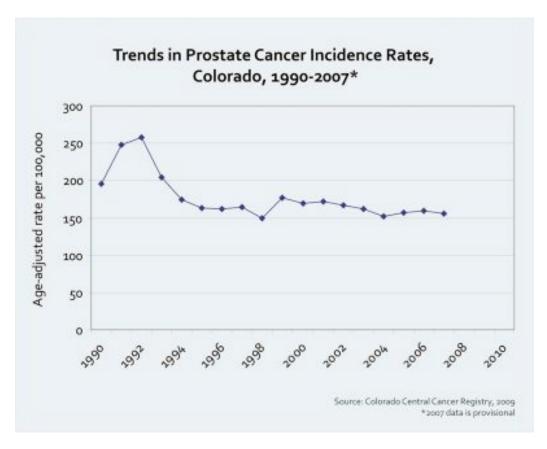


### Prostate Cancer

Nationally, prostate cancer accounts for 30% of all male cancers and 11% of male cancerrelated deaths. Among Colorado men, prostate cancer is by far the most commonly diagnosed cancer and the second most common cause of cancer death.

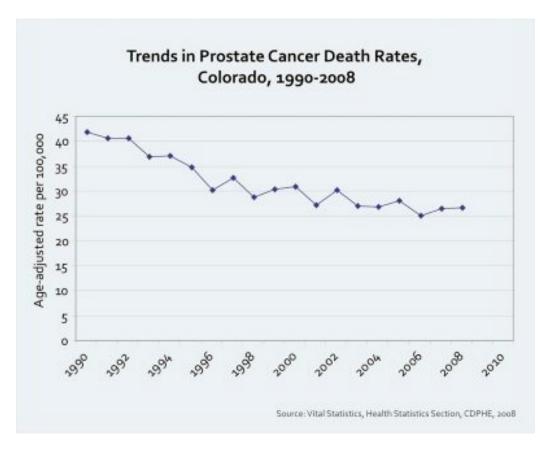
AMONG COLORADO MEN, PROSTATE CANCER IS BY FAR THE MOST COMMONLY DIAGNOSED CANCER AND THE SECOND MOST COMMON CAUSE OF CANCER DEATH. A STEEP RISE IN PROSTATIC CANCER INCIDENCE RATES IN COLORADO FROM THE LATE 1980S TO 1992 WAS FOLLOWED BY ALMOST AS STEEP A DROP IN RATES THROUGH 1998. THIS PATTERN OCCURRED IN MANY STATES THROUGHOUT THE U.S. AND COINCIDED WITH WIDE ADOPTION OF THE PROSTATE SPECIFIC ANTIGEN (PSA) SCREENING TEST

The Colorado incidence rate for prostate cancer was stable between 1997 and 2007. Mortality rates decreased 19% from 1997 to 2007 in Colorado, possibly due to improvements in early detection. Age, race/ethnicity and family history are factors that affect the risk for prostate cancer.



About 80% of all men with clinically diagnosed prostate cancer are age 65 years or older. Because prostate cancer usually occurs at an age when conditions such as heart disease and stroke cause death, many more men die with prostate cancer rather than because of it. Less than 10% of men with prostate cancer die of the disease within five years of diagnosis.

Effective measures to prevent prostate cancer have not been determined. Many physicians recommend screening to their patients, and in recent years, a substantial proportion of men in the United States have been screened. Although screening detects some prostate cancers early in their growth, it is not yet known whether it saves lives or whether treatment reduces disability and death from this disease.



Further, there are concerns that for some men, screening and treatment may do more harm than good. Current medical tests cannot predict the growth of prostate cancers. Slower-growing cancers might not require treatment (surgery or radiation), which commonly causes impotence and incontinence. Thus, the harms of treatment may outweigh the benefits. Moreover, it is unclear how well treatment works for faster-growing prostate cancers. Studies now underway will tell us more about the effectiveness of screening and treatment.

# Objectives: Prostate Cancer

#### Prostate 1

BY 2010, INCREASE TO 65% THE PROPORTION OF MEN OVER AGE 50 WHO REPORT BEING FULLY INFORMED ABOUT AND OFFERED SCREENING BY PROSTATE-SPECIFIC ANTIGEN (PSA)/DIGITAL RECTAL EXAM (DRE) IN THE PRECEDING 2 YEARS.

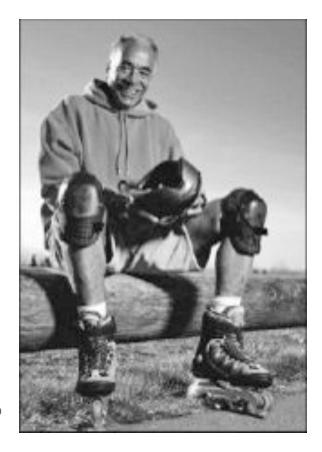
(BASELINE: 41% DISCUSSED WITH DOCTOR, 51% RECOMMENDED, 2000 COLORADO BRFSS)

### Strategies for the Public:

- \* Provide public education to increase awareness about the possible benefits of annual prostate screening for men 50 and older with a life expectancy of at least 10 years.
- \* Continue targeted awareness campaigns aimed at dispelling myths and correcting misinformation regarding prostate cancer treatment.
- \* Create pamphlets in both English and Spanish to educate men about prostate cancer.

### Strategy for Providers:

\* Educate and encourage health care providers to perform annual DRE and offer PSA screening during physical examinations of men age 50 and older who have a life expectancy of at least 10 years.



### Strategy for Health Care Systems:

\* Support programs offering screenings for uninsured and under-insured men.

### Prostate 2

BY 2010, INCREASE TO 75% THE PROPORTION OF AFRICAN-AMERICANS AND OTHER HIGH-RISK MEN OVER THE AGE OF 45 WHO REPORT BEING FULLY-INFORMED ABOUT AND OFFERED SCREENING BY PSA/DRE IN THE PRECEDING 2 YEARS. (BASELINE: TO BE ESTABLISHED)

#### Strategies for the Public:

- \* Establish baseline
- \* Continue targeted awareness campaigns specifically for black males and for men with a strong family history of 1 or more first-degree relatives diagnosed with prostate cancer at an early age, due to evidence showing earlier onset in these high-risk groups.
- \* Continue educational programs for black males (and other high-risk groups) starting at 45 years that involve use of community leaders and health workers to educate their community members about the importance of screening.

### Strategy for Providers:

\* Facilitate an annual prostate cancer symposium/educational workshop for health care professionals, community health workers, and survivors in Colorado to discuss all aspects of prostate cancer, including barriers to screening, outreach efforts to high-risk groups, and the diagnosis and treatment of prostate cancer.

#### Strategy for Health Care Systems:

\* Support specific screening programs for under-served and high-risk populations.

# Lung Cancer

Lung cancer is the most common cause of cancer death among both females and males in both the United States and Colorado. In Colorado, the cumulative lifetime risk of lung cancer is one in 11 for males and one in 16 for females. It is the third most commonly diagnosed cancer overall. Cigarette smoking is the most important risk factor for lung cancer, accounting for approximately 80% of lung cancer deaths in females and 90% in males. After 10 years of abstinence, smoking cessation decreases the risk of lung cancer to 30%-50% of that of continuing smokers. Five- year survival rates for lung cancer are only about 10%. Other risk factors include occupational exposure (e.g., radon, asbestos) and indoor and outdoor pollution (e.g., radon, environmental tobacco smoke). About 1% to 2% of lung cancer deaths are attributable to air pollution.

As smoking cessation and prevention are the most important areas to focus on to reduce both the incidence of and mortality from lung cancer, this is where efforts need to be made (for objectives relevant to these efforts, see chapter on Tobacco). Additionally, continued dissemination of information about the risks of radon exposure is necessary.

# Objectives: Lung Cancer

### Objective 10.1

\* Support ongoing research into development of screening tools for earlier detection.

### Objective 10.2

\* Support ongoing research into development of better treatment regimens.

### Objective 10.3

\* Create a clearinghouse for current clinical trials and increase patient participation in them.

## Ovarian Cancer

In the United States, incidence of ovarian cancer ranks second among all gynecologic cancers. It causes more deaths than any other gynecologic cancer. In Colorado, ovarian cancer is the 5th most commonly diagnosed cancer in women and the 8th most common cause of cancer mortality. The cumulative lifetime risk is one in 60. In women with a personal or family history of breast or ovarian cancer, that risk increases significantly. Other risk factors include advancing age. The 5-year survival rate for ovarian cancer is approximately 50%.

The ovarian cancer plan for Colorado has four objectives. These objectives are aimed at improving 1) awareness, 2) education, and 3) advocacy. 4) Support for ovarian cancer survivors and caregivers is also an important component of the cancer plan. Women who have one first-degree relative with ovarian cancer but no known genetic mutation still have an increased risk of developing ovarian cancer. The lifetime risk of a woman who has a first degree relative with ovarian cancer is five percent (the average woman's lifetime risk is 1.4 percent).

About 10 to 15 percent of women diagnosed with ovarian cancer have a hereditary tendency to develop the disease. The most significant risk factor for ovarian cancer is an inherited genetic mutation in one of two genes: breast cancer gene 1 (BRCA1) or breast cancer gene 2 (BRCA2). These genes are responsible for about 5 to 10 percent of all ovarian cancers.

Eastern European women and women of Ashkenazi Jewish descent are at a higher risk of carrying BRCA1 and BRCA2 mutations. Since these genes are linked to both breast and ovarian cancer, women who have had breast cancer have an increased risk of ovarian cancer.

Another known genetic link to ovarian cancer is an inherited syndrome called hereditary non-polyposis colorectal cancer (HNPCC or Lynch Syndrome). While HNPCC poses the greatest risk of colon cancer, women with HNPCC have about a 12 percent lifetime risk of developing ovarian cancer.

Gynecologic oncologists are physicians trained in recognizing and removing gynecological cancers. Research has shown that the five-year survival rate is greater when initial surgery for ovarian cancer is performed by a gynecologic oncologist. (NCI) The initial surgery and staging of ovarian cancer is critical to determining the appropriate course of treatment, and ultimately survival outcomes. A gynecologic oncologist is an obstetrician gynecologist who is further trained in oncology to specialize in the diagnosis and treatment of women with gynecologic cancers. To find a gynecologic oncologist in your area, visit the Women's Cancer Network at www.wcn.org

### Screening

Although a CA 125 blood test can be a useful tool for the diagnosis of ovarian cancer, in premenopausal women, it is not uncommon for a CA 125 count to be elevated due to benign conditions unrelated to ovarian cancer. Uterine fibroids, liver disease, inflammation of the fallopian tubes and other types of cancer can elevate a woman's CA 125 level. (ACOG Patient Education – 1996) The CA 125 test is more accurate in postmenopausal women. It is also important to note that in about 20% of cases of advanced stage disease, and 50% of cases of early stage disease, the CA 125 is NOT elevated, even though there is ovarian cancer present. As a result, the CA 125 is generally only one of several tools used to diagnose ovarian cancer. One of the most important uses of the CA 125 test, however, is to evaluate progressive disease and tumor response in patients undergoing treatment, and to monitor the levels of women in remission for evidence of disease recurrence.

#### **Symptoms**

Symptoms are relevant, but they are not a definitive diagnostic tool. Since there is no single diagnostic tool for ovarian cancer, symptom awareness remains of key importance. Awareness of symptoms can help women get diagnosed sooner, hopefully at an earlier stage.

The use of oral contraceptives decreases the risk of developing ovarian cancer, especially when used for several years. Women who use oral contraceptives for five or more years have about a 50 percent lower risk of developing ovarian cancer than women who have never used oral contraceptives. Researchers believe that incidence of the most common type of ovarian cancer is heightened by the eruption of eggs from the ovaries. Multiple pregnancies, breast feeding, late puberty and early menopause can reduce risks.

#### Research & Clinical Trials

Clinical trials are carefully designed research studies that involve people. Some clinical trials are conducted to find ways to improve the medical care and treatment that is available to women with ovarian cancer. Some trials test ways to detect and prevent ovarian cancer or its recurrence. There are also clinical trials that study how to improve an ovarian cancer patient's quality of life during and after treatment. The types of trials are:

- \* Phase 1 trials evaluate the safety of a treatment. These studies typically enroll fewer than 50 people who have different types of cancer these trials determine the safe dosage, delivery method and side effects of a drug.
- \* Phase 2 ovarian cancer drug trials test to see if the treatment works against ovarian cancer. These studies typically enroll about 100 women with ovarian cancer
- \* Phase 3 trials test the new treatment against the best existing treatment, also called the "standard of care" or "standard care." These studies typically enroll hundreds to thousands of women to determine if the treatment is safe and effective against ovarian cancer. Phase III data is used to apply for FDA approval

# Objectives: Ovarian Cancer

#### Ovarian 1

\* Continue to support the activities of the Ovarian Cancer Advisory Panel in their efforts to increase awareness about ovarian cancer, and to educate the public and health care providers about advancements in this area.

#### Ovarian 2

INCREASE THE NUMBER OF WOMEN RECEIVING GENETIC COUNSELING WHO HAVE A HIGH RISK OF AN INHERITED PREDISPOSITION TO OVARIAN CANCER. THIS INCLUDES THOSE WOMEN WITH A PERSONAL OR FAMILY HISTORY OF:

- \* Breast cancer, especially under age 50
- \* Ovarian cancer at any age
- \* Male breast cancer
- \* Cancers listed above, plus Jewish ancestry or Hispanic ancestry from the San Luis Valley and northern New Mexico
- \* Colorectal cancer, especially under age 60
- \* Endometrial cancer, especially under age 60
- \* Hereditary Breast/Ovarian Cancer (HBOC, inherited changes to BRCA1/2 genes)
- \* Lynch syndrome (inherited changes to MLH1, MSH2, MSH6, or PMS2 genes)
- \* Those who are of the Ashkenazi Jewish descent

#### Ovarian 3

\* Increase the number of women with ovarian cancer who are referred and treated by a gynecologic oncologist.

#### Ovarian 4

\* Support ongoing research into development of screening tools for earlier detection.

#### Ovarian 5

\* Support ongoing research into development of better treatment regimens.

#### Ovarian 6

\* Create a clearinghouse for current clinical trials and increase patient participation in them.

# Nervous System Cancers

Brain and other nervous system cancers encompass cancerous tumors of the brain and spinal cord. Primary cancers that start in the brain are less common and are different from tumors that start in other organs and spread to the brain (metastatic or secondary brain tumors). The most common type of malignant brain tumor in Colorado, as well as the United States, is glioblastoma. In Colorado, the cumulative lifetime risk of brain and other nervous system cancer is one in 108 for males and one in 158 for females. Five-year survival with primary, malignant brain cancer was 31% for the 1990-1997 time period.

## Objectives: Nervous System Cancers

### Nervous System 1

\* Support ongoing research into development of screening tools for earlier detection.

#### Nervous System 2

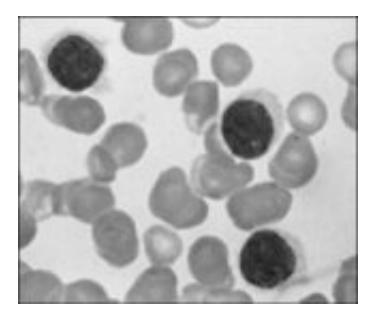
\* Support ongoing research into development of better treatment regimens.

#### Nervous System 3

\* Create a clearinghouse for current clinical trials and increase patient participation in them.

# Leukemias

Leukemias are cancers that begin in cells of the bone marrow and then invade the blood. They encompass both acute (acute lymphocytic leukemia or ALL; acute myeloid leukemia or AML) and chronic forms (chronic lymphocytic leukemia or CLL; chronic myeloid leukemia or CML). Leukemia is often associated with childhood cancer, but according to the ACS it occurs 10 times more frequently in adults than in children. In Colorado, the cumulative lifetime risk of leukemia is one in 45 for males and one in 80 for females. Although Colorado incidence rates for leukemia were about 8%



higher than U.S. rates in 2002-2006, the incidence declined in 2007 to rates that were similar to national rates. Five-year survival rates for adult leukemias were stable at 42%-47% between 1996 and 2003, while five-year survival rates for childhood leukemias stood at 87%.

# Objectives: Leukemias

### Leukemias 1

\* Support ongoing research into development of screening tools for earlier detection.

#### Leukemias 2

\* Support ongoing research into development of better treatment regimens.

#### Leukemias 3

\* Create a clearinghouse for current clinical trials and increase patient participation in them.

# Non-Hodgkin Lymphoma

Non-Hodgkin lymphoma (NHL) is a cancer that arises from the lymphatic system, a part of the immune system which consists of lymph nodes and lymph vessels. Although risk factors for NHL generally relate to impaired immune function, the causes of most lymphomas are not clear. In Colorado, the cumulative lifetime risk of NHL is one in 34 for males and one in 47 for females. In contrast to a type of lymphoma known as Hodgkin's Lymphoma, NHL is more difficult to treat and has lower survival rates. For 2000-2003, the five-year survival for NHL was about 65%, with lower survival for Hispanics and blacks observed in this time period.

# Objectives: Non-Hodgkin Lymphoma

### Non-Hodgkin Lymphoma 1

\* Support ongoing research into development of screening tools for earlier detection.

### Non-Hodgkin Lymphoma 2

\* Support ongoing research into development of better treatment regimens.

#### Non-Hodgkin Lymphoma 3

\* Create a clearing house for current clinical trials and increase patient participation in them.

# Multiple Myeloma

Multiple myeloma is a progressive blood disease. It is a cancer of the plasma cell, an important cell in the immune system that produces antibodies for fighting infection. It is currently considered incurable, but it is treatable. There are several promising new therapies that are helping patients live longer, healthier lives. In Colorado, the cumulative lifetime risk of blood cancer is one in 107 for males and one in 164 for females. Five-year survival is about 35%. Incidence and mortality rates are higher for blacks.

# Objectives: Multiple Myeloma

### Multiple Myeloma 1

\* Support ongoing research into development of screening tools for earlier detection.

### Multiple Myeloma 2

\* Support ongoing research into development of better treatment regimens.

### Multiple Myeloma 3

\* Create a clearing house for current clinical trials and increase patient participation in them.

# **PEDIATRIC**

### Pediatric Cancer

Although significant advancements in the diagnosis and treatment of pediatric cancer have been made over the past several decades, cancer remains the number one cause of death from disease in children in the United States today. More than 12,500 children and young adults are diagnosed with cancer each year in the United States, and the numbers are rising. With the publication of this plan, Colorado is now one of only four states to develop a comprehensive plan to address this devastating disease as it applies to the pediatric and young adult population.

A comprehensive cancer plan tailored to pediatric cancer is critical due to the unique factors and characteristics of pediatric cancer that differ from cancer that affects older Coloradans. The critical and distinguishing factors to be considered include, but are not limited to, the following:

- \* Pediatric cancers are materially dissimilar to adult cancers and as a result treatment protocols designed, developed and tested in the adult cancer population do not result in the same outcomes in the pediatric cancer population.
- \* Early detection is more difficult based on numerous factors, including age of the child, inability to effectively communicate, lack of or a shorter time frame of medical history.
- \* Childhood cancer presents symptoms that are common in non-life threatening or routine childhood illnesses

A greater emphasis on research and treatment advancement is needed. The quality of life, late-effects and survivorship issues facing this population are extensive and demand serious attention. Pediatric cancer impacts parents and siblings in a way that is different than adult cancer patients and families. The following plan lays out sixteen objectives to improve the state of childhood cancer in Colorado.

# TOP FIVE CANCER TYPES DIAGNOSED IN THE PEDIATRIC, ADOLESCENT AND YOUNG ADULT POPULATION ARE:

	0 - 4 Years	5-9 Years	10-14 Years	15-19 Years	20-22 Years	
#1	Acute Lymphoblastic Lymphoma	Brain	Brain	Lymphoma	Melanoma	
#2	Brain	Acute Lymphoblastic Lymphoma	Acute Lymphoblastic Lymphoma	Melanoma	Lymphoma	
#3	Urinary/ Endocrine	Bone & Joint	Bone & Joint	Brain	Male Genital	
#4	Eye & Orbit/ Soft Tissue	Lymphoma	Lymphoma	Male Genital	Endocrine	
#5	Liver	Endocrine/ Lymphoma	Non-Hodgkin's Lymphoma	Bone & Joint	Brain	

#### Pediatric Task Force

In 2007, the Colorado Kids Cancer Association was asked to empanel as the Pediatric Task Force of the Colorado Cancer Coalition and to identify the distinct and specific needs of the Pediatric Cancer Community. These needs are outlined below – the first pediatric chapter included in the Colorado State Cancer Plan.

#### Early Detection

Whereas cancer prevention programs in older populations encourage preventative care and annual screenings for early detection, most infants and young children are already seen for routine well visits by medical professionals for the first several years of their lives and then annually throughout childhood. Education of the medical community regarding symptoms and the early detection of childhood cancer at the scheduled routine visits is critical to early diagnosis. Education of parents and access to care, particularly in rural areas, is also critical to all children to aid in the early detection and treatment of pediatric cancer.

#### **Treatment**

Due to the various types of pediatric cancer and corresponding treatment protocols, it is critical that treatment options incorporate access of care, centralized databases and communication between pediatric cancer care centers.

#### Research

Pediatric cancer research is chronically underfunded. Incorporated into every area of need for children diagnosed with cancer is the need to continue to support and fund the best and brightest minds searching for causes of pediatric cancers as well as those developing new treatment agents that will be the most effective and least toxic.

#### Survivorship

Survivorship issues facing the pediatric, adolescent and young adult populations are of particular concern, especially since the classification of survivors is so broad and emphasizes the gamut of developmental, social and economic issues facing all children. Addressing survivorship issues is of particular importance for this population because time spent in survivorship generally exceeds the amount of time they are in treatment. The possibility of "late effects occurrences" and chronic health issues spans their lifetime.

#### End of Life Services

End of life care and services are critical for the pediatric cancer community. Currently, these services are insufficient to address the specific needs of the pediatric cancer community for dealing with end of life issues for a child. Traditionally, end of life care is viewed with aging populations, not children. Therefore, the lack of services available in the pediatric cancer community needs to be brought to the attention of entities providing these services.

#### Awareness

Coloradans have been instrumental in bringing childhood cancer to the attention of Washington D.C. and the general public. In 2008, Colorado Sen. Wayne Allard and then New York Sen. Hillary Rodham Clinton successfully co-sponsored the first ever designated National Childhood Cancer Awareness Day, September 13, 2008. Colorado Sen. Mark Udall continued the awareness campaign by successfully sponsoring the 2009 Resolution for the second National Childhood Cancer Awareness Day. The Colorado Kids Cancer Association will ensure the awareness of childhood cancer continues to increase. We believe the more information and education made available to the general public and health care professionals, the more likely open, educated discussions can occur regarding childhood cancer, which impacts so many of our children in Colorado and the United States.

#### Advocacy

Advocacy for childhood cancer is an area that is growing in importance. There is a critical need to exert public policy influence on behalf of our children, those who are in treatment and those who are long term survivors.

#### Prevention

While few lifestyle risk factors have been identified for childhood cancers, there are certain areas that warrant very serious conversation. Pediatric cancers tend to be cancers of genetics, and therefore routine cancer screening is not something that can be universally applied to detect or prevent childhood cancer. However, education of the primary care physician population as to the signs and symptoms of more regularly diagnosed types of childhood cancer can go a long way toward early detection, increasing the rate of survivorship.

Certain cancers are related to infectious agents, such as hepatitis B virus (HBV), human papillomavirus (HPV), human immunodeficiency virus (HIV), Helicobacter pylori (H.pylori), and others, and can be prevented through behavioral changes, vaccines, or antibiotics.[1] Recent breakthroughs in understanding HPV have led to an approved vaccine to prevent the spread of this disease.

# Objectives: Pediatric Cancers

#### Pediatric 1

BY 2015, ESTABLISH AND MAINTAIN A PEDIATRIC TASK FORCE TO DEVELOP, FACILITATE AND MONITOR PEDIATRIC CANCER NEEDS IN COLORADO.

#### Strategies:

- \* Identify and share information about the resources available to the children of Colorado and their families who are battling cancer.
- \* Provide a forum in which task force members can network, support each other, share resources as appropriate and learn more about the services in place in our community.
- \* Function as a resource for newly emerging organizations to support their work and to help them understand what community services are already available.
- \* Provide a cohesive body which can support advocacy work on behalf of children with cancer and their families.

#### Pediatric 2

BY 2015, INCREASE THE ENROLLMENT OF PEDIATRICS, ADOLESCENTS, AND YOUNG ADULTS ON COG (CHILDREN'S ONCOLOGY GROUP) STUDIES ACROSS THE STATE OF COLORADO.

#### Strategies:

- \* Increase education of and communication among pediatric medical professionals and facilities.
- \* Increase availability of online medical resources and existing centralized databases.
- \* Educate parents as to the possible indications of the most commonly diagnosed forms of pediatric cancers.
- \* Educate referring doctors about the necessity of enrolling cancer patients on COG studies.

#### Pediatric 3

BY 2015, INCREASE THE NUMBER OF REFERRALS TO PEDIATRIC CANCER CENTERS OF CHILDREN AND ADOLESCENTS SUSPECTED OF HAVING CANCER

#### Strategies:

- \* Educate pediatric health care professionals, family practice, and adult oncologists as to the imperative nature of having children diagnosed with cancer referred to a pediatric cancer care center, thereby ensuring the child has access to the most timely and up to date treatments and standards of care.
- \* Develop strategies that work to ensure:
  - that children in rural and outlying mountain communities have access to quality care by increasing support of currently operating "mobile clinics" provided by Metropolitan-based pediatric care centers. that children have access to quality care regardless of insurance or ability to pay.
  - that health care facilities have internet capabilities for patient resources.
  - that there is integrated and effective sibling support information and opportunities available to medical and psychosocial professionals in all of these pediatric cancer centers.
  - that services of either bilingual staff or properly qualified interpreters are available for patients and families with any language other than English, including sign language for the deaf
- \* Cultivate stronger networks of community resources and patient navigators for families in areas with limited access to care.
- \* Foster more effective distribution of culturally appropriate information and awareness about how to access care and other support resources to non-English speaking children with cancer and their families.

#### Pediatric 4

BY 2015, INCREASE AWARENESS OF THE NEED FOR MORE EXTENSIVE, SPECIFIC RESEARCH INTO THE CAUSES OF PEDIATRIC CANCERS AND INTO THE DEVELOPMENT OF NEW, MORE EFFECTIVE, LESS TOXIC TREATMENTS AND POTENTIAL VACCINES FOR PEDIATRIC CANCERS.

#### Strategies:

- \* Review current research protocols to determine both what is available now and what is lacking.
- \* Make information about current clinical trials available.
- \* Educate parents, primary care pediatricians, family practice, adult oncologists, and patient navigators as to the advantages of enrolling in clinical trials.
- \* Advocate for increased funding for pediatric cancer research.

#### Pediatric 5

BY 2015, INCREASE AWARENESS OF THE NEED TO RECRUIT, MENTOR AND RETAIN SKILLED PEDIATRIC RESEARCH PROFESSIONALS.

#### Strategies:

- \* Begin conversations with State Educational institutions regarding scholarship incentives for students entering into the field of pediatric oncology research.
- \* Explore opportunities for other incentives, ie: Student Loan Payoff programs in exchange for time commitments in the pediatric oncology research and development field.

#### Pediatric 6

BY 2015, IDENTIFY AND INCREASE RESOURCES AVAILABLE TO ENHANCE THE QUALITY OF LIFE SPECIFIC TO CHILDREN, ADOLESCENTS, YOUNG ADULTS WITH CANCER.

- \* Develop strategies that work to ensure:
  - that the schools are prepared to assist in modifying a child's educational plan when needed and/or requested and that each primary oncology center has online capabilities so children in treatment can link into their classrooms and or access teachers and administrators via the internet.
  - that the child's community, including teachers, classmates, peer groups, and parents of other children are helped to understand the needs of a child undergoing cancer treatment and the importance of assimilating the child into normalized routines including school settings.

- that children's treatments are tailored to the family's needs; keeping children at home as much as possible rather than in a hospital.
- \* Develop strategies that work to provide:
  - a network of support for parents and caregivers to ensure they are adequately trained to care for their child's needs throughout treatment.
  - a network of support for parents and caregivers to ensure that they are aware of the psychological and emotional impact on siblings of children with cancer, and they have easy and free access to support tools, resources and information.
- \* Address the specific needs of the adolescent and young adult populations to include psychosocial support, increased risk of depression and specific challenges like driving, school dances, more extensive social situations and greater issues dealing with the varying degrees of "peer pressure."
- \* Raise the awareness of parents and medical professionals about the needs of adolescent and young adult patients to be actively involved in the decision making process regarding the course of their treatment, in medical conversations relating to their care, treatments and other options.
- \* Increase awareness about the support services available to children with cancer and their families.

#### Pediatric 7

BY 2015, ENSURE THAT CHILDHOOD CANCER SURVIVORS AND COLORADO SCHOOL DISTRICTS ARE AWARE OF THE EDUCATIONAL, PHYSICAL, AND PSYCHOLOGICAL CHALLENGES THAT CHILDHOOD CANCER SURVIVORS MAY FACE DURING AND AFTER TREATMENT, AND THAT THEY HAVE ACCESS TO THE TOOLS THAT WILL EASE THESE CHALLENGES.

- \* Educate childhood, adolescent, and young cancer survivors and Colorado educators about common learning problems that are associated with cancer and its treatment.
- \* Schools and childhood cancer treatment centers will work together to implement school re-entry plans for each childhood cancer survivor to ease the re-entry process both during treatment and after treatment is completed. The plan will help survivors, their caregivers, and the schools establish which interventions and accommodations the survivor will qualify for under the federal laws. Part of the plan will be to educate teachers of the accommodations and educational needs of survivors who are currently receiving treatment and the needs of students who are returning to the classroom. The survivor's classmates will be educated about what to expect when the student returns to class.

- \* Any child, adolescent, or young adult who is at risk for late effects or who is having difficulty in school will have neuropsychological testing done by a licensed pediatric psychologist or a neurophysiologist. Periodic evaluations may be needed during academically challenging times, such as entry into elementary, middle, high school, or during pre-college planning.
- \* Empower childhood, adolescent and young adult cancer survivors to advocate for their educational needs from elementary school through college years.
- \* Advocate for childhood, adolescent, and young adult survivors medical records to be entered first into the EMR.
- \* Develop strategies that work to ensure:
  - that childhood cancer survivors and their caregivers are aware of the federal laws that protect their educational rights.
  - that schools are made aware of the educational impact of siblings of children with cancer, and that plans are made to also ease the re-entry time-frame for those brothers and sisters of children with cancer.
  - that high school aged survivors and high school guidance counselors are aware of which colleges and universities are known for their ability to make accommodations for childhood cancer survivors.

#### Pediatric 8

BY 2015, DEVELOP, EVALUATE, AND MAINTAIN GUIDELINES AND SPECIALIZED CLINICS FOR FOLLOW-UP CARE TO HELP PROMOTE SURVIVORSHIP. ENCOURAGE USE OF THE COG LONG-TERM FOLLOW-UP GUIDELINES AT HTTP://WWW.CHILDRENSONCOLOGYGROUP.ORG/DISC/LE/DEFAULT.HTM

- \* Develop strategies that work to ensure:
  - that childhood cancer survivors receive detailed information about their diagnosis and the cancer treatment they received. They also need a comprehensive list of possible late effects, and recommendations for follow up. This information should then be provided to their current and future health care providers.
  - that pediatric, adolescent, and young adult cancer patients are given the necessary information up front about fertility issues later in life.
- \* Develop strategies that work to provide:
  - education to primary care physicians and other specialists about potential late effects, and resources for timely referrals.

- ongoing education on optimum lifestyle choices that will maximize wellness, improve emotional well-being, and decrease long term effects. This education will encompass physical, neurocognitive, and psychosocial functioning.
- education to primary care physicians, other specialists, and patient navigators about how to talk to survivors about potential fertility issues.
- \* Establish stronger collaboration between pediatric oncologists and primary care physicians.
- \* Empower childhood cancer survivors to advocate for their medical needs as they move from childhood to adulthood.
- \* Assist survivors in transitioning from pediatric to adult care and from oncology to primary care for long-term follow up.
- \* Educate health professionals about the importance of stressing survivorship and ongoing care to pediatric, adolescent, and young adult survivors.
- \* Increase access to Long Term Survivorship care planning materials (e.g. Journey Forward)

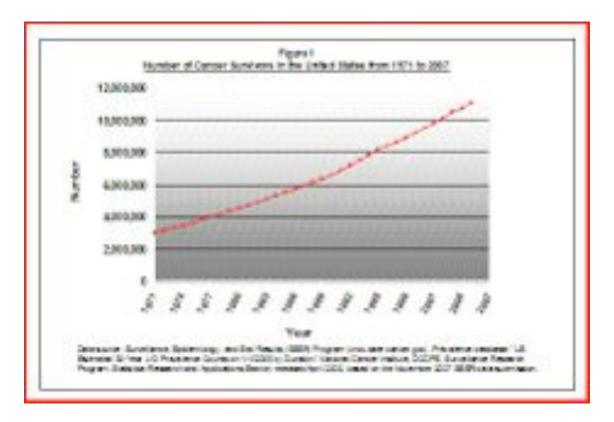
#### Pediatric 9

BY 2015, ENSURE THAT CHILDHOOD CANCER SURVIVORS HAVE EDUCATIONAL PROGRAMS THAT INCREASE ACCESS TO INFORMATION ABOUT LAWS AND REGULATIONS THAT MAY PROTECT THEM IN TERMS OF EMPLOYMENT, INSURANCE, ASSET MANAGEMENT, AND SCHOOL ACCOMMODATIONS.

- \* Educate survivors how to access and evaluate information.
- \* Provide easy-to-use interactive, web-based cancer resource programs (e.g., how to obtain Medicaid/Medicare) for survivors living in Colorado. This program would also explain the state and federal laws and regulations about health insurance.
- \* Educate decision-makers about economic and social barriers related to health care for cancer survivors.
- \* Provide easy-to-use interactive, web-based cancer resource programs explaining the state and federals laws and regulations about employment.
- \* Develop strategies that work to ensure:
  - Ensure that high school aged survivors and high school guidance counselors are aware of which colleges and universities are known for their ability to make accommodations for childhood cancer survivors or employment options available after graduation.
  - Ensure that survivors who may be eligible for Vocational Rehabilitation are aware.

# QUALITY OF LIFE

As shown in Figure 1, recent estimates indicate that there are in excess of 11 million people living with a history of cancer in the United States, reflecting nearly a four-fold increase from the early 1970s. Given this extraordinary growth in the number of cancer survivors, combined with the many daunting challenges faced by cancer patients and survivors at the time of diagnosis, during treatment and beyond, comprehensive state-level cancer control plans must include cancer survivorship as recommended in a recent report from the Institute of Medicine (IOM).



This landmark report, titled From Cancer Patient to Cancer Survivor: Lost in Transition [1], contained 10 key recommendations, one of which recommended that:

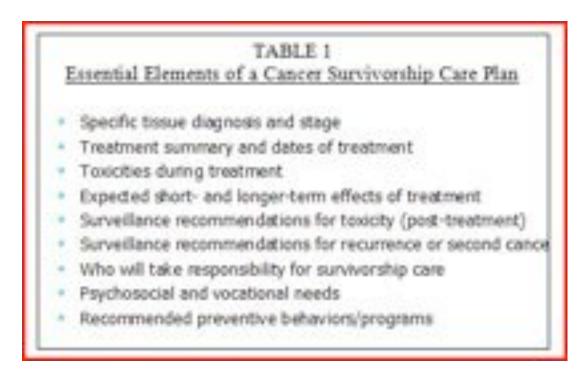
"Congress . . . support [the] Centers for Disease Control and Prevention, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation and refinement of existing state cancer control plans" [Recommendation 6, Executive Summary, page 8].

The Colorado Cancer Coalition (CCC) has been at the forefront nationally in recognizing cancer survivorship as a priority. In the previous Colorado Cancer Plan for 2005-2010, an entire chapter was devoted to this topic, which has now been updated for 2010-2015. Although

many of the key objectives and strategies included in the previous Colorado Cancer Plan have been retained, several new developments and challenges in cancer survivorship, also identified in the IOM report, have likewise been included in this chapter. Especially noteworthy in this regard is the need to provide cancer patients and survivors with treatment summaries and care plans post-treatment. As described in the IOM report as another key recommendation:

"Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This 'Survivorship Care Plan' should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payers of health care" [Recommendation 2, Executive Summary, page 4].

A consensus is now emerging on the essential elements that should be included in these care plans (see Table 1). Recommended components include diagnostic information, a comprehensive summary of treatments received and their toxicities, potential short- and longer-term effects of treatment, surveillance recommendations for toxicity, recurrence and second cancers, and recommendations and referrals to address psychosocial, vocational and behavioral needs. The need to provide cancer survivors with this essential information is so compelling that it has now been elevated to one of the key objectives in this chapter. As others have noted [1-4], these treatment summaries and care plans will need to be understandable and usable for cancer survivors, and they should be accompanied by a conversation to help survivors extract meaning and guidance for managing their survivorship care post-treatment. Also of note is that this chapter specifically acknowledges the challenge and need to provide follow-up care to cancer survivors that includes coordination of care



between oncology specialists and primary care physicians. This fundamental challenge must be addressed, given that the number of cancer survivors in this country requiring follow-up care related to their survivorship far surpasses what the oncology workforce can provide.

Concurrent with this recognized need to provide cancer survivors with care plans post-treatment is the corresponding need to develop either evidence-based or consensus-approved clinical practice guidelines that would be incorporated into these care plans, including guidelines for medical surveillance and follow-up and need-based referrals for psychosocial and behavioral programs for cancer survivors. This need was also highlighted in the IOM Lost in Transition report as one of its 10 key recommendations as follows:

"Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts" [Recommendation 3, Executive Summary, page 5].

Although formulating these clinical practice guidelines must involve a national effort that would transcend any state-level cancer control plan for cancer survivors, the development of a comprehensive state-level plan for cancer survivors must acknowledge this need and promote the development and utilization of such guidelines at every opportunity. For this reason, another main objective highlighted in this plan focuses on this key challenge. This challenge is especially evident for cancer survivors post-treatment, where evidence-based programs and clinical practice guidelines are lacking, especially in the areas of psychosocial and behavioral oncology. As noted recently by Jacobsen [5] when discussing the selection of such programs as referral resources within cancer survivorship care plans:

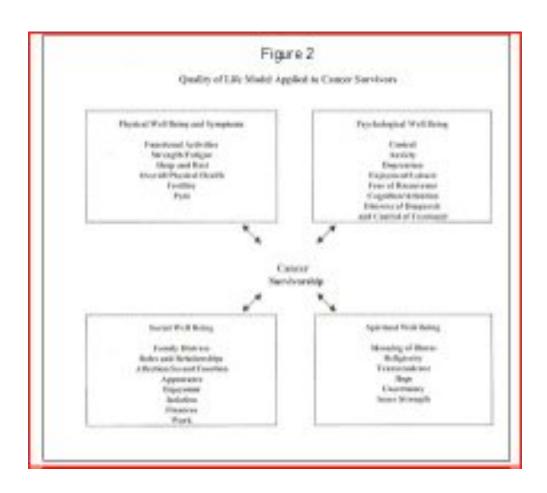
"Ideally, the interventions(s) selected should have been evaluated and found to be efficacious in RCTs conducted with post-treatment cancer survivors. In the likely absence of such evidence, it may be necessary to rely on RCTs or lower level evidence from research conducted with patients undergoing primary cancer treatment or patients with other chronic conditions" (page 4425).

Clearly, we can and should do better than relying on "lower level evidence" to make these referrals to community-based psychosocial and behavioral programs for cancer survivors, or to refer cancer survivors post-treatment to programs where the evidence base comes from "other chronic conditions" or "patients undergoing primary cancer treatment." Accordingly, another key objective included in this plan is to promote more intervention research and program evaluation that could contribute to the development of evidence-based clinical practice guidelines and program referrals for cancer survivors.

Also noteworthy is that many organizations and advocacy groups now acknowledge that cancer survivorship begins at the time of diagnosis, and that the definition of a cancer

survivor should include family members, friends and the caregivers of a cancer patient or survivor. The Colorado Cancer Coalition (CCC) also embraces this definition of cancer survivorship, which is shared by the National Cancer Institute, the American Cancer Society, the Lance Armstrong Foundation, the Centers for Disease Control and Prevention and the National Coalition for Cancer Survivorship. Thus, when we refer to "cancer survivors" in this chapter, it is always within the context of this broader definition of cancer survivorship.

While the CCC does indeed embrace this more encompassing definition of cancer survivorship, we are also acutely aware of the need to target resources and programs across this continuum of cancer survivorship, including targeted resources and programs for newly diagnosed cancer patients, those who are in active treatment, cancer survivors post-treatment, as well as the caregivers and family members of cancer patients and survivors. As a case in point, newly diagnosed cancer patients need resources in the moment to help them make informed treatment decisions (e.g., treatment efficacy, treatment side-effects, complimentary and alternative medicine). Patients in active treatment require resources and programs to help them navigate the health care system and manage treatment side effects, economic or insurance issues, and psychosocial sequelae during treatment. Cancer survivors post-treatment may require similar but also different resources and programs to help them



prepare for life beyond cancer treatment, including medical surveillance and coordination of care post-treatment, managing longer-term physical, emotional and social functioning, late effects of cancer treatment, return to work issues, genetic counseling services, reproductive health programs and services and behavioral programs for cancer survivors (e.g., diet, nutrition and physical activity). In contrast, while caregivers and family members of cancer patients and survivors can be impacted by many of these same issues and concerns, they may also benefit from additional resources and programs to help them protect their own health and well-being and to regain or maintain a sense of balance in their lives. We acknowledge here that these differences exist to emphasize the key point that when information and educational resources and service programs are being recommended in this chapter, it is with the understanding that we are also recommending that these resources and programs be targeted and made available across the full spectrum of the cancer care continuum for survivors.

In addition to the above, we also acknowledge that within each phase of the cancer care continuum, programs and resources for cancer survivors should embrace several concurrent and complementary goals, including helping cancer patients prepare for their journey as cancer survivors, beginning at the time of diagnosis and beyond, and improving survivorship care across multiple domains (medical, psychosocial and behavioral). Ultimately, the long range goal should be to enhance the quality of life (QOL) of cancer survivors, which is likewise recognized as having multiple domains (see Figure 2) that encompass physical, psychological, social and spiritual health and well-being [6]. When viewed from this perspective, the array of programs and resources that derive either directly or indirectly from a state-level plan for

OBJECTIVES											
	1) Increase number of information & educational resources	2) Increase use of information 8. educational resources	3) Increase number of programs/ services	4) Increase use of programs/ services	5) Increase treatment summaries/ core plans	<ul> <li>6) Amirt in developing/ disservinging clinical practice guidelines</li> </ul>	7) Increase program evaluation/ research	8) Increase advocacy efforts			
STRATEGIES	·		74		10		1	4			
1) Assess available resources/programs	1.1		3.1		5,1, 5.3, 5.4	6.1, 6.3	7.1	8.1			
2) Expand resources/ programs	1.2, 1.3, 1.4, 1.5, 1.6, 1.7		3.2, 3.3, 3.4				7.7, 7.8, 7.9, 7.10	8.2, 8.4, 8.5, 8.6, 8.7, 8.9			
3) Create a centralized resource directory/ clearinghouse		2.1, 2.2, 2.3, 2.4		4,1	5.2	6.2, 6.3	7.2, 7.4, 7.5, 7.6	0.1			
4) Conduct professional educational programs	-2	2.5, 2.8	3.2	4.2	5.5	6.4	7.3				
5) Form community partnerships, conduct community summits/ training programs		2.6, 2.9		4.3	5.0	6.4	2.11	8.6, 8.7, 8.8			
6) Conduct media campaigns to promote use of resources/ programs		2.7		4.4	5.7	6.5		8.3			

cancer survivors must also be multidisciplinary, drawing upon the expertise and contributions of oncology specialists, primary care practitioners, psychosocial and behavioral experts, program administrators, legislators and funding agencies, as well as cancer survivors and other advocates, stakeholders and constituencies that share this fundamental commitment to improving cancer survivorship in Colorado.

By way of summary, Table 2 lists the eight key objectives that have been identified to improve cancer survivorship in Colorado, including increasing the number of available information and educational resources (Objective 1) and service programs (Objective 3) for cancer survivors and promoting their use (Objectives 2 and 4); increasing the number of cancer survivors who receive treatment summaries and care plans (Objective 5); assisting in the development and/or dissemination of clinical practice guidelines for cancer survivors (Objective 6); promoting more program evaluation and cancer outcomes and intervention research in cancer survivorship (Objective 7); and finally, enhancing advocacy efforts for cancer survivors in Colorado (Objective 8). To achieve these eight main objectives, 56 different strategies have been identified. However, there are fundamental commonalities across all of these strategies that encompass multiple objectives and unfold in logical fashion. As shown in Table 2, these common strategies include assessing available resources or programs relevant to each objective; expanding or developing new resources and programs where gaps exist; creating a centralized resource or clearinghouse to facilitate access to these resources and programs; and conducting professional educational programs, community summits and other outreach efforts to help promote the use and extend the reach of these resources and programs. Taken together, these key objectives and strategies highlight the many significant opportunities that exist for improving cancer survivorship in Colorado as a major priority of the CCC.

Finally, two cross-cutting themes have also been emphasized in this chapter. The first involves the fundamental need to develop and promote use of information and educational resources and service programs that will be responsive to Colorado's underserved and diverse population of cancer survivors. The second involves the parallel need to develop and promote use of information and educational resources and service programs that specifically target rehabilitation, palliative care and end-of-life care. The Task Force was unanimous in its recommendation that these two themes receive special emphasis to underscore the pressing need to make significant and sustainable progress in both of these high priority areas.

# Objectives: Quality of Life

### Quality of Life 1

INCREASE THE NUMBER OF SUSTAINABLE INFORMATION AND EDUCATIONAL RESOURCES ACROSS THE FULL SPECTRUM OF CANCER SURVIVORSHIP, FROM DIAGNOSIS TO TREATMENT

TO CANCER SURVIVORSHIP POST-TREATMENT, INCLUDING REHABILITATION AS WELL AS PALLIATIVE AND END-OF-LIFE CARE.

- \* Identify available and recommended information and educational resources to promote informed treatment decision-making, to facilitate access to state-of-the-science cancer treatment and IRB-approved clinical trials, and to promote improved quality of life post-treatment. Such resources should include print materials, websites, telephone information systems and other resources provided by the National Cancer Institute, the American Cancer Society, the National Coalition for Cancer Survivorship, the Lance Armstrong Foundation and other recommended and authoritative sources.
- \* Where gaps exist in available information and educational resources for cancer survivors, develop new information and educational resources to fill these gaps.
- \* Conduct professional educational programs and other outreach efforts to increase the number of cancer resource centers at hospitals, medical centers and clinics.
- \* Form partnerships with public libraries, work sites and other community-based organizations to make these information and educational resources available to cancer survivors in their local communities.
- \* Continue to support and expand interactive decision-making support tools available on the CCC website and other vetted websites.
- \* Efforts by the CCC to increase the number of information and education resources for cancer survivors should include, as a high priority, resources that will effectively respond to the needs of low literacy and culturally diverse populations. Such efforts should include developing partnerships with organizations and other intermediaries that can provide access to under-served communities.
- \* CCC should include, as a high priority, increasing the number of information and educational resources that specifically focus on the critically important and distinct areas of rehabilitation, palliative care and end-of-life care.

#### Quality of Life 2

INCREASE THE USE OF THESE INFORMATION AND EDUCATIONAL RESOURCES FOR CANCER SURVIVORS ACROSS THE FULL SPECTRUM OF CANCER SURVIVORSHIP, FROM DIAGNOSIS TO TREATMENT TO CANCER SURVIVORSHIP POST-TREATMENT, INCLUDING REHABILITATION AS WELL AS PALLIATIVE AND END-OF-LIFE CARE.

- \* Create a centralized resource directory and clearinghouse of information and educational resources that can be accessed by the diverse populations of cancer survivors in Colorado (e.g., print, electronic and telephone; low literacy and non-English speaking cancer survivors).
- \* Expand the Colorado Coalition website to include links to other authoritative and approved websites that provide information and educational resources for cancer survivors.

- \* For newly diagnosed patients or patients with a recurrence, provide an oncology practice locator service to help match the patient to the provider organization most appropriate to treat the patient based on the patient's medical profile and geographic proximity to the patient.
- \* For newly diagnosed patients or patients with a recurrence, provide a locator service for IRB-approved clinical trials based on the patient's medical profile and geographic proximity of the trial to the patient.
- \* Conduct professional educational programs, including CME-accredited courses, to increase awareness of these information and educational resources by physicians, nurses, community and clinical navigators and other health professionals, and to encourage referrals to these resources for cancer survivors.
- \* Conduct cancer summits, educational seminars, workshops and other outreach efforts in the community to promote use of these information and educational resources by cancer survivors.
- \* Develop and implement a systematic and on-going campaign to promote use of these information and educational resources by cancer survivors using both traditional media and new social media technology.
- \* Drawing upon the substantial expertise that already exists in Colorado, conduct training workshops to promote the development and implementation of cancer resource centers in hospitals, medical centers and clinics statewide, as well as in public libraries, work sites and other community venues.
- \* Form a "Colorado Association of Cancer Survivorship Information Programs" to continue strategic planning, implementation and dissemination of community-based information and educational programs for cancer survivors statewide.

INCREASE THE NUMBER OF SUSTAINABLE SERVICE PROGRAMS ACROSS THE FULL SPECTRUM OF CANCER SURVIVORSHIP, FROM DIAGNOSIS TO TREATMENT TO CANCER SURVIVORSHIP POST-TREATMENT, INCLUDING REHABILITATION AS WELL AS PALLIATIVE AND END-OF-LIFE CARE.

- \* Identify available and recommended service programs for cancer survivors, including patient navigator programs, cancer support groups, behavioral programs for cancer survivors, cancer survivorship clinics, rehabilitation programs, and palliative care and end-of-life programs.
- \* Where gaps in geography exist in access to these programs and services, conduct workshops and training programs to either implement such programs at hospitals, medical centers and clinics to minimize or eliminate these gaps, and/or to promote referral patterns that would likewise minimize or eliminate these gaps for cancer survivors.

- \* Efforts by the CCC to increase the number of sustainable service programs for cancer survivors should include, as a high priority, efforts to develop and extend the reach of effective and sustainable evidence-based programs for low literacy and culturally diverse populations.
- \* Similar efforts by CCC should likewise include, as a high priority, efforts to develop and extend the reach of effective and sustainable evidence-based programs in the critically important areas of rehabilitation, palliative care and end-of-life care.

INCREASE THE NUMBER OF CANCER SURVIVORS WHO PARTICIPATE IN RECOMMENDED SERVICE PROGRAMS FOR CANCER SURVIVORS, INCLUDING PATIENT NAVIGATOR PROGRAMS, CANCER SUPPORT GROUPS, BEHAVIORAL PROGRAMS FOR CANCER SURVIVORS, CANCER SURVIVORSHIP CLINICS, REHABILITATION PROGRAMS, AND PALLIATIVE CARE AND END-OF-LIFE PROGRAMS.

- \* Create a centralized resource directory and clearinghouse of cancer survivor programs that can be accessed by the diverse populations of cancer survivors in Colorado (e.g., print, electronic and telephone; low literacy and non-English speaking cancer survivors).
- \* Conduct professional educational programs targeting physicians, nurses, clinical and community navigators and other health professionals, including CME-accredited courses, to increase awareness of these service programs and to promote referrals and access to these programs.
- \* Conduct cancer summits, educational seminars, workshops and other outreach efforts in the community to promote use of these service programs by cancer survivors.
- \* Develop and implement a systematic and on-going campaign to promote use of these programs by cancer survivors using both traditional media and new social media technology.

#### Quality of Life 5

INCREASE THE NUMBER OF CANCER SURVIVORS IN COLORADO WHO RECEIVE TREATMENT SUMMARIES AND CARE PLANS POST-TREATMENT. ENCOURAGING COORDINATION OF FOLLOW-UP CARE BETWEEN ONCOLOGY SPECIALISTS AND PRIMARY CARE PRACTITIONERS (PHYSICIANS AND/OR NURSES) SHOULD BE A FUNDAMENTAL CONSIDERATION WHEN FORMULATING THESE SURVIVORSHIP CARE PLANS.

- \* Identify available treatment summaries and care plans or tools to create such documents that are either currently being used in Colorado or are recommended for use by authoritative sources in cancer survivorship.
- \* Create a centralized resource or clearinghouse of these treatment summaries and care plans, and promote the use of this clearinghouse by oncology specialists, primary care physicians, navigators and cancer survivors.

- \* Provide an evaluation tool for treatment summaries and care plans that will assess their comprehensiveness based on recommendations of the IOM. For those treatment summaries and care plans that do not adequately address all components, encourage oncology specialists to include this information, and primary care physicians and cancer survivors to request this information.
- \* Encourage, facilitate and collaborate in an expert review of existing treatment summaries and care plan templates regarding their utility for low literacy and culturally diverse populations. Based on this review, promote and collaborate in efforts to revise or develop new treatment summary and care plan templates as appropriate for low literacy and culturally diverse populations that address all key components recommended by the IOM.
- \* Conduct professional educational programs targeting physicians, nurses, clinical and community navigators and other health professionals, including CME-accredited courses, to increase awareness of the importance of treatment summaries and coordinated care plans with primary care practitioners, and to provide these summaries and care plans to cancer survivors post-treatment. These professional education efforts should include, as a high priority, promoting the use of cancer treatment summaries and care plans that are vetted and approved by CCC for low literacy and culturally diverse populations.
- \* Conduct cancer summits, educational seminars, workshops and other outreach efforts in the community to encourage and empower cancer survivors to request and receive a treatment summary and a coordinated care plan post-treatment. These outreach efforts should also include, as a high priority, promoting the use of cancer treatment summaries and care plans that are vetted and approved by CCC for low literacy and culturally diverse populations.
- \* Develop and implement a systematic and on-going campaign, using traditional media and new social media technology, to encourage cancer survivors to request and receive a treatment summary and a coordinated care plan post-treatment.

FACILITATE AND ENGAGE IN ON-GOING EFFORTS NATIONWIDE TO DEVELOP AND DISSEMINATE EVIDENCE-BASED OR CONSENSUS-APPROVED CLINICAL PRACTICE GUIDELINES FOR USE WITHIN POST-TREATMENT CARE PLANS FOR CANCER SURVIVORS, INCLUDING GUIDELINES FOR MEDICAL SURVEILLANCE AND FOLLOW-UP, AS WELL AS REFERRALS TO PSYCHOSOCIAL AND BEHAVIORAL PROGRAMS FOR CANCER SURVIVORS.

\* Conduct workshops and summits involving oncology specialists, primary care practitioners as well as psychosocial and behavioral experts in oncology to recommend state-of-the-science clinical practice guidelines for cancer survivors in Colorado, informed by corresponding efforts that are occurring nationwide. These clinical practice guidelines should systematically encompass the full spectrum of care provided to

- cancer survivors, including medical surveillance and follow-up, behavioral and psychosocial programs, as well as rehabilitation, palliative care and end-of-life care.
- \* Monitor the on-going development of clinical practice guidelines for cancer survivors at the state, regional and national levels and provide a centralized resource and clearinghouse for disseminating clinical practice guidelines for use in post-treatment care plans for cancer survivors.
- \* Monitor the on-going development of assessment tools to determine the need for services consistent with these clinical practice guidelines (e.g., practice guidelines related to psychosocial morbidity or non-adherence to behavioral recommendations for cancer survivors), and include these assessment tools in the centralized resource to facilitate dissemination and use of clinical practice guidelines in post-treatment care plans for cancer survivors.
- \* Conduct workshops, community summits and engage in other promotion activities, including CME-accredited courses, to promote awareness and use of this centralized resource containing recommended clinical practice guidelines and assessment tools for cancer survivors. These workshops and summits should target academic and community-based hospitals and medical centers, as well as oncology specialists, primary care practitioners, cancer survivors and other advocates and stakeholders.
- \* Develop and implement a systematic and on-going campaign, using traditional media and new social media technology, to encourage cancer survivors to become more aware of these clinical practice guidelines and request that they be assessed and included in their care plans post-treatment.

INCREASE PROGRAM EVALUATION AND OUTCOMES RESEARCH IN CANCER SURVIVORSHIP, WITH THE FORMER ASSESSING CANCER SURVIVORSHIP RESOURCES AND PROGRAMS IN TERMS OF REACH, IMPLEMENTATION FIDELITY, PERCEIVED UTILITY, SATISFACTION AND SUSTAINABILITY, WITH THE LATTER ASSESSING EFFICACY WITH RESPECT TO IMPROVING CANCER SURVIVORSHIP CARE AND/OR SURVIVORSHIP OUTCOMES RELEVANT TO THE DIFFERENT PHASES OF CANCER SURVIVORSHIP (E.G., DURING TREATMENT, POST-TREATMENT, PALLIATIVE AND END-OF-LIFE CARE).

- \* Identify available reports and publications involving evaluations of cancer survivorship programs in Colorado as well as nationwide.
- \* Create a clearinghouse of these reports and publications, and promote the use of this clearinghouse as a resource for program administrators, oncology specialists and other health care professionals, as well as for researchers, program evaluators, cancer survivors and other advocates and constituencies in cancer survivorship.
- \* Conduct educational programs and training workshops targeting physicians, nurses and other service providers, including CME-accredited courses, on the importance of

- program evaluation and outcomes research and the methodologies that can be used in such research.
- \* For cancer survivorship programs approved and/or promoted by CCC, encourage systematic program evaluation, and when appropriate and feasible, outcomes and efficacy research, and provide a centralized resource where summaries of these evaluations can be accessed by program administrators, oncology specialists and other health care providers, as well as by researchers, program evaluators, and other stakeholders and constituencies.
- \* Create a centralized resource and clearinghouse of frequently used assessments in cancer survivorship research, including coding manuals and representative studies that have used these assessments.
- \* Create a centralized resource and clearinghouse of potential funding opportunities and announcements that could promote cancer survivorship research collaborations in Colorado.
- \* Ensure that the Behavioral Risk Factor Surveillance System (BRFSS) includes on a regular basis both the core and supplemental cancer survivorship modules developed by the Centers for Disease Control and Prevention.
- \* Develop quantitative benchmarks using the BRFSS and other sources to monitor progress in cancer survivorship in Colorado, and publish these findings on a regular basis under the auspices of the CCC.
- \* Enhance the utility of the BRFSS to serve as a resource for monitoring progress in cancer survivorship by adding new questions to assess unmet needs and access to appropriate information and educational resources and service programs across the full spectrum of cancer survivorship, including rehabilitation, palliative care and end-of-life care.
- \* Promote research efforts that specifically focus on evaluating cancer survivorship programs, resources and materials for low literacy and culturally diverse populations in Colorado.
- \* Create and maintain a network of volunteer advisors who can assist and partner with community-based cancer survivorship programs to facilitate program evaluation and/or pursue additional opportunities for cancer survivorship research. Such advisors should include oncology specialists and other health professionals, researchers, survivor advocates and survivorship program experts, as well as experts in under-served and culturally diverse populations.

INCREASE ADVOCACY FOR CANCER SURVIVORSHIP PROGRAMS AND RESOURCES AT THE LOCAL, STATE, REGIONAL AND NATIONAL LEVELS.

- \* Identify key organizations and individuals who are actively engaged in advocacy efforts for cancer survivors, and secure their permission to include them in a clearinghouse or registry with their contact information and areas of interest in cancer survivorship.
- \* Develop and implement a systematic and on-going campaign, using traditional media and emerging new social media, to increase the number of organizations and individuals included in this clearinghouse or registry for cancer survivorship advocacy in Colorado.
- \* Promote the use of this clearinghouse or registry to leverage support as well as to broaden and intensify cancer survivorship advocacy in Colorado.
- \* Create and promote a "Cancer Survivorship Advocacy Working Group" to continue strategic planning for cancer survivorship advocacy efforts, and to coordinate and implement such efforts at the local, state, regional and national levels. Members of this working group should include representatives of the advocacy community, health professionals, survivorship experts, researchers, as well as members from other CCC Task Forces. This working group should coordinate their efforts with the existing Policy and Advocacy Task Force of the CCC.
- \* Within the organizational structure of the CCC, designate one person to serve as the key contact point and coordinator for cancer survivorship advocacy efforts conducted under the auspices of the CCC.
- \* Intensify and expand partnerships with the American Cancer Society, the National Coalition for Cancer Survivorship, the Lance Armstrong Foundation and other cancer advocacy groups and constituencies to leverage their support and expertise in advocating for resources, programs and legislation to improve cancer survivorship in Colorado and beyond.
- \* Target a broad spectrum of organizations, agencies and other constituencies to improve cancer survivorship in Colorado, including legislators, policy makers and program administrators, health care organizations and foundations, the mass media and the insurance industry, as well as other organizations and constituencies that can facilitate or enable such improvements in cancer survivorship resources, programs and initiatives.
- \* Conduct cancer summits and training workshops to recruit new cancer advocates, and to educate, train and encourage cancer advocates to become more active and effective in advocating for cancer survivorship at the local, state, regional and national levels.
- \* Include among the high priority areas for advocacy efforts in cancer survivorship:
  - Increased funding and other sources of support to sustain, update and expand information and educational resources across the full spectrum of cancer survivorship, and to eliminate health literacy, sociocultural, communication technology and other barriers that can impede the utility of such resources as well as their accessibility.
  - Increased funding and other sources of support to sustain, update and expand service programs across the full spectrum of cancer survivorship, and to eliminate economic, health literacy, sociocultural, geographic and other barriers

that can impede both the utility and accessibility of these service programs. Such programs should include decision-support programs and tools for making informed treatment decisions, patient navigation programs, programs to help patients and survivors manage short and longer term treatment side effects and encourage recommended medical follow-up, psychosocial and behavioral programs, as well as rehabilitation, palliative care and end-of-life programs and resources.

- Improved access to state-of-the-science cancer treatments, regardless of ability to pay.
- Improved access to IRB-approved clinical trials, regardless of ability to pay.
- Legislation, quality assurance directives and reimbursement incentives for oncologists that will enable cancer survivors to receive treatment summaries and care plans post-treatment, including care plans that incorporate coordination of care between oncologists and primary care physicians.
- Increased efforts to develop and promote the use of clinical practice guidelines for managing cancer survivorship care post-treatment.
- Increased statutory and other legal protections for cancer survivors involving return to work and family leave policies, both during and after completion of primary therapy.
- Increased funding for program evaluation and outcomes research across the full spectrum of cancer survivorship.

# **EVALUATION & RESEARCH**

# Monitoring, Surveillance, Evaluation & Research



Monitoring and surveillance, evaluation, and research are interrelated functions that are overseen by a subcommittee of the Colorado Cancer Coalition (CCC). Monitoring and surveillance is the ongoing, systematic collection, analysis and interpretation of health-related data essential to the planning, implementation and evaluation of public health practices. Program evaluation is the systematic collection of information about the activities, characteristics and outcomes of programs done to make judgments about the program, improve program effectiveness and/or inform decisions about future programming. Evaluations include surveillance and program monitoring. Research increases the extent to which cancer planning and programming decisions are made on the basis of sound evidence. Accurate and complete data and solid research form the underpinnings for comprehensive cancer control. The implementation of monitoring and surveillance, evaluation, and research are essential to all aspects of the Colorado cancer plan and are closely integrated with the timely dissemination of data to those responsible for cancer prevention and control.

Current monitoring and surveillance activities in Colorado are grouped into two main categories: morbidity and mortality and information and risk behavior. Surveillance of cancer morbidity and mortality, conducted by the Colorado Central Cancer Registry (CCCR) and the Health Statistics Section at the Colorado Department of Public Health and Environment, provides information on the occurrences and deaths due to cancer in Colorado.

The CCCR, established within the Colorado Department of Public Health and Environment by Colorado Revised Statutes 1989, Section 25-1-107 (1) (z), collects information from local hospital tumor registries, private pathology laboratories, death certificates, Colorado physicians and surrounding states about cancer cases among Colorado residents. By regulation from the Colorado Board of Health, cancer is a reportable disease in Colorado, and all reports of cancer cases received by the Department, in connection with the Registry, shall remain strictly privileged and

confidential as "medical records and reports" within the purview and intent of Section 25-1-122 (4), Colorado Revised Statutes 1989.

Data from the CCCR are used to describe the incidence of various cancers, stage at diagnosis and relative survival rates. Statistics on mortality from cancer are produced routinely by the Health Statistics Section and published in conjunction with the CCCR's data.

Determination of cancer incidence and mortality rates permit trend analysis and comparison with national cancer incidence and mortality rates. Regional differences within Colorado also can be determined. Routine reports and special studies are produced by the CCCR to keep policy makers and planners informed of changes in cancer incidence trends. Additionally, assessment of cancer risk behaviors for the population as a whole and for selected groups provide information used in designing focused interventions.

Health risk behaviors have been monitored in Colorado since January 1990 by the Colorado Behavioral Risk Factor Surveillance System (BRFSS), funded by the Centers for Disease Control and Prevention CDC). The BRFSS is annual random telephone survey of adults in Colorado that collects information on a number of health behaviors, including tobacco use, diet and cancer screening behaviors.

Since 1988, the Comprehensive Cancer Program (CCP) at the Colorado Department of Public Health and Environment has used a variety of surveys to collect information specific to screening behaviors for breast, cervical and prostate cancer. The purpose of these surveys is to monitor changes in the public's knowledge, attitudes and behaviors relevant to screening and treatment and to monitor penetration of public education and outreach efforts.

Other cancer control programs and organizations throughout the state gather information through surveys and special studies of the populations they serve. Several sources collect information on cancer risk factors and preventive behaviors among Colorado residents.

Additional studies on risk behaviors, physician and patient attitudes on cancer screening and practice, and other special topics have been conducted by such groups as the American Cancer Society (ACS), Susan G. Komen for the Cure Foundation, the University of Colorado Cancer Center, and other professional societies.

Evaluation is a key component of the state plan so that cancer prevention and control efforts can be directed appropriately, based on regional or population-specific risks. The evaluation uses strategies for assessing both processes and outcomes associated with comprehensive cancer control planning and implementation. Additionally, a contracted evaluator conducts an ongoing evaluation of the efforts of the Colorado Cancer Coalition. The CDC provides the framework for the evaluation model utilized by the CCP.

# Objectives: Monitoring, Surveillance, Evaluation & Research

#### Evaluation & Research 1

CONTINUE TO MONITOR AND CARRY OUT SURVEILLANCE ACTIVITIES USING EXISTING SYSTEMS, WHICH ALLOW FOR FURTHER ANALYSIS.

- \* Continue advocacy, funding and support for the following existing data collection systems:
  - Behavioral Risk Factor Surveillance System (BRFSS)
  - Colorado Central Cancer Registry (CCCR)
  - Colorado Women's Cancer Control Initiative (CWCCI)
  - Tobacco Attitudes and Behavior Survey (TABS)
  - Youth Risk Behavioral Survey (YRBS)
  - Youth Tobacco Survey (YTS)
  - Child Health Survey (CHS)
  - Pregnancy Risk Assessment Monitoring System (PRAMS)
  - Vital Statistics
- \* Use cancer-related data for monitoring and surveillance of cancer risk factors, preventive behavior, incidence, stage at diagnosis, treatment, survival, rehabilitation, race/ethnicity, socioeconomic status, insurance status and mortality.
- \* Determine the feasibility of linking cancer screening history to the cancer registry.
- \* Measure and monitor under-served populations (i.e., low socioeconomic status, uninsured). Consider gaining education and household income data from hospitals and improving the quality of data on insurance status.
- \* Compare Colorado cancer data related to Healthy People 2020 targets by race/ethnicity.



\* Review Colorado's cancer data to identify any gaps that may exist in Colorado's data systems (use Georgia's Institute of Medicine (IOM) report for comparison).

#### Evaluation & Research 2

ANNUALLY EVALUATE THE COLORADO CANCER PLAN WITH THE COLORADO CANCER COALITION AND TASK FORCES TO DETERMINE THE SUCCESS OF IMPLEMENTATION.

#### Strategies:

- \* Continue to convene a surveillance and evaluation subcommittee experienced and knowledgeable in monitoring and surveillance, evaluation, and research.
- \* Develop and implement a comprehensive monitoring and evaluation plan to assess the implementation of objectives and strategies of the Colorado Cancer Plan.
- \* Assess and evaluate the efficacy of the objectives and strategies of the Colorado Cancer Plan by determining impact on changes in cancer-related outcomes.
- \* Extend the Patterns of Care Study to Colorado (patterned after Georgia's IOM).
- \* Report evaluation results at each annual Colorado Cancer Conference.

#### Evaluation & Research 3

BY 2015, DEVELOP DATA SOURCES FOR THOSE OBJECTIVES AND STRATEGIES FOR WHICH BASELINE DATA CURRENTLY DO NOT EXIST.

#### Strategies:

- \* Identify gaps in the data (use Georgia's IOM report for comparison).
- st Determine potential data sources or develop data sources as needed.
- \* Propose modifications to any of the existing data collection mechanisms if data elements are inconsistent, lack specificity, or are not used.
- \* Make recommendations on data that need to be added to increase or create capacity for monitoring/surveillance, research, and evaluation.
- \* Establish baseline data for any other chapters (e.g., palliative care, health disparities) for which baseline data should be determined.

#### Evaluation & Research 4

YEARLY, EVALUATE THE EFFORTS OF THE COLORADO CANCER COALITION.

#### Strategies:

\* Assess Coalition member satisfaction.

- \* Assess Coalition member activities on a regular basis to determine if they are implementing the Colorado Cancer Plan.
- \* Identify under-represented groups/regions for membership involvement (e.g., African-Americans, OB-GYN, rural, contact for the uninsured).

## Evaluation & Research 5

ON AN ANNUAL BASIS, COMPILE AND DISSEMINATE DATA IDENTIFIED IN THE AFOREMENTIONED OBJECTIVES 1, 2, 3, 4 (LISTED IN THIS CHAPTER) TO PROVIDE A FULL DISCLOSURE AND IMPARTIAL REPORTING ON THE PLAN'S PROGRESS, ACCOMPLISHMENTS, AND OPPORTUNITIES FOR IMPROVEMENT.

## Strategies:

- \* Continue funding or advocate for funding to incorporate these sources of data into statewide reports.
- \* Collaboratively disseminate reports and information in a meaningful manner to appropriate audiences.
- \* Increase the Colorado Cancer Coalition's involvement in writing and disseminating reports by developing a communication plan for the public (i.e., through press releases).
- \* Increase media exposure to educate the public and professionals about cancer in Colorado.
- \* Produce an Annual Report from the Coalition including prevalence rates, trends, and other pertinent studies related to previously mentioned data sets.
- \* Colorado Cancer Coalition's website.
- \* Establish plans and implement the training of potential users (particularly non-traditional users) to appropriately use available information to increase professional and public understanding and

education about cancer and its impact on Colorado citizens.

#### Evaluation & Research 6

PROMOTE THE IMPORTANCE OF CONDUCTING RESEARCH ON CANCER PREVENTION, TREATMENT, AND SURVIVORSHIP.

## Strategies:

- \* Establish and maintain a tracking system of research projects.
- \* Develop a research agenda working in coordination with the task forces to prioritize research conducted on cancer prevention (including screening), treatment, and survivorship.

## Evaluation & Research 7

BY 2015, INCREASE THE SCOPE OF DATA ON CANCER RISK FACTORS AND PREVENTATIVE BEHAVIOR THROUGHOUT A PERSON'S LIFETIME.

#### Strategies:

- \* Explore development of data collection to capture this information.
- \* Establish a plan to gather information on children and cancer-related behavior.
- \* Add questions to the Behavioral Risk Factor Surveillance System (BRFSS), which inquire about behavioral issues with children in the household; for example, second hand smoke exposure.
- \* Produce a report on prevalence rates, trends, and other pertinent studies related to these data.
- \* Consider examining the relationship between obesity and cancer trends in Colorado using data from hospital records.
- \* Work with health care organizations to develop mechanisms for gathering and reporting cancer-related behaviors (i.e., risk factors and screening).



## Evaluation & Research 8

BY 2015, DEVELOP ENHANCED CANCER REGISTRATION CAPABILITIES.

## Strategies:

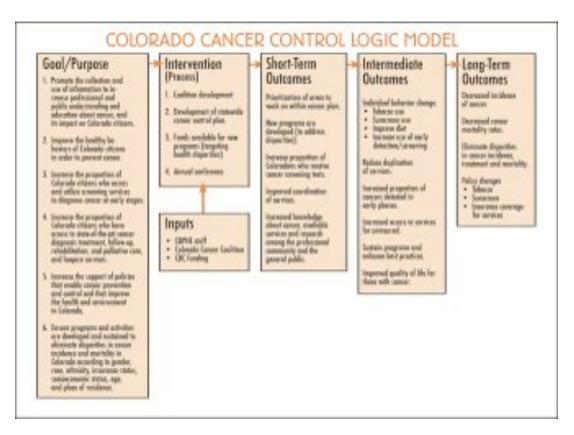
- \* Assist the Cancer Registry in developing partnerships with large private oncology clinics to obtain outpatient treatment information.
- \* Promote recruitment and retention of certified tumor registrars in Colorado.
- \* CCCR Director or other CCCR staff will make presentation to Health Information Management classes (at Regis University and/or Arapahoe Community College) about the cancer registry profession.
- \* CCCR will provide regular training sessions for Colorado registrars to promote continuing education.
- \* Develop measures of socioeconomic status beyond race/ethnicity that are collected by the CCCR.
- \* Use cancer registry data for physician education and/or notification projects. (eg., alerting physicians that specific patients are at increased risk for "X" because they have a set of conditions "Y.")
- \* Facilitate data linkages between CCCR and other databases to obtain follow-up information (e.g., Medicare and Medicaid, for example).

<b>COORDINA</b>	TION &	FVALIL	ATION

# Coordination & Evaluation

In recent years, the state health department and other health organizations have significantly enhanced the number and quality of cancer-related programs conducted in Colorado. Most of these, however, came about through issue-specific grants that impose restrictions and limitations on program activities, cross-program collaboration, and planning across cancer sites and risk factors. Although Colorado has an existing infrastructure for public-private collaboration in which public health functions are integrated into the larger health system, a formal structure is needed to ensure that comprehensive cancer prevention, control, and care happens in a systematic and synchronized manner. The following are objectives and strategies for implementing this plan.

The following logic model is used to guide the efforts of the Colorado Cancer Coalition (CCC) to implement this plan:



The CCC Executive Committee interfaces with health and disease-specific task forces. These task forces are established as volunteers and interested parties convene to address certain issues.

Each member organization is represented on the CCC and may bring issues for discussion and

action for consideration of the CCC as a whole. Participation of individual member organizations in various projects such as this one can be queried via email listserv.

# Governance & Membership

According to the CCC rules of operation, membership is open to any organization whose mission is not in conflict with coalition priorities and who meets all membership requirements. Each member organization is expected to do the following:

- \* Endorse and support the implementation of CCC priorities.
- \* Assist with recommending and recruitment of new members.
- \* Coordinate and collaborate within its own organization to implement strategies that address one or more CCC priorities.
- \* Coordinate and collaborate with one or more other organizations to implement strategies that address on or more CCC priorities.
- \* Provide information at least annually about organization progress and accomplishments.
- \* Attend regularly scheduled meetings (attendance can be in person or via teleconference). If unable to attend, all effort will be made to appoint someone to attend in place.
- \* Share ideas, recommendations, and agree to disagree.



## Budget & Financing

#### Sources of Support Received by the Coalition

Colorado's Comprehensive Cancer Program invests a portion of its Center's for Disease Control and Prevention (CDC) funding dollars in the cancer initiative. The first state appropriation for the CCC was made in 2009. These funds are used for basic infrastructure and communication needs.

While state appropriations represent the bedrock of the coalition's funding in its formative years, the initiative is dedicated to developing a balanced portfolio of financial support. The

CCC has also receives private donations and in-kind gifts. As programs continue to develop, individual contributions, proceeds from events, corporate gifts, and foundation and government grants will be emphasized as essential to the CCC's ability to leverage its state appropriation.

More detailed information about the Colorado Cancer Coalition and its activities can be accessed at www.coloradocancercoalition.org.

# Objectives: Coordination & Evaluation

#### Coordination & Evaluation 1

BY 2015, CONTINUE EFFORTS OF THE COLORADO CANCER COALITION, A PUBLIC-PRIVATE COLLABORATION THAT FOCUSES ON COMPREHENSIVE CANCER PREVENTION AND CONTROL.

(BASELINE: THE CCC HAS MET FORMALLY ON A QUARTERLY BASIS SINCE 1993.)

## Strategies:

- \* Seek multiple funding sources to support the Colorado Cancer Coalition (CCC) and to implement priority strategies of the Colorado Cancer Plan.
- \* Share programs, resources and best practices among CCC members.
- \* Hold an annual Colorado Cancer Summit to share best practices, increase skills and commence new initiatives throughout the state.

## Coordination & Evaluation 2

MONITOR AND COORDINATE CANCER CONTROL AND QUALITY-OF-LIFE ACTIVITIES IN COLORADO.

#### Strategies:

- \* Maintain the use of the Colorado Cancer Coalition websites to continue online information service for cancer control in Colorado.
- \* Continue to maintain and enhance the Colorado Cancer Coalition, enhancing its value, membership and efficacy.
- \* Continue to monitor screening guidelines, and influence prompt dissemination and incorporation of science-based recommendations.
- \* Continue to influence content of cancer- related guidelines to match current evidence.
- \* Keep apprised of, and disseminate information on, the activities of organizations engaged in implementing or supporting cancer control and quality-of-life activities in Colorado.

## Coordination & Evaluation 3

ON A YEARLY BASIS, EVALUATE THE IMPLEMENTATION OF THE COLORADO CANCER PLAN.

## Strategies:

- \* Conduct evaluation of the Plan annually.
- \* Disseminate evaluation information on an annual basis at the Colorado Cancer Summit and revise the Plan as needed.

#### Coordination & Evaluation 4

ON A YEARLY BASIS, DEVELOP AND IMPLEMENT AN EVALUATION PLAN FOR THE COLORADO CANCER PLAN.

#### Strategies:

- \* Recruit and convene a planning and implementation committee experienced and knowledgeable in evaluation techniques.
- \* Assess and evaluate the efficacy of the Colorado Cancer Plan's strategies by determining its impact on the knowledge and behavior of the citizens of Colorado, and by measuring the resulting changes in cancer-related outcomes.
- \* Develop an evaluation plan and receive approval for its content by majority vote of the Colorado Cancer Coalition.
- \* Perform an annual evaluation and avail the community of its outcomes through the Coloradocancerplan.org website.

# REFERENCES & RESOURCES

# Introduction

• Cancer in Colorado, 1997-2007: Incidence, Mortality, and Survival

Steele CB, Cardinez CJ, Richardson LC, Tom-Orme L, Shaw K. Surveillance for Health Behaviors of American Indians and Alaska Natives--Findings from the Behavioral Risk Factor Surveillance System, 2000-2006, CANCER, 113(S5):1131-41, 2008.

# Health Equity

#### References:

- Joseph A. Salvato states in his popular book <u>Environmental Engineering and Sanitation</u> that Environmental Health is, "The systematic development, promotion, and conduct of measures which modify or otherwise control those external factors in the indoor and outdoor environment which might cause illness, disability or discomfort through interaction with the human system."
- According to the CDPHE report, <u>Cancer and Poverty; 1995-2006</u>, "Those from poorer areas had worse survival for all cancers combined for most of the race/ethnicity, gender, and age groups. Five-year survival rates were 8-13 percent lower for persons living in poorer areas." In addition, Coloradans with lower incomes were more likely to smoke tobacco, to be obese, to be less physically active, and to not participate in screening tests for breast, cervical, or colorectal cancer. The people living in poorer neighborhoods and who had no health insurance were also more likely to be diagnosed with cancer at a more advanced stage and were more likely to die within the first 5 years following cancer diagnosis.

# Objective 1.1:

INCREASE PUBLIC AND PROFESSIONAL AWARENESS ABOUT CANCER-RELATED HEALTH INEQUITIES EXPERIENCED BY COLORADO POPULATIONS.

#### Resources:

Colorado Health Disparities Profiles

http://www.chd.dphe.state.co.us/HealthDisparitiesProfiles/dispHealthProfiles.aspx

The Colorado Health Disparities Regional Profiles site is an initiative of the Health Statistics Section at the Colorado Department of Public Health and Environment (CDPHE) and Project TEACH (Teaching Equity to Advance Community Health) in response to the health data needs of our communities. Users can look for key health indicators by ethnic/racial groups by geographical areas of the state.

C-Change: Collaborating to Conquer Cancer: Formerly Known as the National Dialogue on Cancer

http://c-changetogether.org

The mission of C-Change is to eliminate cancer as a public health problem, at the earliest possible time by leveraging the expertise and resources of our members.

C-Change Cancer Core Competency Initiative: Strengthening Cancer Competencies in the Non-Oncology Health Workforce

http://www.cancercorecompetency.org/

This website provides insight into the work force crisis and presents a web-based toolkit outlining a step-by-step approach to a competency-based approach to program development.

• Cancer and Poverty in Colorado, 1995-2006. Denver, Colorado: Colorado Department of Public Health and Environment, 2008.

http://www.cdphe.state.co.us/pp/ccpc/cancerpoverty08.pdf

This report provides updated information on the relationship between poverty and cancer by adding data from the years 2001-2006 to the analysis from a previous report on this topic and may be useful to policy makers, health care professionals and community groups to assist in developing and evaluating prevention and intervention strategies, identifying high risk populations and prioritizing resource allocations for cancer-related services.

Colorado Clinical and Translational Sciences Institute (CCTSI) (includes Project Teach)

http://cctsi.ucdenver.edu/Pages/index.aspx

The Colorado Clinical and Translational Sciences Institute (CCTSI) is the academic home of biomedical research that reaches from labs into lives. Biomedical research reaches its potential when lab results generate improved health care without disparity. In the same way, health care practice reaches its full potential when real-life biomedical outcomes inform lab investigations.

Colorado Department of Public Health and Environment, Colorado Health Data

http://www.chd.dphe.state.co.us/default.aspx

You can access up-to-date data from many programs within the state health department through this page.

 Colorado Department of Public Health and Environment, Office of Health Disparities. Racial and Ethnic Health Disparities in Colorado 2009

http://www.cdphe.state.co.us/ohd/

This 2009 report updates and expands on the findings of the 2005 report while retaining a focus on Colorado's four major communities of color: Hispanics/Latinos, African-Americans/Blacks, American Indians and Asians/Pacific Islanders. Several new features have been added.

• Intercultural Cancer Council (ICC)

http://iccnetwork.org/cancerfacts/

The ICC Cancer Fact Sheets were created because medically under-served populations, such as racial and ethnic minorities, experience disproportionately greater suffering and compromised health from cancer compared to the U.S. population as a whole.

 Intercultural Cancer Council (ICC), Cultural Competence in Cancer Care: A Health Care Professional's Passport pocket guide

http://iccnetwork.org/pocketquide/index.html

This pocket guide takes the health care professional on a cross-cultural journey to increase awareness, knowledge, attitude and skills while working with disadvantaged and racial/ethnic patients and families. These families are encountered in a variety of primary care settings, including community health centers, outpatient clinics, private medical offices and hospitals.

 Promoting Health Equity—A Resource to Help Communities Address Social Determinants of Health, US DHHS, Centers for Disease Control and Prevention, 2008,

http://www.cdc.gov/nccdphp/dach/chaps/pdf/SDOHworkbook.pdf

This workbook is for community-based organizations seeking to affect the social determinants of health through community-based participatory approaches and nontraditional partnerships.

US DHHS, National Cancer Institute, Center to Reduce Cancer Health Disparities

http://crchd.cancer.gov/

The Center to Reduce Cancer Health Disparities (CRCHD) is central to the NCI's efforts to reduce the unequal burden of cancer in our society and train the next generation of competitive researchers in cancer and cancer health disparities research. One in four deaths in the United States is attributable to cancer, and one in three Americans will eventually develop some form of cancer. The burden of cancer is too often greater for the poor, ethnic minorities and the uninsured than for the general population.

Quick Health Data Online, Health Disparities Report

http://www.healthstatus2020.com/owh/disparities/ChartBookData\_list.asp

The 2009 Health Disparities Profiles examines key health indicators at the state level for different racial and ethnic populations in each of the 50 states, the District of Columbia, Guam, Puerto Rico and the US Virgin Islands. Twenty-one health indicators are presented that highlight some of the key areas related to health disparities among different populations. It can be used as a reference for policymakers and program managers to identify areas where major health disparities exist in each state.

• US DHHS, Centers for Disease Control and Prevention, Office of Minority Health and Health Disparities

http://www.cdc.gov/omhd/Populations/populations.htm

Though health indicators such as life expectancy and infant mortality have improved for most Americans, minorities experience a disproportionate burden of preventable disease, death and disability compared with non-minorities. These trends compel the public health community to examine issues of health disparity among the various racial and ethnic groups that comprise the country's population. This site has detailed data about each of these groups.

• US DHHS, Office of Minority Health, National Partnership for Action to End Health Disparities

http://minorityhealth.hhs.gov/npa/

The mission of the National Partnership for Action is to mobilize and connect individuals and organizations across the country to create a nation free of health disparities, with quality health outcomes for all people. This will be a road map for the elimination of the health disparities that burden our nation.

## Objective 1.2:

EXPAND CULTURALLY-RELEVANT AND PATIENT-CENTERED CANCER HEALTH EDUCATION, OUTREACH PROGRAMS, AND CANCER-RELATED INTERVENTIONS.

#### Resources:

• National Standards on Culturally and Linguistically Appropriate Services (CLAS):

http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15

The CLAS standards are primarily directed at health care organizations; however, individual providers are also encouraged to use the standards to make their practices more culturally and linguistically accessible. The principles and activities of culturally and linguistically appropriate services should be integrated throughout an organization and undertaken in partnership with the communities being served.

• American Cancer Society - cancer information services

 $\frac{\text{http://www.cancer.org/docroot/AA/content/AA}\_2\_2\_Cancer\_Information\_Services.asp?}{\text{sitearea}=AA}$ 

Minority Nurse

http://www.minoritynurse.com/cancer/nurses-culture-and-cancer

Through culturally competent outreach, education, research and patient care, nurses can make a dramatic difference in reducing minority cancer disparities.

Cancer Prevention & Control – culturally competent effective interventions

http://www.thecommunityguide.org/cancer/index.html

CancerCare

http://www.cancercare.org

A national nonprofit organization that provides free, professional support services for anyone affected by cancer.

Susan G. Komen for the Cure – Breast Cancer Resources

http://ww5.komen.org/

Developing Effective Cancer Education Print Materials for Hispanics/Latinas

http://ww5.komen.org/uploadedFiles/Content\_Binaries/Hispanic.pdf

Promotoras for Cancer Prevention

http://www.fhcrc.org/about/pubs/center\_news/2005/jun2/sart3.html

Native American Cancer Research

http://natamcancer.org/index.html

• Quality Health Services for Hispanics: The Cultural Competency Component

http://www.hrsa.gov/culturalcompetence/

LARASA

http://www.larasa.org/

LARASA has education and health initiatives that deliver direct services to and act as a resource for students and families. They work to increase access to adequate health care and health insurance for Latino children and families, both native-born and immigrant.

## Gay, Lesbian, Bisexual and Transgender & Cancer Organization:

Cancer and the GLBT Community

http://www.jri.org/glbtnew/AmericanCancerSocietyMaterials.htm

LGBTIQQA Cancer Survivorship

http://www.coloradoglbt.org/CancerCare\_Survivorship.aspx

Connecting You With LGBT-Friendly Health-Care Professionals

http://www.coloradoglbt.org/Health.aspx

## Survivorship:

Cancer Rehabilitation for Low Income and Hispanic Breast Cancer Patients (Project REGAIN)

 $\underline{\text{http://www.uccc.info/for-healthcare-professional/cancer-center/prevention/Survivorship/cancer-center-based-projects.aspx}$ 

# Community Based and Not-for-profit Organizations, Foundations & Public Health Associations:

• CO Foundation for Public Health & Environment

http://www.cfphe.org/

Colorado Environmental Coalition

http://www.ourcolorado.org/

Alliance for Sustainable Colorado

http://sustainablecolorado.org/about-us

CO Environmental Health Association

http://www.cehaweb.com/about.html

CO Public Health Association

http://www.coloradopublichealth.org/documents/CPHAStrategicPlan2008.pdf

Piton Foundation

http://www.piton.org/CommunityFacts

Colorado Progressive Coalition

http://progressivecoalition.org/

• Cross-Community Coalition

http://www.familytofamilydenver.org/CrossCommunityCoalition/index.htm

National Environmental Health Association - Located in Denver

http://www.neha.org/index.shtml

#### State Government Agencies

University of Colorado at Denver Division of Health Care Policy and Research

http://www.ucdenver.edu/academics/colleges/medicalschool/departments/medicine/hcpr/Pages/hcpr.aspx

Colorado School of Public Health

http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/Pages/index.aspx

AMC Cancer Prevention & Control Program at the University of Colorado Cancer Center

http://www.coloradocancerblogs.org/target-cancer/marcus-prevention-and-control-program

Colorado State University Extension Offices

http://www.ext.colostate.edu/

Environmental Health Services

http://www.ehs.colostate.edu/

#### National & World Organizations

Academy of Health Equity

http://www.academyhealth.org/index.cfm

• Robert Wood Johnson Foundation - Commission to Build a Healthier America:

http://www.commissiononhealth.org/

• Unnatural Causes Documentary Website:

http://www.unnaturalcauses.org/

• World Health Organization:

http://www.who.int/social\_determinants/en/

• Prevention Institute - Health Equity and Community Health Publications:

http://www.preventioninstitute.org/publications.html

• Centers for Disease Control and Prevention; Healthy Communities Program

http://www.cdc.gov/healthycommunitiesprogram/overview/healthequity.htm

National Center on Minority Health and Health Disparities

http://www.nimhd.nih.gov/

Blue Cross and Blue Shield of Minnesota Foundation:

http://www.bcbsmnfoundation.org/pages-exploretheissues-tier4-Social\_Determinants\_of\_Health\_General\_?oid=7784

## Objective 1.3:

DEVELOP SPECIFIC STRATEGIES TO ADDRESS PATIENT ACCESS BARRIERS ACROSS THE CANCER CONTINUUM FOR UNDERSERVED COMMUNITIES

#### Resources:

United States Military Cancer Institute

http://usmci.org/

The United States Military Cancer Institute (USMCI) is a tri-service program whose goal is to initiate, develop, coordinate and enhance multi-institutional cancer research, care and education within the military system. The Institute is a component of Uniformed Services University (USU) and is headquartered at Walter Reed Army Medical Center (WRAMC).

• Center for Prostate Disease Research

http://www.cpdr.org/

Reports from the Robert Wood Johnson Foundation

"Barriers of and Facilitators to Physician Recommendation of Colorectal Cancer Screening" By: Guerra CE, Schwartz JS, Armstrong K, Brown JS, Halbert CH and Shea JA In: Journal of General Internal Medicine, 22(12), pp.1681-1688 Publisher: Springer Published: December 2007

http://www.rwjf.org/humancapital/product.jsp?id=26354

#### Patient Navigation:

• C-Change Resources

http://www.cancerpatientnavigation.org/index.html

Colorado Patient Navigator Training Program

www.patientnavigatortraining.org

Harold P. Freeman Patient Navigation Institute

http://www.hpfreemanpni.org/

Pfizer's Patient Navigation in Cancer Care

http://www.patientnavigation.com/

Patient Navigator Research Program

National Cancer Institute's Center to Reduce Cancer Health Disparities

http://crchd.cancer.gov/

Health Literacy Barriers to Health Care

http://www.nlm.nih.gov/pubs/cbm/healthliteracybarriers.html

#### Susan G. Komen Foundation Affiliates:

 Susan G Komen - Aspen Affiliate Komen Denver; Southeastern Komen P.O. Box 4810 Aspen, CO 81612 Phone: (970) 920-0250 Fax: (970) 920-3571

Email Address: info@komenaspen.org

Susan G Komen - <u>Denver Metropolitan Affiliate</u>

Denver, CO

1835 Franklin St. Denver, CO 80218

Phone: (303) 744-2088 Fax: (303) 744-8724

Email Address: info@susangkomen.org

 Susan G Komen - <u>Southeastern Colorado Affiliate</u> Colorado Springs, CO

625 N. Cascade Ave, Suite 110 Colorado Springs, CO 80903

Phone: (719) 632-8887

Email Address: info@komencs.org

#### Reports:

- Burhansstipanov L, Christopher S, Schumacher A. Lessons Learned from Community-Based Participatory Research in Indian Country. Cancer Control: Journal of the Moffitt Cancer Center. November 2005. 70-76.
- Burhansstipanov L, Krebs LU, Grass R, Wanlis E., Saslow D. "A Review of Findings and Recommendations related to American Indian Breast Cancer and Screening." Journal of Cancer Education:2005: 20: (Suppl.): 71-79.
- Burhansstipanov L & Olsen SJ. Cancer Prevention and early detection in AIAN populations; Clinical Journal
  in Oncology Nursing: 2004: 8: 2: 182-186

#### Promotora Programs:

• Community College of Denver Community Health Worker Certificate Program

http://www.cdphe.state.co.us/ohd/grant/CommunityHealthWorkernewDenverHealth.pdf

Community Health Worker National Education Collaborative

www.chw-nec.org

• The Promotora/CHW Model. A Strategy to Reduce Health Disparities and Improve Wellness 4.14.08 "Health Equity and Justice Now" [2002; title of presentation.]

http://www.nmqf.org/presentations/08J3LemusM.pdf

• The Network of Promotoras and Community Health Workers Contact Information:

www.visionycompromiso.org
Maria Lemus, Executive Director
Phone: (510)-303-3444
Mholl67174@aol.com

Melinda Cordero, Director Phone: (626)-864-6117 PromotorasinCA@aol.com

• The Impact of a Promotora on Increasing Routine Chronic Disease Prevention among Women Aged 40 and Older at the U.S.-Mexico Border.

http://heb.sagepub.com/cgi/content/abstract/31/4\_suppl/18S

The REACH La Vida Program

Designated a best practice model by the federal Health Resources and Services Administration (HRSA). As part of the fiscal year 2007 REACH cooperative agreement pro-gram, Hidalgo Medical Services is one of 18 entities selected to become a Center of Excellence in the Elimination of Disparities (CEED). These CEEDs will serve as a regional and national network of resource centers that will disseminate strategies that work in specific ethnic groups. REACH also funds 22 Action Communities that will implement effective public health interventions in their local communities.

http://www.cdc.gov/washington/cdcatWork/pdf/reaching\_hispanics.pdf

## Objective 1.4:

DEVELOP SYSTEMS AND INFRASTRUCTURE TO SUPPORT THE DELIVERY OF THE LATEST, MOST APPROPRIATE CANCER PREVENTION, EARLY DETECTION, TREATMENT, AND QUALITY OF LIFE CARE FOR UNDERSERVED COMMUNITIES.

#### Resources:

National Center for Frontier Communities

www.frontierus.org

Office of Management and Budget

www.whitehouse.gov/omb/fedreg/directive\_15.html

 Sullivan Commission's Report on Health Professions Diversity 9/20/2004 Sullivan Commission, Washington, D.C. http://www.aacn.nche.edu/media/pdf/sullivanreport.pdf

Missing Persons: Minorities in the Health Professions, provides detailed recommendations on how to increase the representation of minorities in the nation's medical, dental and nursing workforce.

Health and Human Services - Bureau of Health Professions (HRSA)

http://bhpr.hrsa.gov/

HRSA Bureau of Health Professions programs help to assure access to quality health care professionals in all geographic areas and to all segments of society. BHPR puts new research findings into practice, encourages health professionals to serve individuals and communities where the need is greatest, and promotes cultural and ethnic diversity within the health professions workforce.

StateHealthFacts.org Minority Health

This site includes information about minority health professionals and medical school enrollees and graduates, in addition to data by race/ethnicity for population demographics, insurance coverage, health status, and other topics.

National Institutes of Health Research Training and Research Career Opportunities Website

http://grants.nih.gov/training/resources.htm

# Objective 1.6:

DEVELOP, IMPLEMENT, AND EVALUATE PUBLIC EDUCATION INITIATIVES THAT FOCUS ON HOW CANCER INCIDENCE AND MORTALITY RATES IN COLORADO DIRECTLY CORRELATE WITH A PERSON'S BUILT ENVIRONMENT (THE PLACES A PERSON LIVES, WORKS AND PLAYS), WITH SOCIOECONOMIC STATUS, LEVEL OF EDUCATION ATTAINMENT, AND OTHER SOCIAL DETERMINANTS OF HEALTH.

#### Resources:

Piton Foundation

http://www.piton.org/CommunityFacts

The Piton Foundation is a private, operating foundation established in 1976 by Denver oil man Sam Gary. It is funded by the Gary-Williams Energy Corporation to develop and implement programs to improve education, expand economic opportunities for families, and strengthen lower-income communities.

Colorado Foundation for Public Health and the Environment

http://www.cfphe.org/

Colorado Department of Public Health & Environment: Office of Health Disparities

http://www.cdphe.state.co.us/ohd/

Prevention Services Division, Social Determinants of Health Work Group

http://www.cdphe.state.co.us/

• The Alliance for a Sustainable Colorado

http://sustainablecolorado.org/about-us

The mission of Alliance for Sustainable Colorado is to catalyze the shift to a truly sustainable world by fostering collaboration among nonprofits, businesses, governments, and academia. We are

working to advance economic, environmental, and social sustainability in Colorado by building cross-sector alliances and networks.

Colorado Environmental Health Association

http://www.cehaweb.com/about.html

CEHA was established in 1947 as the Rocky Mountain Section of the National Association of Sanitarians and enjoys an outstanding reputation statewide as an innovative, progressive organization dedicated to advancing the cause of general, professional or technical environmental health.

Colorado Progressive Coalition

http://progressivecoalition.org/

CPC focuses in four program areas statewide: Racial Justice, Health Justice, Economic Justice, and Civic Engagement. With offices in Greeley, Pueblo, and Denver, we help build a stronger progressive movement in Colorado. Our mission is to ensure that our political and economic democracy works for everyone -- not just the wealthy or well-connected.

State Education and Prevention Partnership (STEPP)

http://www.colorado.gov/cs/Satellite/CDPHE-PSD/CBON/1251618783058

## Objective 1.7:

EXPAND THE DEVELOPMENT OF COMMUNITY-DRIVEN AND COMMUNITY-BASED PARTICIPATORY RESEARCH ON COLORADO DISPARITIES IN THE CANCER CARE CONTINUUM.

#### Resources:

#### COLORADO AGENCIES THAT CONDUCT COMMUNITY-BASED PARTICIPATORY RESEARCH

Native American Cancer Research

http://natamcancer.org/index.html

Latino Research and Policy Center

http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/lrpc/Pages/LRPC.aspx

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- The Sullivan Commission. Missing persons: minorities in the health professions. A report of the Sullivan Commission on Diversity in the Healthcare Workforce, 2004
- U.S. Department of Health and Human Services, National Institutes of Health, Eliminating Tobacco-Related Health Disparities: Summary Report National Conference on Tobacco and Health Disparities 2002, National Cancer Institute. 2005
- U.S. Department of Health and Human Services. Making Cancer Health Disparities History. Report of the Trans-HHS Cancer Health Disparities Progress Review Group, Submitted to the Secretary, March 2004
- U.S. Department of Health and Human Services. National Standards for Culturally and Linguistically Appropriate Services in Health Care. Office of Minority Health. 2001.

#### Colorado Department of Public Health & Environment:

Data links:

http://www.chd.dphe.state.co.us/default.aspx

http://www.cdphe.state.co.us/hs/informatics.html

Office of Health Disparities

http://www.cdphe.state.co.us/ohd/index.html

Office of Planning and Partnerships

http://www.cdphe.state.co.us/opp/cophip.html

Consumer Protection Division

http://www.cdphe.state.co.us/cp/index.html

Air Pollution Control Division

http://www.cdphe.state.co.us/ap/index.html

Hazardous Materials and Waste Division

http://www.cdphe.state.co.us/hm/index.htm

CO Foundation for Public Health & Environment

http://www.cfphe.org/

## Breast Cancer

#### Collaborations With Potential Impact On Breast Cancer

Several programs exist in Colorado to increase breast cancer education, awareness, screenings and support systems for women and men in Colorado.

- The Colorado Women's Wellness Connection (WWC) program provides annual clinical breast exams to women statewide who are between the ages of 40-64, at or below 250% of the federal poverty level, uninsured or underinsured, and lawfully present in the United States. WWC also provides mammograms to women age 50 64 and women age 40 -49 if they are identified as high risk. Women can access services by calling the Women's Wellness Connection hot-line at 1-866-951-WELL or through its network of 46 local health departments, safety-net clinics, rural hospitals and federally qualified health centers. The WWC program is currently serving 27% of the eligible population in Colorado with breast cancer screening services compared to the national rate of 14% (WWC, 2009).
- Susan G. Komen for the Cure® has three affiliates in the state that currently provide services in 25 of the 64 Colorado counties that contain 81% of Colorado's population. Komen affiliates provide funds for breast cancer screening services to women and men who do not qualify for the WWC program. Susan G. Komen for the Cure® affiliates may also provide some funding for case management services among low-income, uninsured women. Affiliates of Komen also complete a statewide community assessment every two years that identifies barriers women face with screening, diagnostic services and treatment. Information for each affiliate can be acquired here: Denver Metropolitan Affiliate www.komendenver.org; Aspen Affiliate: www.komenaspen.org; Southeast Affiliate: http://www.komendenver.org/.
- The Food and Drug Administration administers the Mammography Quality Standards Act (MQSA) Program to ensure that all women have access to quality mammography for the detection of breast cancer in its earliest, most treatable stages.
- American Cancer Society is the nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer through research, education, advocacy and service.
- The Avon Foundation provides grants to organizations and institutions, predominantly 501(c)(3) or equivalent, in the areas outlined in their mission statement: breast cancer, domestic violence and emergency disaster relief.
- Colorado Mammography Society (CMS) The CMS is a member only organization for mammography technicians and radiologists.
- The health insurance organizations in Colorado include Medicaid, Medicare, Kaiser Permanente, Aetna, Blue Cross Blue Shield, Cigna, United Health Group, and Well Point. These organizations have the ability to impact screening through the design and coverage provided in their preventive health care screening benefits (inclusive of mammograms).

#### Breast Cancer 1 References:

#### Evidenced-Based Interventions to Increase Mammography Screening Rates:

• The American Cancer Society (ACS), The U.S. Preventive Services Task Force (USPSTF), the National Cancer Institute (NCI) and Susan G. Komen for the Cure® agree that the regular use of screening mammograms, followed by timely treatment when breast cancer is diagnosed, can help reduce the chances of dying from breast cancer. These organizations also generally agree that screening mammography has the most benefit between the ages of 50 and 69 when provided every 1-2 years. Evidence is lacking on the benefit of regular screening mammography for women between the ages of 40 and 49 and women ages 70 and older. The ACS, Komen for the Cure and NCI all agree that women should start annual mammography screening at age 40. Furthermore, the USPSTF could not determine the benefits of clinical breast exam (CBE) with mammography; however, the ACS and Komen recommend yearly CBE in combination with mammography (NCI, 2007; USPSTF, 2009; ACS, 2008). The USPSTF also recommends against the promotion of breast self-examination (BSE) (USPSTF, 2009), however, the ACS still recommends monthly practice of BSE in combination with yearly CBE and mammography (ACS, 2003). Based on the controversial evidence-base around clinical guidelines, practitioners and women should work together to promote informed decision-making.

# Cervical Cancer

#### Cervical Cancer 1:

#### Colorado Baseline Data

According to Colorado Behavioral Risk Factor Surveillance System (BRFSS) data, there appears to be slight declining trend in the number of women 18 and older reporting having had a Pap test in the past 3 years. In 2004, nearly 90% of women surveyed reported having a Pap in the past 3 years; in 2008 the number is 85%.

## Social Determinants Related to Screening

According to the National Healthcare Disparities Report, 2008 (http://www.ahrq.gov/research/findings/nhqrdr/nhqrdr08/), patient and provider interactions encompass various aspects of care, including whether patients can get appointments in a timely manner, whether they feel respected and listened to, and whether they understand their care. One interaction is communication. Poor provider-patient communication can result from a number of complex factors, including a provider's lack of familiarity with cultural norms, language barriers, a patient's low health literacy, a chaotic work environment, and a lack of time during a visit. Minorities are more likely to experience poor provider-patient communication and are more likely to receive care in clinics where providers face workplace challenges and have a more complex patient mix. To improve cervical cancer screening rates and reduce mortality in ethnic/minority populations, addressing these health care disparities will require special attention to cultural attitudes and perceptions that affect health behaviors and patterns of health care access and utilization.

Women with a history of sexually transmitted diseases (STDs) might be at increased risk for cervical cancer, and women attending STD clinics might have other risk factors that place them at even greater risk. Prevalence studies indicate that precursor lesions for cervical cancer occur approximately five times more frequently among women attending STD clinics than among women attending family planning clinics (Kamb ML. Cervical cancer screening of women attending sexually transmitted disease clinics. Clin Infect Dis 1995;20 (Suppl 1):S98–S103).

#### EVIDENCE BASED STRATEGIES SHOWN TO IMPROVE SCREENING

According to findings of the CDC Guide to Community Preventive Services (http://www.thecommunityguide.org/index.html), the following proven interventions are being recommended for increasing screening rates:

• Client Reminders: Reminders include letters, postcards, or phone calls to alert clients that it is time for their cancer screening. Some may be a note only that the test is due, while others include facts about the screening or offer to help set up an appointment.

- Small Media: Small media include videos and printed materials such as letters, brochures, and newsletters. These materials can be used to inform and motivate people to be screened for cancer. They can provide information tailored to specific individuals or targeted to general audiences.
- One-on-One Education: One-on-one education is provided in person or by telephone to encourage individuals to be screened for cancer. Health care providers can deliver one-on-one education in clinical settings, at home, or in local gathering places. Brochures, informational letters, or reminders may also be used. The information can be general or tailored to the needs of each person.

Physicians and other providers can play an important role in encouraging patients to be screened for cervical cancer. Recommended strategies include:

- Provider Assessment and Feedback: These interventions assess how often providers offer or deliver screening services to clients (assessment) and then give providers information about their performance (feedback). The feedback may describe the performance of an individual provider or of a group of providers (e.g., mean performance for a practice). The performance may be compared with a goal or
- Provider Reminders and Recall: Reminders inform health care providers it is time for a client's cancer screening test (called a "reminder") or that the client is overdue for screening (called a "recall"). The reminders can be provided in different ways, such as in client charts or by e-mail.

#### Cervical Cancer 2:

#### Baseline Data

The National Immunization Survey (NIS) is sponsored by the National Center for Immunizations and Respiratory Diseases (NCIRD) and conducted jointly by the NCIRD and the National Center for Health Statistics (NCHS). In 2007, NIS HPV vaccination coverage was reported for the first time and showed that 25.1% of U.S. females 13-17 years of age had received at least one HPV vaccination. In 2008, the NIS assessed state-level vaccination coverage and reported Colorado's HPV vaccination (>1 HPV vaccine dose) coverage level for females 13-17 years of age is 34% compared to the national rate of 37%.

#### Social Determinants Associated With HPV

There are several emerging studies that demonstrate differences in populations that receive the vaccine, those that need and are receptive to education about the vaccine, and persistent myths about HPV vaccine.

- Vaccine awareness differs by race, education and income. Interventions to increase awareness of HPV could benefit from tailoring information to prescreening age, screening age, and post-screening age women. (The Impact of Human Papillomavirus Information on Perceived Risk of Cervical Cancer. Hughes, et al. Cancer Epidemiol Biomarkers Prev. Feb 3, 2009.)
- Barriers to vaccination are cost and access to vaccine and concern that immunization with the vaccine may promote adolescent sexual behavior. HPV vaccine programs should emphasize high vaccine effectiveness, the high likelihood of HPV infection, and physicians' recommendations, and address barriers to vaccination. (Predictors of HPV vaccine acceptability: a theory-informed, systematic review. <u>Brewer NT</u>, <u>Fazekas KI</u>. Preventive Med. 2007 Aug-Sep;45(2-3):107-14. Epub 2007 Jun 2.)

Given information, mothers of teens in Mexico had high acceptance rates of vaccinating their adolescent children against HPV. (Parental Attitudes About Sexually Transmitted Infection Vaccination for Their Adolescent Children. Gregory D., et al. Arch Pediatr Adolesc Med. 2005;159:132-137.) Teenage girls surveyed indicated no increased interest in risky sexual behavior if they were to be

vaccinated. (Attitudes about human papillomavirus vaccine in young women. (Kahn JA, et al. Int J STD AIDS. 2003 May:14(5):300-6.)

#### Evidenced-Based Interventions to Increase HPV Vaccination Rates

According to findings of the CDC Guide to Community Preventive Services (http://www.thecommunityguide.org/ index.html), there are no specific evidence-based interventions for increasing HPV vaccination at this time. Therefore, the following proven interventions are being recommended for increasing HPV vaccination coverage:

- Provider Reminder Systems: Provider reminders let providers or other appropriate staff knows when individual clients are due for vaccinations, through notations, stickers, or other prompts in clients' charts, or through computer databases or registries. Reminders can be directed to the primary healthcare provider or clinic staff.
- Interventions that should be implemented in combination:

- Expanded access in healthcare settings;
- Reducing patient out-of-pocket costs:
- Patient or family incentives;
- Patient reminder/recall systems;
- Clinic-based patient education;
- Community-wide education;
- Vaccination requirements; Provider assessment and feedback;
- Provider education: and
- Standing orders.

For detail on individual strategies, please go to The Community Guide, Vaccinations for Preventable Diseases: Targeted Coverage at (<a href="http://www.thecommunityguide.org/vaccines/targeted/index.html">http://www.thecommunityguide.org/vaccines/targeted/index.html</a>).

## Colon & Rectum Cancer

- American Cancer Society CRC Screening Guidelines
- Colorado Clinical Guidelines Collaborative (CCGC)
- United States Preventative Service Task Force (USPSTF) Guidelines

# Melanoma

#### Skin Cancer Facts & Prevention

- Sun Safe Colorado
- ACS Parents Guide to Skin Protection
- ACS Skin Cancer Facts
- Cancer Council of Victoria, Australia Sun Smart program CDC Choose Your Cover
- EPA UV Index
- Harvard Center for Cancer Prevention
- National Council on Skin Cancer Prevention National Safety Council's Skin Cancer Prevention Program
- Rays Awareness
- Skin Cancer Foundation
- Sun Safety for Kids
- The National Melanoma Awareness Project
- World Health Organization Skin Cancer Information

#### Skin Cancer Prevention News

- Cancer Consultants Oncology Resource Center
- Medline Plus Skin Cancer
- Skin Cancer News Only
- Topix.net Skin Cancer News

#### Health & Medicine

- American Academy of Dermatology
- American Cancer Society
- Centers for Disease Control and Prevention (CDC)
- Colorado Department of Public Health and Environment
- World Health Organization

## Pediatric Cancer

### For Objectives 7, 8 and 9 - HTTP://WWW.JOURNEYFORWARD.ORG/

Center for Disease Control and Prevention

10 Leading Causes of Death by Age Group, Data 2006. Retrieved September 28, 2009 from:

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http://www.familiesusa2.org/assets/pdfs/uninsured-kids-2008/colorado.pdf

National Action Plan for Childhood Cancer

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http://quickfacts.census.gov/gfd/states/08000.html

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http://www.who.int/cancer/palliative/en/

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